# Patient engagement for patient safety: The why, what, and how of patient engagement for improving patient safety

Candan Kendir,

Rie Fujisawa,

Óscar Brito Fernandes,

Katherine de Bienassis,

Niek Klazinga

OECD

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# PATIENT ENGAGEMENT FOR PATIENT SAFETY

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Candan Kendir*, Rie Fujisawa*, Óscar Brito Fernandes**, Katherine de Bienassis*, Niek Klazinga*

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The Economics of Patient Safety Part VI

# Patient Engagement for Patient Safety

The why, what, and how of patient engagement for improving patient safety.

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# Acknowledgements

# Executive summary

Patients' and citizens' perspectives and their active engagement are critical to make health systems safer and people-centred — and are key for co-designing health services and co-producing good health with healthcare professionals and building trust. Patients, families, caregivers and citizens can contribute towards improving patient safety at the clinical (local), institutional (e.g., hospital, nursing home), community (e.g., primary care, home care) and national (in the development of national policies) levels of healthcare systems. This report, the sixth in the series on the Economics of Patient Safety, covers (i) the economic impact of patient engagement for patient safety, (ii) the results of a pilot data collection to measure patient-reported experiences of safety and (iii) the status of initiatives on patient engagement for patient safety in 21 countries, based on the results retrieved from a snapshot survey. This report classifies patient engagement for patient safety as: strong (e.g., *patients or citizens are partners or co-designers of a patient safety initiative and have a decision-making role in the development cycle of a patient safety initiative – co-producing safe people-centred healthcare*), medium (e.g., *patients or citizens were involved at some stages of developing a patient safety initiative*) or low (*e.g., patients or citizens were informed or consulted at some stage of developing a patient safety initiative*).

The following principal findings emerged:

- According to the surveys conducted, **up to about one in six patients reported safety incidents**. **Up to 8% of patients experienced medication errors**. While over 90% of hospitalised patients had medication reviews in Latvia and the Netherlands, medication reviews at the time of discharge are not yet fully implemented in other countries.

- **There is little but growing evidence on the return on investment of patient engagement for patient safety.** Low engagement of patients in their care journey is associated with higher healthcare costs. Technology can help stimulate engagement, reduce staff costs and improve patient engagement. In the United States, the implementation of Partnership for Patients' Hospital Improvement Innovation Networks was associated with reductions in hospital-acquired conditions and credited to have prevented 20 500 hospital deaths and saved USD 7.7 billion in healthcare costs from 2014 to 2017.

- **There is limited information available regarding cost of unsafe care relevant to patients, such as safety incidents that have resulted in litigation and the amount of compensation settlements.** Currently, only countries such as France, Korea Ireland, Latvia and the United States can report on safety incidents that resulted in litigation or produce national estimates of how much is spent on settlements with patients.

- **Less than half of countries (9 out of 21) responded to the OECD survey on Patient Engagement for Patient Safety reported having systems of no-fault liability in place** to compensate patients who suffer any treatment-induced injury irrespective of conviction for medical malpractice or negligence. Countries that indicated having a system of no-fault compensation to patients include Austria, Belgium, France, Japan, Korea, Latvia, New Zealand, Portugal, and Switzerland.

- **Over a third of OECD countries** (e.g., Austria, Belgium, Canada, Estonia, Latvia, Poland, and the United States) **have conducted at least one survey that includes questions measuring patient-reported experiences of safety** among adult patients who were discharged from the hospital. A few OECD counties (e.g., Canada, Denmark, Germany, Ireland, New Zealand, and the United Kingdom (England)) have also conducted at least one survey including questions to measure experiences of healthcare safety among people who have used primary care services.

- **Most countries engage patients or citizens during the development cycle of patient-safety initiatives, but the level of engagement varies both within and across countries.** Patient or citizen engagement was strong among four responding countries for initiatives such as establishing of networks of patient safety advocates and champions (i.e., Canada, Ireland, New Zealand, and Slovenia) and advancing national initiatives based on specific safety themes (i.e., Canada, Ireland, New Zealand, and Portugal). Among six responding countries, patient engagement in defining safety standards linked to accreditation and certification initiatives was considered strong (i.e., Canada, France, Ireland, New Zealand, Romania, and Türkiye). Two countries (Canada and Israel) identified strong engagement of patients or citizens in educational programmes of future or current healthcare professionals, and three countries (i.e., Canada, New Zealand, and Portugal) reported strong engagement of patients in health literacy initiatives. None of the 21 responding countries reported strong engagement of patients in developing materials for public reporting of patient safety events and indicators.

- **Nearly all countries (20 out of 21) reported having a national patient safety policy or strategy.** In 15 out of 20 countries, national patient safety policies or strategies included explicit references to patient engagement, and more than half (11 out of 20) engaged patients or citizens in the development of the policy.

- **Most countries have a legal right to safe patient care, but just over half reported having mechanisms in place to enforce that right**, such as legal recourse or alternative courses of action. Of the countries with a legal right to safe patient care, half indicated that patients and citizens were engaged in the development of the legal structure.

This report provides seven key recommendations for enhancing patient engagement for patient safety:

1. **Building trust for safer healthcare through stronger patient and family engagement**: Trust in healthcare systems is fundamental to patient safety. Trust can be built through increased patient and family engagement during the care journey and in all patient safety improvement efforts at the national and subnational levels. Safe, high-quality healthcare that is jointly co-developed by those that demand and need care and those who design and deliver care is essential to realising patient safety.

2. **Institutionalising patient engagement for patient safety**: Patient experiences related to safety events often do not get shared, reported, or integrated into the development of patient safety solutions. More efforts are needed to institutionalise the engagement of patients, families and carers, and communities in patient safety improvement initiatives, as well as learning from the first-hand experiences of patients and families.

3. **Establishing better platforms and networks for sharing experiences and good practices in patient engagement:** Countries need to create mechanisms for patients, families and carers to systematically share and hear their stories about care experiences and health outcomes and ensuring that such information informs the design of patient safety initiatives.

4. **Strengthening patient engagement for patient safety at institution and clinical levels**: Countries can further engage patients in prioritising funding allocation to patient safety research projects, embedding patient engagement in developing safety initiatives such as service design,

improving clinical communication protocols and training, and defining the organisation's culture of transparency and accountability at the institution level. Countries can also promote contributions of patients, families, caregivers and citizens in developing processes and procedures to ensure delivery of safe care at the clinical level.

5. **Enhancing monitoring of patient safety for keeping track of progress and building accountability**: Data on patient experiences should be monitored as part of broader data collections on patient safety including professionals' experiences with patient safety culture and patient safety events measured through administrative data sources. Efforts could be made to classify patient safety incidents by using common terminologies in a comparable manner across data sources to maximise their use for promoting safe healthcare. Further efforts are needed to broaden data collection to other settings beyond hospitals such as primary care and long-term care.

6. **Anchoring collection and use of patient safety data to OECD's Recommendations of the Council on Health Data Governance:** Implementing OECD's Recommendations of the Council on Health Data Governance is essential for protecting privacy of individuals providing data on patient safety and promoting adequate data use (including secondary use of data).

7. **Improving quality of patient-reported safety indicators and systematically using them for improving patient safety**: Measurements of patient-reported safety convey stories of patient safety events in a concise and comparative manner, leading to higher attention from policy-makers, healthcare providers, professionals and citizens to improve patient safety together. Further efforts are needed to improve the quality of patient-reported safety indicators. This can be achieved by fostering a safety culture that encourages reporting of safety events, involving patients in survey design, enhancing survey accessibility, ensuring adequate representativeness with meaningful sample sizes, and using patient safety data in a timely manner in quality improvement cycles.

As countries are striving towards ensuring safe care and making health systems more people-centred, engaging patients, families and carers, and communities is essential to achieve this goal. Engaging patients, families and carers, and communities requires a systematic approach at *macro, meso, and micro levels*. International learning on patient engagement for patient safety is also key to advance the national efforts towards enhancing trust, creating patient safety culture and ensuring safe care.

# Résumé

Les points de vue des patients et des citoyens ainsi que leur engagement actif sont essentiels pour rendre les systèmes de santé plus sûrs et centrés sur la personne. Ils sont essentiels à la conception conjointe des services de santé, à la coproduction d'une bonne santé avec les professionnels de la santé et à l'instauration de la confiance. Les patients, les familles, les soignants et les citoyens peuvent contribuer à l'amélioration de la sécurité des patients au niveau clinique (local), institutionnel (par exemple hôpital, maison de retraite), communautaire (par exemple soins primaires, soins à domicile) et national (dans l'élaboration de politiques nationales). Ce rapport, le sixième de [la série sur l'économie de la sécurité des patients](), couvre (i) l'impact économique de l'engagement des patients pour la sécurité des patients, (ii) les résultats d'une collecte de données pilote pour mesurer les expériences de sécurité rapportées par les patients et (iii) l'état des initiatives sur l'engagement des patients pour la sécurité des patients dans 21 pays, sur la base des résultats extraits d'une enquête instantanée. Ce rapport classe l'engagement des patients pour la sécurité des patients comme : fort (*par exemple, les patients ou les citoyens sont partenaires ou co-concepteurs d'une initiative de sécurité des patients et ont un rôle décisionnel dans le cycle de développement d'une initiative de sécurité des patients – coproduisant des soins centrés sur la personne*), moyen (*par exemple, les patients ou les citoyens ont été impliqués dans certaines étapes de l'élaboration d'une initiative sur la sécurité des patients*) ou faible (*par exemple, les patients ou les citoyens ont été informés ou consultés à une certaine étape de l'élaboration d'une initiative sur la sécurité des patients*).

Les principales conclusions suivantes ont été dégagées :

- Selon les enquêtes menées, **jusqu'à environ un patient sur six a signalé des incidents de sécurité. Jusqu'à 8 % des patients ont été victimes d'erreurs de médication**. Alors que plus de 90 % des patients hospitalisés ont fait l'objet d'une évaluation de leurs médicaments en Lettonie et aux Pays-Bas, les évaluations des médicaments au moment de leur sortie ne sont pas encore pleinement mises en œuvre dans d'autres pays.

- **Il existe peu de données probantes, mais de plus en plus nombreuses, sur le retour sur investissement de l'engagement des patients en faveur de leur sécurité**. Un faible engagement des patients dans leur parcours de soins est associé à des coûts de santé plus élevés. La technologie peut contribuer à stimuler l'engagement, à réduire les coûts de personnel et à améliorer l'engagement des patients. Aux États-Unis, la mise en œuvre du Partnership for Patients' Hospital Improvement Innovation Networks a été associée à une réduction des pathologies nosocomiales et aurait permis d'éviter 20 500 décès à l'hôpital et d'économiser 7,7 milliards de dollars en coûts de santé entre 2014 et 2017.

- **Il existe peu d'informations disponibles sur le coût des soins dangereux pour les patients tels que les incidents de sécurité qui ont donné lieu à des litiges et le montant des indemnisations**. Actuellement, seuls des pays comme la France, la Corée, l'Irlande, la Lettonie et les États-Unis peuvent signaler les incidents de sécurité ayant donné lieu à des litiges ou produire des estimations nationales des sommes dépensées pour les règlements avec les patients.

- **Moins de la moitié des pays (9 sur 21) ayant répondu à l'enquête de l'OCDE sur l'engagement des patients pour la sécurité des patients ont déclaré avoir mis en place des systèmes de responsabilité sans faute pour indemniser les patients qui subissent un préjudice induit par le traitement, indépendamment de leur condamnation pour faute professionnelle médicale ou négligence.** Les pays qui ont indiqué disposer d'un système de responsabilité sans faute pour les patients sont l'Autriche, la Belgique, la France, le Japon, la Corée, la Lettonie, la Nouvelle-Zélande, le Portugal et la Suisse.

- **Plus d'un tiers des pays de l'OCDE** (par exemple l'Autriche, la Belgique, le Canada, l'Estonie, la Lettonie, la Pologne et les États-Unis) **ont mené au moins une enquête mesurant les expériences de sécurité déclarées par les patients adultes sortis de l'hôpital.** Quelques pays de l'OCDE (par exemple le Canada, le Danemark, l'Allemagne, l'Irlande, la Nouvelle-Zélande et le Royaume-Uni (Angleterre)) ont également mené au moins une enquête mesurant les expériences en matière de sécurité des soins de santé parmi les personnes ayant eu recours aux services de soins primaires.

- **La plupart des pays impliquent les patients ou les citoyens pendant le cycle de développement des initiatives de sécurité des patients, mais le niveau d'engagement varie à la fois au sein des pays et entre eux.** L'engagement des patients ou des citoyens était fort dans les quatre pays répondants pour des initiatives telles que l'établissement de réseaux de défenseurs et de champions de la sécurité des patients (c'est à dire le Canada, l'Irlande, la Nouvelle-Zélande et la Slovénie) et la promotion d'initiatives nationales basées sur des thèmes de sécurité spécifiques (c'est à dire le Canada, Irlande, Nouvelle-Zélande et Portugal). Parmi les six pays ayant répondu, l'engagement des patients dans la définition des normes de sécurité liées aux initiatives d'accréditation et de certification a été considéré comme fort (c'est à dire le Canada, la France, l'Irlande, la Nouvelle-Zélande, la Roumanie et la Turquie). Deux pays (le Canada et Israël) ont identifié un fort engagement des patients ou des citoyens dans les programmes de formation des professionnels de la santé futurs ou actuels, et trois pays (le Canada, la Nouvelle-Zélande et le Portugal) ont signalé un fort engagement des patients dans les initiatives de littératie en santé. Aucun des 21 pays ayant répondu n'a signalé un engagement fort des patients dans l'élaboration de matériels destinés à rendre publics les événements et les indicateurs liés à la sécurité des patients.

- **Presque tous les pays (20 sur 21) ont déclaré disposer d'une politique ou d'une stratégie nationale en matière de sécurité des patients.** Dans 15 pays sur 20, les politiques ou stratégies nationales en matière de sécurité des patients comprenaient des références explicites à l'engagement des patients, et plus de la moitié (11 sur 20) ont impliqué les patients ou les citoyens dans l'élaboration de la politique.

- **La plupart des pays disposent d'un droit légal à des soins sûrs pour les patients, mais un peu plus de la moitié ont déclaré avoir mis en place des mécanismes pour faire respecter ce droit, tels que des recours juridiques ou des lignes d'action alternatives.** Parmi les pays dotés d'un droit légal à des soins sûrs pour leurs patients, la moitié ont indiqué que les patients et les citoyens étaient impliqués dans le développement de la structure juridique.

Ce rapport fournit sept recommandations clés pour améliorer la participation des patients à la sécurité des patients :

1. **Bâtir la confiance pour des soins de santé plus sûrs grâce à un engagement plus fort des patients et de leurs familles :** La confiance dans les systèmes de santé est fondamentale pour la sécurité des patients. La confiance peut être construite grâce à un engagement accru des patients et de leurs familles pendant le parcours de soins et dans tous les efforts d'amélioration

de la sécurité des patients aux niveaux national et infranational. Des soins de santé sûrs et de haute qualité, développés conjointement par ceux qui exigent et ont besoin de soins et par ceux qui conçoivent et dispensent les soins, sont essentiels pour garantir la sécurité des patients.

2. **Institutionnaliser l'engagement des patients pour la sécurité des patients :** Les expériences des patients quant aux événements liés à la sécurité ne sont souvent pas partagées, signalées ou intégrées dans le développement de solutions de sécurité des patients. Des efforts supplémentaires sont nécessaires pour institutionnaliser l'engagement des patients, des familles, des soignants et des communautés dans les initiatives d'amélioration de la sécurité des patients, ainsi que pour tirer les leçons des expériences directes des patients et des familles.

3. **Établir de meilleures plateformes et réseaux pour partager des expériences et des bonnes pratiques en matière d'engagement des patients :** les pays doivent créer des mécanismes permettant aux patients, aux familles et aux soignants de partager et d'entendre systématiquement leurs histoires sur les expériences de soins et les résultats de santé et de veiller à ce que ces informations éclairent la conception des initiatives en matière de sécurité des patients.

4. **Renforcer l'engagement des patients pour la sécurité des patients au niveau des établissements de santé et au niveau clinique :** les pays peuvent impliquer davantage les patients dans la priorisation de l'allocation de fonds aux projets de recherche sur la sécurité des patients, en intégrant l'engagement des patients dans le développement d'initiatives de sécurité telles que la conception de services, l'amélioration des protocoles de communication clinique et de la formation, et définir la culture de transparence et de responsabilité de l'organisation au niveau institutionnel. Les pays peuvent également promouvoir la contribution des patients, des familles, des soignants et des citoyens à l'élaboration de processus et de procédures garantissant la prestation de soins sûrs au niveau clinique.

5. **Améliorer le suivi de la sécurité des patients pour suivre les progrès et renforcer la responsabilité :** Les données sur les expériences des patients devraient être surveillées dans le cadre de collectes de données plus larges sur la sécurité des patients, y compris les expériences des professionnels en matière de culture de sécurité des patients et les événements liés à la sécurité des patients mesurés au moyen de sources de données administratives. Des efforts pourraient être faits pour classer les incidents liés à la sécurité des patients en utilisant des terminologies communes de manière comparable entre les sources de données afin d'optimiser leur utilisation pour promouvoir des soins de santé sûrs. Des efforts supplémentaires sont nécessaires pour élargir la collecte de données à d'autres contextes au-delà des hôpitaux, comme les soins primaires et les soins de longue durée.

6. **Ancrer la collecte et l'utilisation des données sur la sécurité des patients aux recommandations du Conseil de l'OCDE sur la gouvernance des données de santé :** La mise en œuvre des recommandations de l'OCDE du Conseil sur la gouvernance des données de santé est essentielle pour protéger la vie privée des personnes fournissant des données sur la sécurité des patients et promouvoir une utilisation adéquate des données (y compris utilisation secondaire des données).

7. **Améliorer la qualité des indicateurs de sécurité rapportés par les patients et utiliser les indicateurs systématiquement pour améliorer la sécurité de patients:** les mesures de la sécurité rapportée par les patients transmettent des récits d'événements liés à la sécurité des patients de manière concise et comparative, ce qui conduit à une plus grande attention de la part des décideurs politiques, des prestataires de soins de santé, des professionnels et des citoyens pour améliorer ensemble la sécurité des patients. Des efforts supplémentaires sont nécessaires pour améliorer la qualité des indicateurs de sécurité déclarés par les patients. Cela peut être réalisé en favorisant une culture de sécurité qui encourage la déclaration des événements liés à la sécurité, en impliquant les patients dans la conception de l'enquête, en améliorant l'accessibilité

de l'enquête, en garantissant une représentativité adéquate avec des tailles d'échantillon et en utilisant les données sur la sécurité des patients en temps opportun dans les cycles d'amélioration de la qualité.

Alors que les pays s'efforcent de garantir des soins sûrs et de rendre les systèmes de santé plus centrés sur la personne, il est essentiel d'impliquer les patients, les familles, les soignants et les communautés pour atteindre cet objectif. La participation des patients, des familles, des soignants et des communautés nécessite une approche systématique aux niveaux macro, méso et micro. L'apprentissage international sur l'engagement des patients en faveur de la sécurité des patients est également essentiel pour faire progresser les efforts nationaux visant à renforcer la confiance, à créer une culture de sécurité des patients et à garantir des soins sûrs.

# Acronyms

| | |
|---|---|
| ACC | Accident Compensation Legislation |
| HIINs | Partnership for Patients' Hospital Improvement Innovation Networks (United States) |
| HIQA | Health Information and Quality Authority |
| HPRA | Health Products Regulatory Authority |
| HSE | Health Service Executive |
| HTA | Health Technology Assessment |
| ONIAM | Office National d'Indemnisation des Accidents Médicaux (France) |
| WHO | World Health Organization |

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## Boxes

# 1. The pivotal need for patient engagement for patient safety

1.      To make health systems safer and people-centred, the perspectives of patients, families and carers, and communities[1] are key. Their perspectives are also essential for the co-production of health and building trust (OECD, 2021). Beyond the individual patient-clinician interaction, patient perspectives can be better integrated at all levels of healthcare systems (micro, meso, and macro levels). As countries implement reforms to support more resilient health systems and address current economic challenges such as inflation and labour shortages, they will need to further institutionalise the role of patients, families and carers, and communities in their efforts to ensure safe, patient-centred care.

2.      This report, the sixth in the series on the Economics of Patient Safety, presents the status of initiatives on patient engagement for patient safety and the economic benefits of patient engagement for patient safety in OECD member countries. The report is structured as follows: Chapter 1 explains why patient engagement for patient safety is important, how patients can be engaged across levels of the healthcare system, and the economic benefits of patient engagement for patient safety initiatives; Chapter 2 describes the OECD's set of survey questions to measure patient-reported experiences of safety and the results of a pilot data collection; Chapter 3 shows the status of patient engagement for patient safety in 21 countries based on the results retrieved from a snapshot survey; and Chapter 4 shows the status of patient engagement for the national patient safety and quality strategies and provides OECD recommendations for embedding patient engagement for the national patient safety and quality strategies.

## 1.1. Against the backdrop of the COVID-19 response, ensuring safe healthcare is an ongoing challenge

3.      Healthcare system responses to the COVID-19 pandemic have often been weak in focus on patient-centredness, revealing a lack of deeply embedded people-centred policies in OECD healthcare systems. Patient representation in health policy decision-making was largely absent as countries needed to make rapid decisions to contain the spread of the virus, such as measures restricting mobility and measures implemented in hospital and long-term care settings. For example, among 57 patient organisations in Europe, nearly two-thirds indicated there was no patient involvement or consultation in management and decision-making processes during the pandemic (OECD, 2021).

4.      Patients are a key source of information about the prevalence of healthcare-related harm. Yet, many of these events still go unreported (Eurobarometer, 2010). Measurement of patient experiences as they relate to patient safety is far from systematic in most countries, and international comparability remains limited. Capturing patients' experiences directly is an avenue to enhance understanding of the

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[1] The notion of communities refers to groups of people that may or may not be spatially connected, but who share common interests, concerns or identities (e.g., patient and civil society organisations) (World Health Organization, 2009). Communities could be local, national or international, with specific or broad interests.

incidence of safety events and to improve signal detection (Weigmann, 2016). The role of family and caregivers in medical care extends beyond a comforting presence—they are essential partners in patient safety. Family and caregivers are relied on to provide medical and medication information, communicate with healthcare professionals, help in the coordination of transitions in care, documenting care, be informed of or participate in medical decisions, and speak up if they notice any risks or errors. The idea that family and caregivers make care safer is supported by research findings showing that their presence improves patient safety—even during COVID-19 (Gandhi, 2022).

5.      The WHO Global Action Plan on Patient Safety calls for engaging patients, families and communities as partners in safe care as one of its core guiding principles underpinning the development and implementation of its framework for action (Box 1.1) (WHO, 2021). The programme "Patients for Patient Safety", an outcome of this objective, aims to advance the development and use of interventions to enhance patient participation in safety initiatives. The outcomes of the 2023 Global Ministerial Summit on Patient Safety reiterate the importance of engaging patients, families and carers, and communities for patient safety. Ministers, high-level representatives, and experts gathered in Montreux on 23 and 24 February 2023 to advance their joint endeavour of strengthening patient safety globally, and engagement has been one of the key action points[2]. Action point 8 states that *"Engage and empower patients, families and care givers in care delivery as well as solutions to advance Patient Safety and reduce avoidable harm in health care".*

6.      Embedding patients, families and carers, and communities voice in health policy is critical to drive the performance of healthcare systems and make them safer and more people-centred—and is also key for building agency, trust, a sense of ownership of the system, and foster co-production of health and accountability of other actors in the system, such as policy-makers and healthcare professionals (Brito Fernandes, 2022).

7.      Beyond the patient-clinician interaction, the patient voice can be better integrated at the meso and macro levels of healthcare systems—there are lessons to be learned from sharing international good practices (Chapter 3. Patient safety can be improved through the active engagement of patients, families and carers, and communities in activities and policies that can contribute towards improving patient safety on the clinical (local), institutional (e.g., hospital, nursing home), community (e.g., primary care, home care), and national levels of healthcare systems (in the development of national policies). Enhancing the inclusiveness of development and execution of patient safety activities will not only contribute to safer care, as documented in the previous five reports in the series on the economics of patient safety, (Slawomirski, Auraaen and Klazinga, 2017[8]; Auraaen, Slawomirski and Klazinga, 2018[9]; de Bienassis, Llena-Nozal and Klazinga, 2020[10]; de Bienassis, Slawomirski and Klazinga, 2021[11]; de Bienassis et al., 2022[12]), but also a better use of available scarce healthcare resources.

8.      The speed at which policies were introduced or adopted in recent years suggests that with sufficient will, there is potential to progressively strengthen a people-centred agenda, including a clear role for patients, families and carers, and communities in patient safety. As countries implement reforms to support more resilient healthcare systems and address current economic challenges, such as inflation and labour shortages, they will need to further institutionalise the role of patients in their efforts to ensure safe, patient-centred care. Hence, strengthening patient engagement for patient safety is not only essential to effectively reduce harm through promoting safe healthcare and increased patient reporting, but also contributes to public trust and an efficient use of limited resources.

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[2] Global Ministerial Patient Safety Summit 2023 – 23rd & 24th February 2023 – Montreux, Switzerland (pss2023.ch)

**Box 1.1. Global Patient Safety Action Plan WHO Strategic Objective 4: Actions for Governments to Engage and empower patients and families to help and support the journey to safer healthcare**

**Strategy 4.1: Engage patients, families and civil society organizations in co-development of policies, plans, strategies, programmes and guidelines to make healthcare safer**

- Develop a national patient safety rights charter or bill with legal standing, to include concepts such as patient rights to safety, respect, autonomy, reliable care, information and transparency; and promote the concept of safe, respectful care as a human right.
- Embed the WHO Framework on Integrated People-centred Health Services in the design and delivery of safe health services.
- Create formal mechanisms to include patients and families in national governance mechanisms, working groups, task forces and committees that plan and take action to improve patient safety in the country.
- Create alliances with existing patient and civil society organizations on patient safety.
- Embed patient and family engagement standards in accreditation and evaluation.
- Include goals related to patient and family engagement as key components of short- and long-term strategic plans.

**Strategy 4.2: Learn from the experience of patients and families exposed to unsafe care to improve understanding of the nature of harm and foster the development of more effective solutions**

- Establish platforms, networks and events to bring together patient safety advocates, champions, patients and patient organizations to share their experience of avoidable harm or unsafe care and best practices in patient and family engagement.
- Create mechanism and strengthen platforms for sharing healthcare experiences of patients and families, including patient reporting on outcomes and experiences that highlight patient safety problems and point to solutions for patient safety improvement.
- Ensure that the patient and family experience of harm informs the design of all patient safety programmatic areas (for example, policy, education and training, research and information).

**Strategy 4.3: Build the capacity of patient advocates and champions in patient safety**

- Support and empower the development of networks of patient advocates and champions, and collaborate with the WHO Patients for Patient Safety programme.
- Establish, train and support a panel of patient and family advocates for patient safety to act as speakers at national and local conferences.
- Share the findings of patient safety reporting and learning systems with patient advocates and champions.

**Strategy 4.4: Establish the principle and practice of openness and transparency throughout healthcare, including through patient safety incident disclosure to patients and families**

- Develop national guidance for informed consent, for patient access to their medical records, and for a patient and family to escalate care concerns if they perceive a patient to be deteriorating.
- Develop a guidance framework and procedures for enabling healthcare professionals to disclose to patients and families the adverse events that have caused (or could have caused) inadvertent harm.
- Consider introducing legislation on disclosure policies to inform patients and families where guidance has not been effective

**Strategy 4.5: Provide information and education to patients and families for their involvement in selfcare and empower them for shared decision-making**

- Incorporate activities to enhance public education, including in schools and communities, and increase awareness of patient safety in the national patient safety plan.
- Include patient and family engagement in the patient safety education curriculum, and develop a specific curriculum for school-aged children.
- Develop mechanisms for providing information and education to patients and families to enable them to partner with healthcare organizations and with other stakeholders.
- Develop and disseminate public service announcements with clear messages about what patient and family engagement is and why it is important.
- Promote use of digital technologies, including smartphones, in improving awareness about patient safety and enhancing patient and family engagement.

WHO monitors progress made in patient engagement for patient safety based on the following indicators:

- Number of countries that have a patient representative on the governing board (or an equivalent mechanism) in 60% or more hospitals;
- Number of policies and guidelines on safer health care co-developed with patient and family representatives or patient organizations at national, subnational or health care facility levels;
- Number of countries or provinces that have established networks of patient advocates and champions;
- Number of countries, provinces or health care facilities that have established a patient and family advisory committee (or its equivalent);
- Number of countries, provinces or health care facilities that have developed and implemented procedures for disclosure of adverse events to patients and families;
- Number of countries, provinces or health care facilities that measure patient-reported experiences or related safety outcomes.

Source: (WHO, Global Patient Safety Action Plan 2021–2030: Towards eliminating avoidable harm in health care, 2021)

## 1.2. Meaningful patient engagement is critical for ensuring safe healthcare

9.      There is a growing evidence base showing the importance of patient engagement for patient safety in preventing and managing incidents, learning from them, and improving safe delivery of care (Bell, et al., 2022). The Promoting Respect and Ongoing Safety Through Patient Engagement Communication and Technology (PROSPECT) study in the US, for example, showed that implementation of a structured team communication and patient engagement programme in Intensive Care Units was associated with one third less adverse events and improved patient satisfaction (Dykes, et al., 2017). The OpenNotes movement in the US (inviting patients to read their clinicians' notes online) demonstrated that the patient-feedback tool enhanced safety through patient-reported documentation errors (Bell, et al., 2016).

10.      To improve the value of engagement, meaningful participation is key. Several frameworks have been developed to assess how patient engagement might occur across levels of health systems. The typology of different levels of citizen engagement was first defined by Arnstein in the 1960s (Arnstein, 1969). From most engaged to least, Arnstein defines eight levels of citizen engagement—*citizen control, delegated power, partnership, placation, consultation, informing, therapy, and manipulation*—showing the extent of citizen's power in determining the outcome. Arnstein's ladder provides a basis for the more recent frameworks for patient engagement (Carman, et al., 2013; Yorkshire Quality and Safety Research Group, 2016).

11.      The OECD's Framework on People-Centred Health Systems defines five key dimensions for the engagement of patients and, more broadly, citizens in policymaking—*ensuring voice, choice, co-production, respectfulness, and integration of care* (OECD, 2021). This framework explores the participation of patients in health policymaking and the extent of their participation. Complementary OECD research has assessed the level of stakeholder engagement, namely patients, providers, and others, in the design, development, and field trial implementation of the international PaRIS survey[3] of people living with chronic conditions (Kendir, et al., 2023). The PaRIS survey collects patient-reported outcome and experience measures on various dimensions including patient safety. The study used an adapted framework classifying the level of engagement in four ascending levels: *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), and *co-designing* (e.g., having a decision-making role in a steering group).

12.      Patient engagement can take various forms across different levels of a healthcare system based on the extent of patients' roles in care decisions from least to most active role—*information, involvement, partnership or shared leadership* (Carman, et al., 2013; Yorkshire Quality and Safety Research Group, 2016). **Informed/consulted** is the least active engagement level including sharing information with patients about safety initiatives. For example, putting posters about hand washing in the hospital corridors can be considered an informative engagement at the organisational level. **Involved** represents more active engagement compared to informed/consulted, yet less active than partnership/co-design. An example of being involved could be about incident reporting portals or surveys which are accessible to patients at the organisational or national levels. The level of **partnership/co-design** is the most active engagement in which patients can be part of design or decision-making. For example, patients and their caregivers can take an active role in quality and safety committees of institutions advising on patient safety concerns or initiatives at the organisational level. Table 1.1 provides more examples of patient engagement on different levels of healthcare systems.

**Table 1.1. Selected examples of patient engagement for patient safety across various levels of healthcare on different engagement levels**

|  | Informed/ consulted | Involved | Partner/ co-designed |
|---|---|---|---|
| **Clinical care level (Micro level)** | Informing patients about safety incidents | Involving patients in incident analysis | Patients and providers work together to improve patient safety in their own care |
| **Organisational level (Meso level)** | Posters in the corridor of hospitals about patient safety topics | Incident reporting on adverse events | Patients as part of quality and safety improvement committees |
| **National level (Macro level)** | Public consultations for patient safety policy initiatives | Patients as advisors to quality and safety initiatives | Patients have a decision-making role in steering committees or working groups |

Note: From left to right, the level of engagement (i.e., active participation) increases.
Source: Authors based on (Arnstein, 1969) (Carman, et al., 2013) (Yorkshire Quality and Safety Research Group, 2016)

## 1.3. Patient-reported measures in enhancing patient engagement for patient safety

13.      To make health systems more responsive to the needs of patients and promote people-centredness, it is indispensable to measure and monitor their experiences with healthcare and use these

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[3] https://www.oecd.org/health/paris/

data to inform policymaking and improve healthcare quality. In patient safety, patient-reported measures are particularly crucial since administrative data reported by providers are often under-reported. Since patient-reported measures complement existing patient safety indicators based on administrative data and could inform the extent and type of patient safety issues occurred in the health system, several countries included questions to measure and monitor patient-reported experiences of safety in their routine surveys (e.g., Australia, Austria, Canada, Denmark, Estonia, Ireland, Mexico, New Zealand, Norway, Slovenia, Sweden, Switzerland, the United Kingdom (England), and the United States).

14.     To harmonise these monitoring efforts, the OECD developed a set of survey questions (see Box 2.2) on patient-reported experiences of safety that can be used for national and international monitoring and evaluation of health systems' performance. The development of survey questions focused on aspects of patient safety that have clinical and policy importance and are important to patients across countries. These survey questions cover aspects of patient safety which can be assured or improved by changes in providers' practices or health policy across countries. This set of survey questions on patient-reported experiences of safety measure domains such as prevention of patient safety incidents, patient-reported incidents, and incident management. A few countries including Belgium, Canada, Estonia and Poland have included these questions in their surveys and a few comparable questions were also included in the Commonwealth Fund's International Health Policy Survey which covers 11 OECD countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States), in recent years (see Chapter 2. ).

## 1.4. The importance of building public trust in patient safety and safety of the provision of care

15.     In the 2023 Global Ministerial Summit on Patient Safety, policymakers have recognised the importance of building trust for patient safety. Action point 6 calls for action on trust by stating "*Reinforce a safety learning culture and transparency while promoting public trust across all healthcare services among all stakeholders, including patients and the public*".

16.     Trust in healthcare systems and patient safety are closely related (de Bienassis, Mieloch, Slawomirski, & Klazinga, 2023). When patients trust the healthcare system, they are more likely to seek care when needed, agree with treatments, ask questions, and may also be more likely to express concerns and report adverse events or errors (Kvarnström, Westerholm, Airaksinen, & Liira, 2021; Rasiah, et al., 2020). Moreover, when patients trust the healthcare system and their providers, they may be more likely to engage in their care and participate in efforts to prevent harm. Moreover, trust can be built through improved patient engagement and involvement in healthcare delivery and policymaking.

17.     Concerns about health system safety have been exacerbated in recent years through poor messaging and a lack of clear information, fostering mistrust in the population. Over the course of the COVID-19 pandemic, countries have observed increased levels of distrust in government capacity to handle the crisis and operate health systems effectively. Trust in healthcare institutions (on a 1-10 scale) has declined from 6.4 in the fourth quarter of 2020 to 5.7 in the third quarter of 2022 across EU countries (Eurofound, 2022). This result is aligned with low levels of engagement in policymaking as suggested by a OECD survey, which found that only 35% of responding countries actively involved stakeholders in their design of COVID-19 response strategies (OECD, 2021). Better communication—effectively packaging and delivering information to diverse population groups in an understandable and acceptable manner—is needed in the current environment in which unreliable information is crowding (Alfonsii, Varazzanii, Hui, Tan, & Sullivan-Paul, 2022; OECD, 2022).

18.     Public communication is a critical function of health systems, essential for coherent messaging both internally and externally, and is a key tool for effective policy design and implementation. Effective public communication is key to supporting the open government principles, ultimately serving to enhance

good governance and build citizen trust. Good communication empowers individuals to understand issues and act on the information they receive.

19.    In the case of patient safety, public communication is essential to communicate risk and build trust and is essential to the timely and beneficial dissemination of critical information. By proactively releasing up-to-date, reliable, and comprehensible information, such as that pertaining to medication safety, in accordance with access to information laws, people can have confidence in the efficacy of regulations and policies.

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**Box  1.2. Key terms/definitions used in this report**

**Patient engagement**

"Patient engagement as patients, families, their representatives, and health professionals working in active partnership at various levels across the healthcare system—direct care, organizational design and governance, and policy making—to improve health and healthcare." (Carman, et al., 2013)

**Levels of healthcare**

- System (macro)-level patient safety strategies, programmes and initiatives that are best approached and implemented across an entire system. Implementation would typically require legislative or high-level policy levers, and often benefit from broad (societal level) public engagement.
- Organisational and institutional (meso)-level patient safety programmes, initiatives or practices that - while often aimed at a particular clinical area or patient profile – should be implemented across an entire healthcare organisation or institution.
- Clinical (micro)-level patient safety practices that may span organisations but are optimally initiated at practice level and managed within the clinical microsystem (which includes the involvement of patients and their surrogates, and administrative staff working with practitioners and patients).  (Slawomirski, Auraaen and Klazinga, 2017[8])

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## 1.5. The economics of patient engagement for patient safety

20.    A people-centred approach is a critical element in safe, high-quality care. Previous papers in the Economics of Patient Safety series have highlighted that patient and family engagement is strongly associated with better outcomes and less harm, and that such organisational interventions are very likely to represent good economic value (Slawomirski, Auraaen and Klazinga, 2018[28]; Slawomirski, Auraaen and Klazinga, 2017[29]; de Bienassis et al., 2022[12]).

21.    Assessment of the economics of patient safety can take numerous forms (see Figure 1.1). The assessments made in the previous economics of patient safety reports have primarily assessed two of these methods: (1) assessment of macro-economic costs related to increased utilisation of health services following adverse events by calculating preventable spending by the health system, and (2) quantification of the return on investment of better practices by conducting analysis of implementation of financial incentives within the system (e.g., investment in prevention). Yet, the evidence bases for assessing the macro-economic costs related to increased utilisation of health services that could have been averted due to lack of adequate patient engagement requires further development.

22.    On the other hand, financial incentives from a macro-economic perspective for patient engagement in aspects of care have been documented. For example, studies of clinical trials have found significant benefits of engagement, such as improving enrolment, adherence, and retention (Levitan et al., 2018). Patient engagement has also been linked to health costs. Research from the US using data on 30 000 patients found patients with the lowest activation scores (engagement levels) incurred health-

costs between 8 to 21 percent higher than those with the highest scores, even adjusting for health status and other factors (Hibbard, Greene, & Overton, 2013).

23. New to the type of analysis previously conducted in this series, this report will document examples of costs to the health system that result from legal compensation (see Section 1.5.2). While these costs may not be directly related to the scope of patient engagement, they are examples of costs that have the most direct relevance to patients and can subsume significant portions of healthcare budgets. For example, the costs driven by the lack or poor operationalisation of duty of candour legislation (see Section 4.1). Future work may also further examine quantification of the long-term impacts for individuals who have experienced a patient safety event. Examples from the US looking at long-term individual economic impacts of experiencing health-related events could serve as an example (O'Hara, Slobogean, Klazinga, & Kringos, 2021).

**Figure 1.1. Conceptualisation of types of economic analyses to quantity the economic impact of patient safety events**
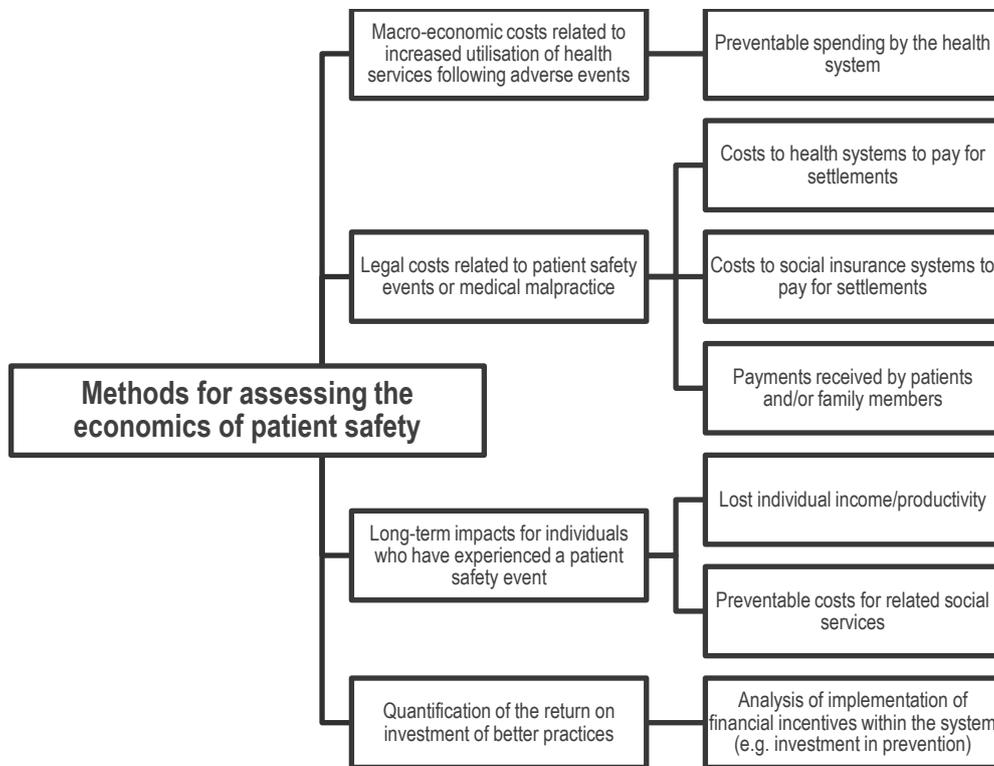


Source: Authors.

### 1.5.1. More analysis is needed to understand the scope of possible impact of patient engagement for patient safety

24. While the evidence bases for return on investment of patient engagement for patient safety is nascent, the research basis is growing. A review of almost 3 000 papers examining the impacts of engaging patients for patient safety, found that while the scope of improvement varied across studies and intervention, no study showed evidence of harm from patient engagement outcomes (Sharma, et al., 2018). A 2014 review of assessing studies on promoting engagement by patients and families to reduce adverse events in acute care settings found that none of the reviewed studies directly evaluated the costs

or cost-effectiveness of practices designed to promote patient or family engagement with safety (Berger, Flickinger, Pfoh, Martinez, & Dy, 2014).

25.     Some discrete interventions show promise. A recent assessment of a novel digital monitoring system to prevent and identify surgical site infections after joint replacement, for example, was found to both reduce staff costs and improve patient engagement (Yahanda, et al., 2019). At the system level, in the US, the implementation of the Partnership for Patients' Hospital Improvement Innovation Networks (HIINs) was found to reduce hospital-acquired conditions and credited to have prevented 20 500 hospital deaths and save USD 7.7 billion in healthcare costs between 2014 to 2017 (CMS, 2022).

26.     A specific area where patient engagement has been found to reduce both harms and costs relates to transitions in care. Medication reconciliation/review at time of transition of care is another intervention that has been adopted by many countries to improve medication safety and person-centred care (de Bienassis, Esmail, Lopert, & Klazinga, 2022). This activity often involves developing a complete list of a person's medications, reviewing them for accuracy, and assessing and documenting any changes.

### 1.5.2. Data on the scope of payments to patients because of patient safety harms is limited

*The scope and costs of litigation related to medical malpractice and harms experienced in healthcare*

27.     The costs of patient harm can be derived from numerous sources. Costs of excess care (i.e., healthcare provided to address harms caused over the course of care) has been the estimation method primarily used to assess the costs of patient harm in previous reports in the Economics of Patient Safety series. However, another source of costs to health systems relates to payments made to patients because of litigation in response to adverse events. Currently, few countries can report on the number of patient safety incidents that result in litigation or assess national estimates of how much is spent annually on patient safety settlements with patients.

28.     In 2021, **Ireland** documented 3 626 Clinical Claims corresponding to an overall estimated outstanding liability EUR 3.41 billion (National Treasury Management Agency, 2021). While clinical claims made up only 32% of the overall number of active claims documented by the State Claims Agency at the end of 2021, they comprised 75% of the overall estimated outstanding liability. In **France**, data are only available for disputes settled out of court by the Office National d'Indemnisation des Accidents Médicaux (ONIAM). In 2021, 1 149 people were compensated out of court, including 803 direct victims. Total victim expenditure compensated via ONIAM was EUR 165 million in 2021 (ONIAM, 2022). In 2021, the average amount of compensation in France via this system was EUR 142 500. In the **United States**, between 2021 and 2022 medical malpractice payment reports were filed, corresponding to payments of USD 6.8 billion (HRSA, 2022).

29.     In **Korea**, according to the Medical Dispute Mediation and Arbitration Statistics Yearbook 2021, there were 154 and 861 arbitration decisions and settlements in 2021, respectively (not all of which can be attributed to patient safety incidents), totalling approximately KRW 10.5 billion (approximately EUR 7.5 million)[4]. In **Latvia**, 38 cases were settled from the 150 applications examined by the Health Inspectorate in 2021, resulting in payments made by the Medical Risk Fund[5] of approximately EUR 1.2 million.

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4 All values for litigation and settlements are from the Korean Medical Dispute Mediation and Arbitration Statistical Yearbook 2021.
5 Operational rules of the medical risk fund: https://likumi.lv/ta/id/262102-arstniecibas-riska-fonda-darbibas-noteikumi
Statistics on Medical Risk Fund: https://www.vi.gov.lv/sites/vi/files/media_file/vi_publ_parsk_2021.pdf page 27-28

*Systems of no-fault compensation to compensate patients for patient safety events*

**30.**     Systems of no-fault liability compensate patients who suffer any treatment-induced injury and need not be related to instances of medical malpractice or negligence (Horwitz & Brennan, 2017). According to the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey*, 9 out of 21 responding countries reported having these systems in place. Countries that indicated having a system of no-fault compensation to patients who have been impacted by certain safety events include **Austria, Belgium, France, Japan, Korea, Latvia, New Zealand, Portugal** and **Switzerland.**

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**Box  1.3. 2023 OECD Assessment of Policies to Engage Patients for Patient Safety Survey**

In March 2023, the OECD, with the support of the Government of Germany, conducted analysis on the status of initiatives on patient engagement for patient safety and the economic benefits of patient engagement for patient safety being undertaken to improve patient engagement for patient safety in OECD member countries (as part of the Economics of Patient Safety Series).

The survey included 34 questions, covering the following areas:

- Policy context related to patient engagement for patient safety;
- Legal context related to patient engagement for patient safety;
- Patient engagement as a lever for designing and implementing patient safety strategies; and
- Priorities in relation to patient engagement for safety activities.

**Survey participation**

Twenty-one countries (Austria, Belgium, Canada, Colombia, Costa Rica, Czech Republic, France, Germany, Iceland, Ireland, Israel, Japan, Korea, Latvia, the Netherlands, New Zealand, Portugal, Romania, Slovenia, Switzerland, and Türkiye) participated in the survey. Data from this survey informed this current report, which explores the advances countries have made to drive improvements in patient safety and improve people-centred care. The full survey questionnaire can be found in 4.3.Annex B.

Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey.

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31.     In **Belgium**, the law of 31 March 2010 on the compensation of damage caused by healthcare introduced a new subjective right of compensation for victims of medical incidents in the Belgian legal system for medical incidents without liability. According to this law, a victim of a medical incident and any surviving relatives can receive compensation from the Fund for Medical Injuries if there is no (proven) liable healthcare provider and the victim has suffered abnormal and serious damage. In certain cases, the Fund for Medical Injuries will also intervene if the healthcare provider is liable. In **France**, the régime d'indemnisation des accidents médicaux non fautifs is also managed by ONIAM. Compensation provided through the system is allocated for each type of damage and is published based on publicly reported indicative benchmarks[6].

32.     **New Zealand's** Accident Compensation Legislation (ACC) includes provisions for injury experienced by people receiving care by registered health professionals and for harm experienced over the course of treatment (New Zealand Legislation, 2001)[7]. In **Portugal**, no fault compensation covers incidents related to the delivery of healthcare, including those related to patient accidents (e.g., falls,

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6 https://www.oniam.fr/procedure-indemnisation/bareme-indemnisation

7 In addition, the recently updated 'healing, learning and improving from harm' policy (previous adverse events policy 2017) comes into effect 1 July 2023 and provides consumers and whānau the opportunity to notify an event of harm occurring when accessing healthcare (Health Quality & Safety Commission New Zealand, 2023).

pressure ulcers), behaviour (both on the part of health professionals and the patient), medical devices and equipment, documentation, infection associated with healthcare, and clinical procedures (e.g., diagnosis, evaluation, procedure/treatment), among others. In **Korea**, the medical accident compensation system covers incident during the delivery process (e.g., neonatal cerebral palsy, corresponding to an approximate payment of KRW 30 million / EUR 21 000), adverse drug reactions, and vaccination damage. In **Japan**, the Japan Obstetric Compensation System for Cerebral Palsy provides compensation to the families of children with cerebral palsy who develop the condition in connection with childbirth. In **Austria**, the Hospital Act states that the provinces must make provisions for compensations for patients where a fault cannot be proven, the scope of compensation is also regulated at the provincial level. In **Canada**, while a general no faulty liability system does not exist, a no-faulty liability system was set up for vaccine injury (Public Health Agency of Canada, 2020).

33.      Initial evidence from countries that can provide data on the legal costs of adverse events shows that the financial burden can be considerable. In addition, it is very likely that many of the patient safety events leading to the need for financial compensation might have been prevented through various investments in patient safety improvement, including, potentially, better patient engagement for patient safety. Despite the available evidence, more information is needed to understand the economic impact of patient engagement for patient safety. Additional research questions for future exploration are documented in Box 1.4.

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**Box 1.4. Further development is needed to understand the economic impact of patient engagement for patient safety**

- Quantification of the value of having patients, families and carers as members of the care team in producing good health outcomes (OECD, 2021)
- Cost of non-compliance associated with low trust in health institutions
- (Dis)Incentives in the financing models of healthcare services towards increasing safety through patient engagement
- Quantification of economic gains of patient engagement in reducing harms in healthcare

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# 2. Measurement of patient safety from the patient perspective

34.      Given the increasing importance of patients, families, carers and communities' perspectives in understanding and informing the extent of patient safety incidents occurring, co-designing high quality safe care delivery and improving ways to prevent unsafe care and handle safety events, efforts to monitor patient-reported experiences of healthcare safety have expanded across countries in recent years. Yet, their perspectives in assuring safe care, preventing harms and signalling potential risks of patient safety events not only for themselves but also for others receiving healthcare are not often sufficiently and systematically explored and utilised. In this context, the OECD has worked with survey methodology experts and patient representatives and developed a set of survey questions and patient-reported experiences of safety indicators to improve national and international reporting of patient safety from the patient perspective. Several OECD countries have started using these measures for improving patient safety and health system strengthening.

35.      This chapter starts with the rationale for measuring patient-reported experiences of safety, followed by national and international efforts to develop patient-reported safety indicators which include development, testing, and implementation of a set of survey questions to measure patient-reported experiences of safety, and results of pilot data collection conducted in OECD countries. The chapter then highlights national efforts worthy to note for utilising patient-reported measures for improving healthcare safety and concludes with further development which could be explored in relation to measuring patient safety from the patient perspective.

## 2.1. The significance of measuring patient-reported experiences of safety is increasing

36.      Patient-reported measures have been used to monitor and evaluate people-centred care delivery and inform people-centred health policymaking. In the area of patient safety, patient-reported measures are particularly crucial since administrative data, reported by providers for reimbursement and conventionally used to monitor patient safety such as a foreign body left in during a surgery, are often under-reported, leading to difficulties in grasping the actual extent of patient harm occurring in health systems. The extent of underreporting varies across countries and sometimes even within countries. In some cases, higher, never or adverse event rates may be due to more developed patient safety monitoring systems and stronger patient safety culture and signal high policy priority in patient safety, rather than worse care. Beside these variations, differences in coding practices, diagnostic practices and treatment guidelines add to the complexity in within- and cross-country comparisons of these patient safety indicators based on administrative data source. In this context, patient-reported experiences of safety are considered important as they complement existing patient safety indicators based on administrative data and could inform more comparatively the extent and type of patient safety events occurring in the health system.

37.    There are other benefits in measuring patient-reported experiences of safety. Measuring patient experiences improves health literacy of patients, families, carers and citizens, and contributes to building public trust in health systems and safe delivery of healthcare and to promote their engagement in safe healthcare delivery (see Chapter 1). Patient-reported experiences, for example, could inform additional insights on how to assure safe care, prevent unsafe care, and manage and handle patient safety incidents in a people-centred manner. They could also help understand healthcare users' perceptions on unsafe care, which refer not only to physical harms such as pain and infections and emotional distress, but also to other issues such as poor communication and not feeling confident about safety in care and treatment, which could be difficult for healthcare professionals to notice as essential components for delivering safe care but could signal risks associated with unsafe care. Patients, families and caregivers may also have concerns about safety throughout the care pathway, for example, in relation to care coordination and follow-up care. These concerns could be raised by patients and their families and carers who experienced hospitalisation. However, healthcare professionals who had just provided hospital care to patients may not notice concerns about care coordination since their primary focus may be the quality and safety of hospital care that they take a lead role in providing, rather than the care to be provided after hospitalisation by other healthcare professionals. Thus, patients, families and carers' perspectives are valuable for co-designing high quality safe care delivery and improving healthcare quality throughout the patient pathway.

38.    Given the importance of monitoring and evaluating patient-reported experiences of safety to improve the quality of healthcare and promote people-centred care delivery, in recent years, an increasing number of OECD countries have developed and validated (population-based) surveys that include questions about experiences of safety. Over a third of OECD countries (e.g., Australia, Austria (PaBe_Ergebnisbericht_2022 (goeg.at)), Canada, Denmark, Estonia, Ireland, Latvia, Mexico, New Zealand, Norway, Poland, Slovenia, Sweden, Switzerland, the United Kingdom (England), and the United States) have conducted a survey including at least one question measuring experiences of healthcare safety among adult patients who were discharged from the hospital. A few OECD counties (e.g., Canada, Denmark, Germany (see Box 2.1), New Zealand, and the United Kingdom (England)) have also conducted a survey including questions to measure experiences of healthcare safety among people who have used primary care services. In New Zealand, patient surveys including questions to measure patient experiences of safety such as good communication, care coordination and sharing of information about managing condition, follow-up care and medication have been implemented in primary care, hospital inpatient and outpatient care settings (Patient experience | Health Quality & Safety Commission (hqsc.govt.nz)). In Ireland, the National Care Experience Programme (NCEP), a partnership between the health and social care regulator (Health Information and Quality Authority, HIQA), the national public healthcare provider (Health Service Executive, HSE), and policy makers (Department of Health), conducts national care experience surveys (https://yourexperience.ie/) with the aim of learning from people's experiences in order to improve the quality of health and social care services. Since its establishment, the programme has conducted regular acute hospital inpatient surveys and has expanded into other clinical and non-acute care settings including, maternity, maternity bereavement, nursing homes and end-of-life care. Additional surveys of cancer care and mental health services are currently in development. Surveys routinely include questions regarding involvement in decision making, provision of information on medication side effects and response to complaints.

> **Box  2.1. German patient experience survey in ambulatory care**
>
> Germany conducted a patient survey for ambulatory care, which included 18 questions on patient safety covering various domains such as communication, access to information and medication and asking to describe experiences of patient safety harms, errors, incidents directly related to GP practice visit. The survey instrument was built based on existing patient surveys in primary care, and additional domains and items were included after applying the Delphi method to a group of patient safety experts. In order to reduce the number of questions, an open-ended question was also included. The instrument was finalised after cognitive tests conducted with patients.
>
> Support was obtained from German Safety Alliance and a physician association in the region participating in the study, and through these partners, GP practices were recruited for the survey implementation. Data were collected through paper-based and online survey. To assure high response rates, two reminders were sent to practices to follow up. The overall response rate was high among patients visiting participating practices (70%). Following data collection, the survey instrument was found to have good validity. The information collected through this survey was also used as one of the inputs for an incident reporting project.
>
> Together with German and international expert panels, best evidence on clinical audit, feedback strategies and literature on nudging were used to design a reporting tool which could effectively lead to practice changes and policy actions. Additionally, an online reporting tool was developed for GP practices where they can see their own report compared to their peer groups.
>
> Source: OECD Working Party on Patient-Reported Safety Indicators.

39.      Population-based international surveys for adult patients such as the Commonwealth Fund's International Health Policy Survey and Special Eurobarometer on Patient Safety and Quality of Care, also included a few questions to measure patient-reported experiences of safety. The Commonwealth Fund's International Health Policy Survey was run in 2020 among 11 OECD countries (Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States) and included questions related to patient safety; a new edition of the survey will be conducted in 2023. The Special Eurobarometer on Patient Safety and Quality of Care was conducted in all 28 European Union member states in 2009 and 2013.

## 2.2. The OECD's set of survey questions was developed to measure patient-reported experiences of safety and tested for national and international comparisons

40.      To harmonise these national and international efforts, the OECD formed a working group in 2019 to develop a set of survey questions to measure and monitor patient-reported experience of safety that can be used for national and international monitoring and evaluation of health system performance. As of now, 15 OECD countries (Belgium, Canada, the Czech Republic, Estonia, France, Germany, Italy, Japan, Latvia, the Netherlands, Poland, Portugal, Slovenia, Sweden, and the United Kingdom (Wales)) and representatives from European Patients' Forum and the Commonwealth Fund, based in the United States, participate in the working group. The indicator development work focuses on aspects of patient safety that have clinical and policy importance and are important to patients across countries, and cover aspects of patient safety which can be improved by changes in providers' practice or health policy across countries.

41.      Since patients' input and involvement is crucial, together with survey methodological experts, patient representatives who have taken part in patient-led patient safety initiatives, were appointed by each participating country, and they were involved in survey development to ensure the relevance of survey questions to patients themselves. During the survey development, participating countries undertook focus group discussions with patients themselves to make sure survey questions and

response categories measure what are intended to measure and based on their input phrasing and response categories of survey questions were refined.

42.     After several iterations, the OECD working group developed a set of survey questions measuring domains such as prevention of patient safety incidents/promotion of patient safety, and patient-reported incidents and management of patient safety issues for patients discharged from hospitalisation. Hospitalised patients were selected as the target population for the survey as most countries participating in the working group considered that a possibility of testing such survey would be higher than surveys for the general population, or patients receiving care in other settings including primary care. Eighteen survey questions were developed and among them, two questions are open-ended to allow patients to provide any information related patient safety incidents that they have experienced, and to learn from them to improve the delivery of people-centred safe care (see Box 2.2; Patient-Reported Safety Indicators: Question Set and Data Collection Guidance).

43.     For some important topics related to patient safety, survey questions were not developed because they were considered inadequate for international comparisons, such as ID checks and hand hygiene. This is because there are wide variations in healthcare professionals' practices, for example, in checking patient's ID across countries and providers within countries and it was found difficult to develop a standard survey question that would be clear and understandable to respondents across countries. These topics, however, may still be important to inform national and local governments and providers in seeking ways to prevent patient safety events and promote safe care within countries. Thus, together with the set of survey questions developed, the possibility of measuring other important priority patient safety topics in the national context would need to be explored when developing national surveys.

44.     Several countries including Belgium, Canada (New Brunswick), Estonia, Latvia, and Poland have implemented at least part of the survey questions developed by the OECD's working group to measure patient experiences of safety in their national or regional surveys, and conducted data collection in recent years, as shown below. The Netherlands and Sweden have also conducted national surveys which included at least one question similar to the OECD-proposed questions.

45.     In **Poland**, the National Centre for Quality Assessment in Healthcare developed a Patient Experience Study and collects, analyses and reports patient-reported experience of healthcare safety. Poland translated a set of survey questions proposed by the OECD working group, developed a survey by adapting from these questions and including additional questions and validated the survey tool prior to data collection. A standardised user-friendly data collection and reporting tools, which are compatible with the existing system, were developed by involving quality and patient safety specialists, hospital boards and IT specialists to facilitate national rollout of this survey. A simple online tool was also designed for patients, allowing them to answer questions through their mobile phone or PC. The survey implementation started in 2020 at hospitals participating voluntarily in this project and no charge was incurred to these hospitals. Survey response rates were not initially high, and to increase response rates, a monthly webinar was held to exchange good practices among participating hospitals. Following this, survey implementation has expanded rapidly, and the national rollout is going very well; in 2021, 9 000 survey responses were collected, in 2022, 135 hospitals implemented the survey and on average 150 patients responded daily, amounting to 54 000 responses in a year, and in 2023, 140 hospitals are participating in the survey implementation and on average 250 patients respond every day, possibly reaching 100 000 survey responses by the end of the year. The survey is available in Polish and English, and there is a plan to develop it in other languages to cover hospitalised patients with different linguistic backgrounds.

**Box 2.2. Patient-reported incident measures: survey questions and response categories**

1. **During this hospital stay, did you feel that there was good communication about your care and treatment between doctors, nurses and other hospital staff?** Always; Usually; Sometimes; Rarely or never; Not sure; Decline to answer

2. **During this hospital stay, were you told who or which part of hospital to contact if you have any concerns or worries about your care or treatment?** Yes; No; I do not remember; Decline to answer

3. **During this hospital stay, did you feel comfortable to speak out at any time about anything that you might wish to raise with hospital staff?** Yes, definitely; Yes, to some extent; No, not really; No, definitely not; Not sure; Decline to answer

4. **If you spoke out, was this welcomed?** Yes, definitely; Yes, to some extent; No, not really; No, definitely not; Not sure; I did not need to speak out; Decline to answer

5. **During this hospital stay, did you feel confident in the safety of your treatment and care?** Yes, definitely; Yes, to some extent; No, not really; No, definitely not; Not sure; Decline to answer

*Errors, violation, patient abuse and deliberately unsafe acts can occur in hospital and we would like to know if you have experienced any patient safety incident during this hospital stay. Patient safety incident refers to "an event or circumstance that could have resulted, or did result, in unnecessary harm to [you]" (WHO, 2009[3]).*

6. **Did you experience any patient safety incident(s) during this hospital stay?** Yes; No; I don't know; I do not remember; Decline to answer To those who answered "Yes" to Q6 -> Please describe the patient safety incident(s) that you have experienced. _____

7. **To those who answered "No" to Q6 How did you find out that you experienced patient safety incident(s)?** I was told by a hospital staff; I noticed it myself; I was told by my family; I was told by somebody else; I do not remember; Decline to answer To those who answered "I noticed it myself; I was told by my family; I was told by somebody else" to Q8

8. **Did you report your experience to a hospital staff?** Yes; No; I do not remember; Decline to answer To those who answered "Yes" to Q6

9. **Was this/these incident(s) managed in a way you wanted?** Yes; No; I do not remember; Decline to answer To those who answered "Yes" to Q10

10. **Please select all the reasons why this/these incident(s) were managed in a way you wanted.** Hospital staff provided an explanation for the incident(s); Hospital staff apologised; Hospital staff offered support; I was able to tell my story; I was invited to take part in analysing what had caused the incident; Other reasons [please specify]; I do not remember; Decline to answer To those who answered "No" to Q10

11. **Please select all the reasons why this/these incident(s) were managed in a way you did not want.** Hospital staff did not provide an explanation for the incident(s); Hospital staff did not apologise; Hospital staff did not offer any support; I was not able to tell my story; I was not invited to take part in analysing what had caused the incident; Other reasons [please specify]; I do not remember; Decline to answer To those who answered "Yes" to Q6

12. **During this hospital stay, other than this/these patient safety incident(s), was there a time when you were in any way upset as a result of the way you were cared for or treated by hospital staff?** Yes; No; I do not remember; Decline to answer OR To those who answered "No; I don't know; I do not remember; Decline to answer" to Q6

13. **During this hospital stay, was there a time when you were in any way upset because of the way you were cared for or treated by hospital staff?** Yes; No; I do not remember; Decline to answer To those who answered "Yes" to Q13 Please describe your experience(s). _____

14. **Did you speak to any hospital staff about this/these experience(s)?** Yes; No because I did not know whom to speak to; No because of other reasons; I do not remember; Decline to answer

15. **Before you left the hospital, did you get all the information you needed in order to know what symptoms or health problems to look out for after you left the hospital?** Yes, definitely; Yes, to some extent; No, not really; No, definitely not; Not sure; Decline to answer

16. **Before you left the hospital, was it clear to you how your care or treatment will continue after your hospital stay?** Yes, definitely; Yes, to some extent; No, not really; No, definitely not; Not sure; Not applicable, I did not need any follow-up care or treatment; Decline to answer 10

17. **Before you left the hospital, did a hospital staff explain how to take all your prescribed medications including those you were taking before this hospital stay (e.g., the time to take your medication, side effects to watch out for, etc.) in a way that was easy to understand?** Yes, definitely; Yes, to some extent; No, not really; No,

> definitely not; Not sure; Not applicable, I did not have any prescribed medications; Decline to answer Some questions on patient's socio-economic background for disaggregated analysis, at the end of the survey
>
> Source: OECD Working Group on Patient-Reported Safety Indicators.

46.     In **Belgium**, the PAQS which aims to promote, support and organise the development and implementation of initiatives for improving quality of care and patient safety in healthcare institutions in Brussels and Walloon regions, conducted a pilot data collection of patient-reported experiences of safety. It first conducted forward and backward translation of a set of the OECD-developed survey questions, and adapted questions to the local context by incorporating feedback collected from two rounds of focus group discussions with patient representatives. Although delayed due to the COVID-19 pandemic, in 2021, the target population for pilot data collection was recruited systematically based on a set of criteria, and three health insurance funds in Brussels and Walloon regions invited patients who were hospitalised in French-speaking hospitals to participate in the online survey. Psychometric analysis was conducted to evaluate the validity and reliability of the survey instrument. It is envisaged that results of the pilot data collection will inform the implementation of future pilot projects foreseen and further development of the survey tool.

47.     In **Canada**, patient-reported experience measures in relation to communication and continuity of care have been monitored over time, and to corroborate the data/public accountability, the New Brunswick Health Council regularly conducts a patient experience survey including additional questions related to patient safety, which are comparable to those developed by the OECD working group. The surveys[8] in Canada are validated in both French and English, and the latest survey in New Brunswick (https://nbhc.ca/surveys/2023-hospital-acute-care-survey) is being conducted in 2023.

48.     Several OECD countries also made progress in measuring patient-reported experiences of healthcare safety in recent years despite the COVID-19 pandemic, underlining the importance of patient safety and patient engagement for patient safety. **Estonia** translated the survey questions developed by the OECD working group, collected data by using some of the questions in 2020 and expanded the data collection from patients discharged from a wider range of hospitals in recent years. **Latvia** developed also a survey including questions developed by the OECD's working group and has started collecting data from several adult hospitals and a children hospital in 2020. The data collection has expanded to patients discharged from 20 out of 56 hospitals and responses were collected from over 8 000 patients in 2021. The Commonwealth Fund's International Health Policy Survey was also conducted during the pandemic in 2020 and collected several measures to monitor and report differences in patient experiences of safety across 11 OECD countries.

49.     More recently, in **Italy**, the National Agency for Regional Healthcare Services (AGENAS) is carrying out a project in collaboration with the University of Genova and ASL Toscana Nord Ovest. As part of this project, these organisations plan to translate the OECD-developed survey questions, adapt them to the national context and conduct content and face validation and psychometric analysis using data collected in two hospitals in the Liguria and Tuscany regions.

50.     Additionally, patient experience measures are also being developed to improve prevention of patient safety incidents in **France**. The Haute Autorité de Santé focuses on developing indicators on hand hygiene based on a patient survey as part of the 2022-2025 National Strategy on Prevention of Infection and Antimicrobial Resistance to complement the existing indicators measured using hydroalcoholic solution in France. The survey composed of 5 questions was developed by a working group represented by patients, and following focus group discussions conducted in 2022, pilot data collection is being undertaken in 2023. Based on the results of pilot data collection, the survey instrument will be validated, and regular data collection will be considered.

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[8] https://nbhc.ca/surveys/hospital-acute-care-survey

## 2.3. Across OECD countries, up to about one in six patients reported patient safety incidents and preventive practices need to become a norm

51.      The OECD conducted a pilot data collection based on a set of questions developed by the working group, and a pilot study found that the proportion of patients reporting experiences of patient safety incidents varies between 4 and 17% across countries. According to the Commonwealth Fund's 2020 International Health Policy Survey, the proportion of adult patients reporting experiences of medical mistakes in the past two years varied between 6% in France and 10% in Germany and the United States. Among hospitalised patients, the proportion of adult patients who experienced patient safety incidents during the last hospitalisation was 4% in Latvia, New Brunswick (Canada) and Estonia, and 9% in Poland (Figure 2.1). It should be noted that a larger proportion of patients are likely to have experienced medical mistakes because patients may not report physical harms if they are not immediately recognisable (unlike pain and infection) and if they are not informed of their occurrence by a provider.

**Figure 2.1. Patients reporting that patient safety incident occurred during treatment or care, 2020 (or nearest year)**
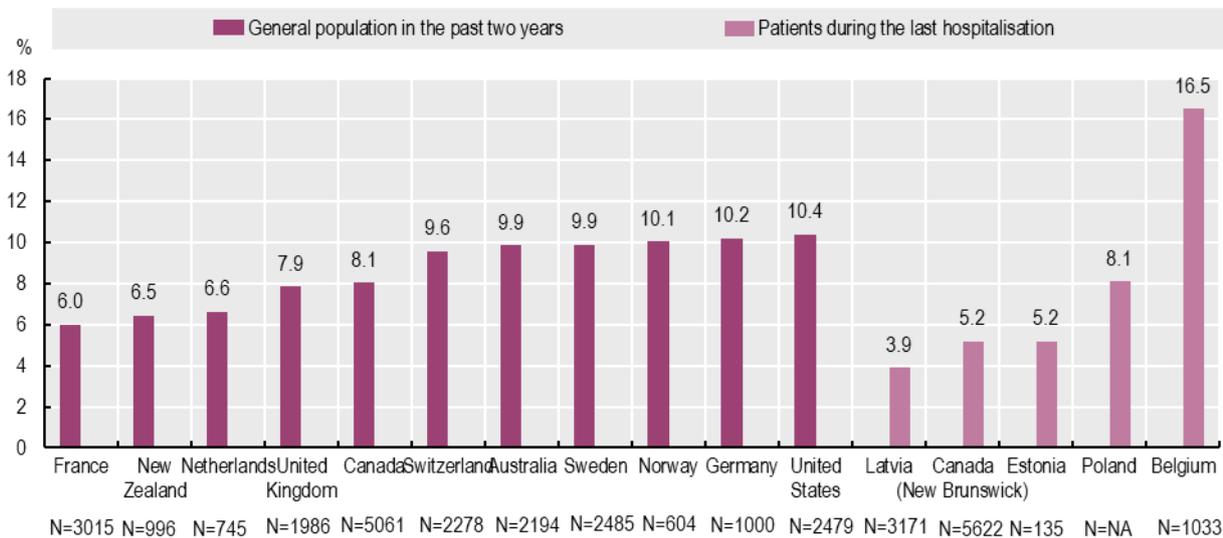


Note: Data for the general population are from the Commonwealth Fund 2020 International Health Policy Survey and they refer to people aged between 18 and 64 who reported having a medical mistake in the past two years. Data for other countries refer to people who reported experiences of patient safety incident during hospitalisation which happened in the past few months. Data refer to 2021 for Belgium, Latvia and Poland, 2020 for Estonia and 2019 for Canada. NA refers to not available. The Polish survey asks if patients experienced patient safety incidents in relation to medication-related incidents, surgery/anaesthesia, blood transfusion, medical equipment, wrong-site surgery, patient fall, suicide attempt, methicillin-resistant staphylococcus aureus infection, maternity death, foreign object left in body after surgery, patient burn in operation room. Thus, it may be possible to that experiences of other patient safety incidents may not be captured through the survey.
Source: OECD Pilot Data collection on Patient-Reported Experience of Safety, 2020-2022.

52.      According to the first pilot data collection conducted in Belgium, the proportion of patients who reported experiences of safety was 16.5%, much higher than that in other countries and this could be due to several reasons. First, the survey was conducted for the first time in Belgium and the response rate was very low at about 5%, so it may be possible that the survey was responded more often by patients who had experiences of unsafe care than others who received safe care as discharged patients who were invited to survey may have not been sufficiently aware that the objective of the survey was to improve healthcare safety in general, hence leading to selection bias. Second, it may be possible that a higher proportion of patients are informed of patient safety incidents when they happened. Third, people may be generally more aware of patient safety and what it entails than people in other countries. The

survey in Belgium, in fact, collected a wide range of patient safety incidents reported by patients including issues related to behaviours and nutrition, compared to survey conducted in other countries (Box 2.3). Since it is the first study undertaken in the country, care needs to be taken in interpreting patient experiences of safety and further research is needed to improve comparability of the data collected in order to utilise patient-reported experiences measures to promote patient safety.

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**Box 2.3. Variation in the level of awareness about patient safety may lead to differences in patient-reported experiences of safety**

The WHO has developed a conceptual framework for the international classification for patient safety and the framework includes incident types (clinical administration, clinical process/procedure, documentation, healthcare associated infection, medication/IV fluids, blood/blood products, nutrition, oxygen/gas/vapour, medical device/equipment, behaviour, patient accidents, infrastructure/building/fixtures and resources/organisational management) [WHO, Conceptual framework for the international classification for patient safety version 1.1: final technical report January 2009, 2009] and codes are defined in ICD-11 (WHO, 2023). In countries in which survey respondents provided description on their experiences about patient safety incidents, open-ended text was classified afterwards. Belgium classified survey responses into procedures, medication errors, accidents, care associated infection, clinical administration and medical equipment, beside behaviours and nutrition. Aligning with the WHO framework, Canada used healthcare-medication-associated conditions, healthcare-associated infections, patient accidents, procedure-associated conditions [Canadian Institute for Health Information, 2016]. Estonia used broader groupings and patient-reported experiences of patient safety incidents have been categorised into physical, emotional or both issues.

However, awareness about patient safety and the scope of patient safety incidents perceived may be different among patients, families and caregivers within and across countries, and this may lead to cross-country differences in patient-reported safety incidents rates collected through surveys. For example, patients, caregivers and families may not recognise that behavioural issues that patient experienced are related to unsafe care if the awareness of patient safety is not sufficiently high, and they may not report their experiences related to staff or patient behaviours as patient safety incidents, either. On the other hand, if the awareness of patient safety is high, patients may report such experiences as patient safety incidents in their response to the survey. According to the pilot data collection conducted in Belgium, behavioural issues accounted for 4.4% of patient-reported patient safety incidents but these data were not available in open-ended text collected through surveys in other countries participated in the OECD's pilot data collection. This is likely because patients in other countries did not consider these as patient safety incidents. Cross-country differences in patient-reported incident rates hence need to be interpreted with care.

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53.      Among different types of patient safety incidents, medication-related incidents are frequently reported in many countries. The proportion of people who reported wrong medication or wrong dose given by a doctor, nurse, hospital or pharmacist in the past two years ranged from 5% in Germany to 8% in Norway (Figure 2.2). The proportion of patients who experienced medication-related errors during the last hospitalisation was lower at 0.7% in Latvia and 4.3% in Belgium. These data need to be interpreted with care because patients may not know about all cases of medication error, resulting in underreporting. The OECD-proposed open-ended question allows patients to describe their experiences with patient safety incidents and could capture a wide range of patient safety incidents beside medication-related mistakes. For example, in Belgium, the WHO's international classification for patient safety (2009[41]) was used to classify patient safety incidents; beside medication errors which were the second most frequently reported incident at 20%, 26% of patient safety incidents were related to procedures, 12% was accidents, 11% was healthcare associated infections, 10% was about clinical administration, 6% was related to medical equipment, 4% referred to behavioural issues, and 4% was about nutrition. In Latvia, beside medication mistakes accounting for 15% of patient-reported patient safety incidents in 2021, experiences of a fall (11%), being mixed with another patient (10%), incidents during surgeries (9%), and incidents related to equipment (4%) were also reported frequently by hospitalised patients who reported

experiences of safety incidents. Although less frequent, hospitalised patients also reported bed sores (2%), transfusion failure (1%), wrong-site surgery (0.7%), methicillin-resistant staphylococcus aureus infection (0.7%) and experiences of trying to commit suicides (0.7%).

**Figure 2.2. Patients reporting that they experienced a medication-related mistake, 2020**
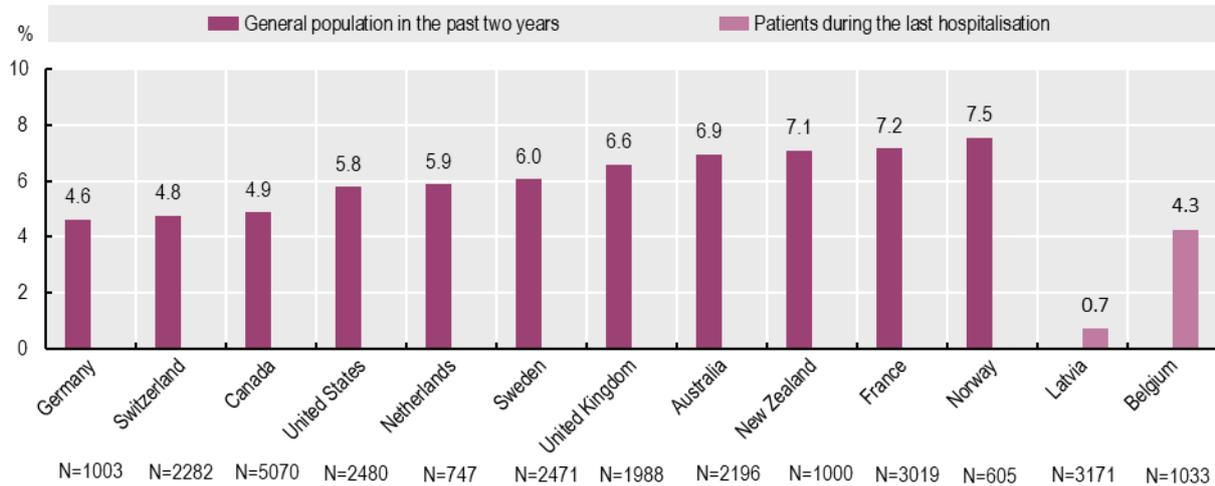


Note: Data for the general population are from the Commonwealth Fund 2020 International Health Policy Survey and refer to people aged between 18 and 64 who experienced medication mistakes in the past two years. Data for hospitalised patients refer to medication-related mistakes occurred during the hospitalisation which took place in the past few months.

Source: OECD Pilot Data collection on Patient-Reported Experience of Safety, 2020-2022

54. While certain preventive measures could avoid patient safety incidents or minimise its occurrence, they are not always implemented by healthcare professionals and cross-country variations exist. Even though over nine in ten patients in the United States reported that they received information in writing about what symptoms or health problems to watch out for after hospital discharges, almost half of the hospitalised patients in Norway reported that they did not receive such information in writing and the proportion was also low in Sweden (Figure 2.3). It may be possible that patients in these countries are more likely to receive such information in format other than in written form such as verbally or weblink. Possibly reflecting various forms of sharing information, the proportion of hospitalised patients who reported receiving information about symptoms and health problems was high at above 90% in Estonia and Latvia and almost 90% in Belgium. The OECD-proposed survey does not specify the format of information received and using the OECD-proposed question, almost 95% of patients in Estonia reported that they received information about symptoms and health problems to watch out for after hospital discharges.

**Figure 2.3. Patients reporting that they got information about what symptoms or health problems to watch out for after hospital discharge, 2020**
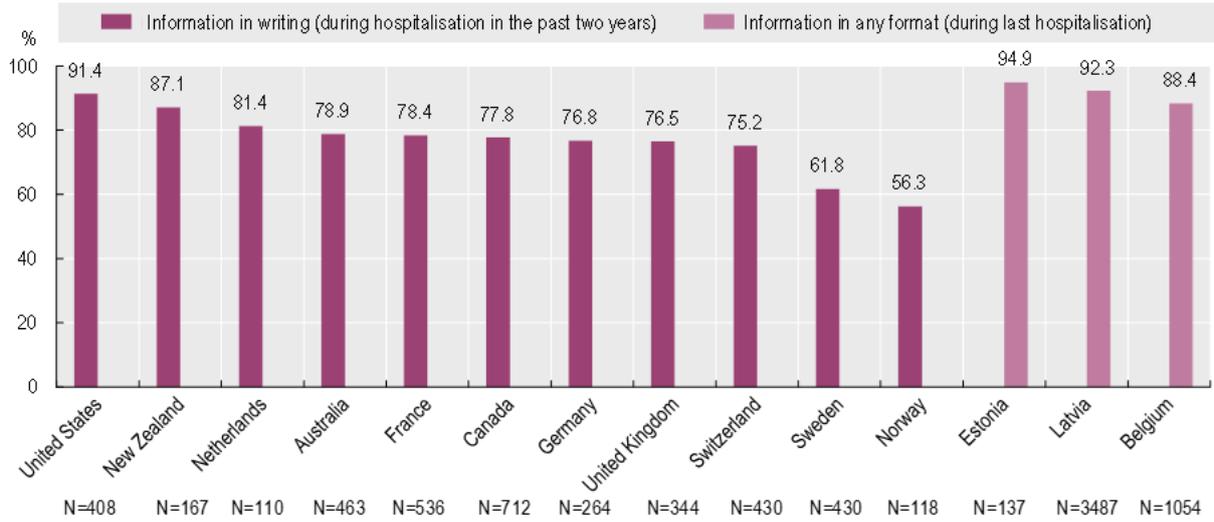


Note: Data refer to hospitalised patients. Data for patients who received information in writing are from the Commonwealth Fund 2020 International Health Policy Survey and they refer to patients aged between 18 and 64. Data for other countries refer to adult patients who received information in any format at the recent hospital discharge which happened in the past few months.
Source: OECD Pilot Data collection on Patient-Reported Experience of Safety, 2020-2022.

55.     Medication reviews can also prevent safety incidents (see Chapter 1), but they are not systematically done in some countries. According to the Commonwealth Fund's International Health Policy Survey, nine in ten patients who had hospitalisation in the past two years reported that medications were reviewed before discharge in the Netherlands, but the proportion was lower in Norway and Germany where only six or seven in ten hospitalised patients reported that medication reviews were done (Figure 2.4), possibly reflecting recall bias. However, in Latvia and Belgium, where hospitalised patients responded to surveys within a few months after discharge, the proportion of those who reported having medication review was high at 94% in Latvia and 85% in Belgium. To minimise the occurrence of safety incidents, clear explanation about all medications needs to be given to patients. Using the OECD-proposed question which asks if easy-to-understand explanation on how to take each medication is provided or not, the national survey in Poland found that on average more than nine in ten discharged patients received clear explanation on medications while in some hospitals, only about six in ten hospitalised patients received such explanation. In Estonia, almost all patients surveyed at Pärnu Hospital (99%) reported having received easy-to-understand information on all prescribed medications, but more could be done since 17% of the respondents reported that they were not clear about medication side-effects.

**Figure 2.4. Patients reporting that all prescribed medications were reviewed before hospital discharge, 2020**
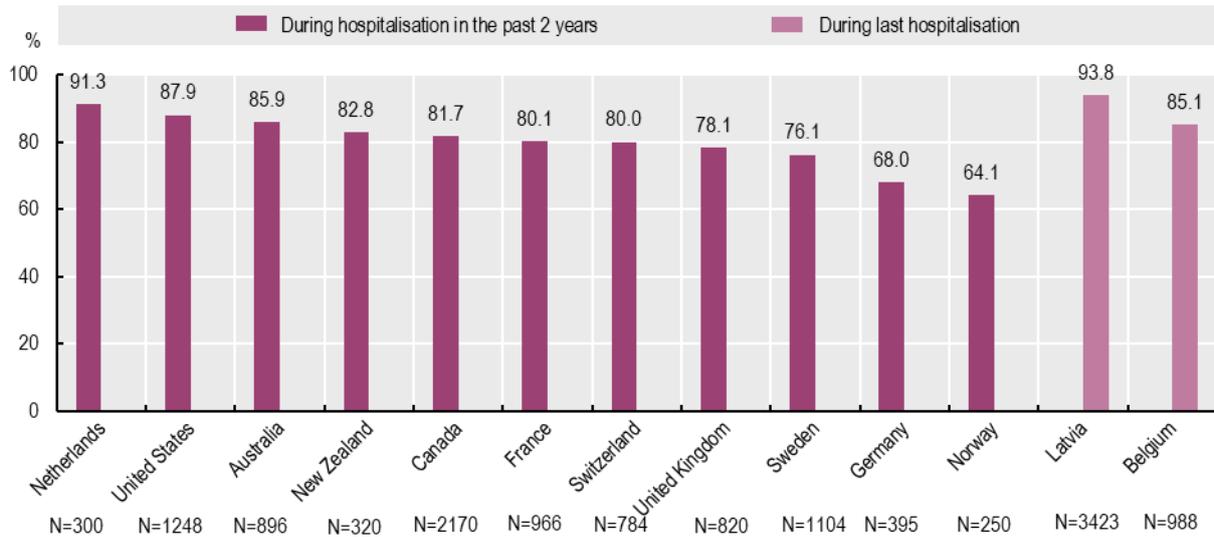


Note: Data from the Commonwealth Fund 2020 International Health Policy Survey refer to patients aged between 18 and 64 who had hospitalisation in the past two years. Data for other countries refer adult patients who had hospitalisation in the past few months.
Source: OECD Pilot Data collection on Patient-Reported Experience of Safety, 2020-2022.

56.        Planning for seamless continuity of care can also minimise patient safety incidents. In countries such as Switzerland and the United States, follow-up care is arranged systematically and about 8 or 9 in 10 discharged patients reported that they had such arrangement made in 2020. On the other hand, in Germany and Norway, follow-up care is not sometimes arranged and less than 7 in 10 discharged patients aged between 18 and 64 reported such arrangement was made (Figure 2.5). In Estonia, which used the OECD-proposed survey questions in their survey, 97% of hospitalised patients reported that they were clear about continuation of care or treatment after discharge. In Poland, which used the same OECD-proposed question, the proportion was also found high among patients hospitalised in most hospitals but in one hospital, only six in ten hospitalised patients reported that they were clear about care continuation.

**Figure 2.5. Patients reporting that arrangements was made for follow-up care with a doctor or other health care professionals, 2020**



Note: Data refer to general population aged between 18 and 64 and are from the Commonwealth Fund 2020 International Health Policy Survey.
Source: OECD Pilot Data collection on Patient-Reported Experience of Safety, 2020-2022.

57.    Patients need to know where to report when they have concerns or worries about treatment received. Internationally comparable evidence is not yet available since an OECD-proposed question for this has not been tested widely. In Pärnu Hospital in Estonia, 1 in 20 patients did not know where to report. In Poland, on average, almost 8 in 10 hospitalised patients were aware of where to report but variations were large across hospitals and in some hospitals, less than 1 in 5 hospitalised patients knew who or where to contact. International monitoring also needs to be undertaken in other areas which OECD proposed to measure including prevention of patient safety incidents such as good communication among healthcare professionals and patients' feeling comfortable to speak out.

## 2.4. A few OECD countries are systematically using patient-reported safety indicators for healthcare quality improvement

58.    Following collection of patient-reported experiences of safety, a few OECD countries have started developing and utilising patient-reported safety indicators in view of monitoring patient safety, reducing patient safety incidents and promoting patient engagement for safe healthcare delivery in recent years. Many of them have started to regularly report these patient-reported measures publicly to monitor the extent and types of patient safety incidents, involve patients, families and caregivers to promote safe healthcare and inform policy-making for safe healthcare delivery. **Estonia** started data collection in 2019 and since then data are collected every year and patient-reported experiences of safety have been reported on World Patient Safety Day to raise awareness on patient safety and to promote measures to prevent and reduce patient safety incidents. Patient-reported experiences of safety are regularly reported also in **Canada, Latvia**, and **Poland**. While hospital names are not identifiable when reporting these survey data by hospital in most countries, **New Brunswick (Canada)** reports these data with hospital names online to incentivise providers to minimise patient safety incidents[9]. In **Poland**, although hospital

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[9] https://nbhc.ca/surveys/hospital-acute-care-survey

names are not included in comparative reports showing hospital-level data, hospitals are free to report their own results if they wish to highlight their high quality safe care.

59.     Using patient-reported safety indicators, several countries including Canada, Latvia and Poland also provide feedback to providers to reduce patient safety incidents. In **Poland**, a tool to report provider performance was developed. It is simple but flexible and providers can monitor patient-reported safety indicators and trends in different time periods, and visualise results in graphics. Through this automated and dynamic reporting tool, hospitals can monitor 15 patient-reported safety indicators and could benchmark performance of their hospital or unit with performance of their peers which are updated every six months. In **New Brunswick (Canada)**, each hospital can also get their data by unit level to be able to incorporate into the governance model for improving patient safety and developing quality improvement plans. In **Latvia**, hospitals used to use patient-reported data on healthcare safety on their own to implement measures to promote patient safety and minimise incidents, but it is moving towards providing feedback to hospitals and department levels more systematically in a standardised manner. They plan also to publish a comparative report based on the data collected in 2021 and 2022.

60.     **Canada** and **Poland** also try to further institutionalise the use of patient-reported experiences of safety to drive improvement in healthcare quality and use them as part of hospital accreditation.

## 2.5. Efforts to improve measurements in patient safety and analyse patient safety from multiple perspectives need to continue

61.     The significance of patient-reported experiences is increasing and their experiences with healthcare is becoming an important source of information to improve healthcare quality and promote people-centred safe care, so efforts need to be made to further improve quality of these data. In many OECD countries, a patient survey is not conducted in a sufficiently large scale and response rates are often low, raising questions over representativeness and reliability of the data collected on patients-reported experiences. Patient-reported data may be also affected by different biases. For example, surveys are not usually responded immediately after hospitalisation or experiences of patient safety incidents, leading to recall bias. Survey respondents may be skewed towards those who have poor experiences with healthcare, leading to non-response bias. Continued efforts therefore are needed to improve the quality of patient-reported data, for example, by increasing sample size, raising awareness on the importance of answering patient surveys for improving patient safety, improving access to surveys, and pursuing methodological development to reduce biases. The quality of patient-experience measures can be assessed based on other data existing in the area. **New Brunswick (Canada)**, for example, assessed the comparability of patient-reported experiences of safety and the data collected in medical records and found that they were comparable with each other.

62.     Even if quality of these data is improved, limitations remain in patient-reported experiences of safety. This is because patients may not be able to report all patient safety incidents that they experienced if they are not immediately and easily recognisable and if they are not informed of their occurrence by a healthcare provider. The level of health literacy may also influence differences in the perception on patient safety incidents and the scope of patient safety incidents (for example, patients with low health literacy may not realise that they experienced safety incidents), which can partly explain variation in survey responses on experiences with healthcare safety.

63.     Given the limitations of patient-reported experience measures, patient safety needs to be evaluated with multiple data sources reflecting multiple perspectives including that of patients, professionals and payers as safety risks inherent to health care delivery need to be collectively dealt with, and safety culture and safe healthcare need to be jointly created and pursued. Beside administrative data sources (Section 2.1) and patient-reported measures, medical records could be explored since they may capture potential errors and harms that may not be sometimes perceived by patients such as the case

of wrong medications given, although they may not include harms which are perceived by patients after hospitalisations and harms such as miscommunication, distress and worry, signalling risks of patient safety incidents, that are collected in patient surveys. Patient safety culture measures collected from healthcare professionals could be also assessed to evaluate differences and similarities in the perception of safety culture between patients and professionals and to identify ways to promote and co-design safety culture together. Information collected from incident reporting systems (Box 2.4) could be additionally analysed. In some countries including Australia (see Box 2.5), Italy, Portugal (see Chapter 3), the United Kingdom and the United States, patients can report incidents that they experienced through a dedicated incident reporting system which is also used by healthcare providers and professionals, so patient-experiences of healthcare safety can be evaluated through this data source.

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**Box 2.4. WHO sets guidance for patient safety incident reporting and learning systems**

WHO's *Patient safety incident reporting and learning systems: technical report and guidance* provides an up-to-date perspective on patient safety incident reporting and learning systems, including how to fill in existing gaps in these systems, and practical guidance on the establishment and effective use of patient safety incident reporting and learning systems (WHO, 2020). WHO also developed Minimal Information Model for Patient Safety (MIM PS) to provide a tool to start collecting data on patient safety incidents to assist in data analysis and extract the minimal, but necessary information to learn from incidents in order to avoid recurrence of same types of incidents in the future. Also, the MIM PS can be used as mapping source from any types of existing reporting systems of patient safety incidents which means no need to develop the new reporting systems based on MIM PS (WHO, 2018).

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**Box 2.5. Australia's Emergency Medicine Events Register (EMER)**

EMER (https://emer.acem.org.au/) is an adverse event and near-miss reporting system that is peer-led, online, anonymous and confidential and it is the first emergency medicine specific incident reporting system in Australia. It is a partnership initiative of the Australian College of Emergency Medicine and the Australian Patient Safety Foundation. EMER was implemented across Australia and New Zealand in 2014, and initially, only open to clinicians, it was expanded in 2016 to enable consumer reporting.

Patients/families can report the free text questions on patient safety events happened, result of their experience, how their experience could have been prevented, and what the emergency department could have done better, along with their gender, age, the time of occurrence. Patient-reported incidents in free text are categorised using similar codes to clinician categories to enable comparisons of reporting by patients and clinicians, and further analysed by expert data analysts and reviewed by those involved in emergency medicine and consumer advocates. Learnings are disseminated through publications, conference presentations and workshops for improving care provided in emergency care departments.

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64.     In order to promote national and international monitoring of patient safety based on multiple data sources, further work is needed to classify and code patient safety incidents systematically in a comparable manner by using common terminologies across data sources within and across countries. Systematic classification will allow assessment on the variations in the scope of patient safety incidents perceived by people across countries and differences in the types of incidents occurring within and across countries. This will also allow developing strategies to tackle patient safety issues in a more systematic manner.

65.     Monitoring and reporting of patient-reported experiences of safety are not an end in itself, and further analyses of these data together with other data sources need to be conducted to identify approaches to promote prevention of patient safety events, reduce patient safety incidents and co-design safe healthcare. For example, pilot data collection in **Belgium** found that patient-reported safety incidents are negatively associated with patient safety culture such as good communication among healthcare professionals, patients feeling confident in the safety of treatment and care and related to longer hospitalisations and poorer perceived health status. In **Italy**, there is a plan to analyse patient-reported experience data which will be collected together with clinical outcomes of patients (such as mortality, failure to rescue, readmission, length of hospitalisation, adverse non-mortality outcomes), hospital characteristics (such as medical and nursing staff, number of beds, hospital type) and patient safety culture reported by healthcare professionals in participating hospitals. Thus, further analyses of patient-reported experience measures together with other relevant data sources are needed, for example to identify people with high risk of experiencing patient safety incidents and co-design measures to make safer healthcare.

66.     The OECD's working group has thus far focused on measuring patient experiences of safety in hospital settings, but national and international efforts to monitor and analyse patient experiences of safety need to continue in other settings. For example, OECD's Patient-Reported Indicator Survey (PaRIS; https://www.oecd.org/health/paris/) collects questions related to healthcare safety from patients with chronic conditions seeking primary care. By the end of 2023, internationally comparable data on the number of regularly used prescribed medications among patients with chronic conditions and patient experiences of medication reviews will become available for 20 participating countries. This will underscore the importance of measuring healthcare safety from the patient perspective in primary care settings. Based on developments in national and international patient surveys for other settings such as primary care, long-term care, mental health care and end-of-life care, survey questions to measure patient safety could be further developed for national and international comparisons in the future. This is particularly important in the context in which the number of patients with chronic conditions or disability are growing, because more patients encounter multiple service providers and have higher risk of experiencing safety events, and there is a need to minimise such risks.

67.     To protect privacy of individual providing data and to promote adequate data use, patient-reported experiences of safety data need to be collected and used based on the OECD's Recommendations of the Council on Health Data Governance. OECD's Recommendations of the Council on Health Data Governance sets out guidance related to clear provision of information to individuals, informed consent and appropriate alternatives, review and approval procedures for the use of personal health data for research and other health-related public interest purposes, and transparency. Since data on patient safety incidents are very sensitive in nature, particular and systematic attention needs to be made to protect individual's privacy while seeking ways to utilise these data for improving patient safety and health care quality.

# 3. The state of the art of engaging patients for patient safety

68.      The efforts of many countries in deepening their people-centred healthcare agendas contributes to countries seeking ways of embedding the voice of patients in decision-making cycles in a routine fashion in their healthcare systems, notably in areas such as patient safety. As stated in Action 5 of the 2023 Global Ministerial Summit on Patient Safety[10], patient engagement for patient safety requires initiatives spanning the macro, meso, and micro levels of healthcare systems that together contribute to create an environment of collaboration among policymakers, leaders, healthcare providers, patient and civil society organisations, and the public to ensure that patient safety initiatives are successful and contribute to create a culture of safety. For example, at the system (macro) level, patients can be engaged in health literacy initiatives or other national initiatives on specific safety themes; at the organisational (meso) level, patients can be engaged in service design or development; and at the clinical (micro) level, patients can be engaged in hazard or root-cause analyses towards safety protocols creation.

69.      In the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey*, a set of patient engagement for patient safety initiatives were selected based on a quick literature scan and the key findings of the first report of the OECD series on Economics of Patient Safety (Slawomirski, Auraaen and Klazinga, 2017[8]). In this report, several patient safety initiatives were assessed in terms of their impact on patient safety and implementation costs by a panel of academic experts and policymakers. The patient safety initiatives perceived as generating highest value (impact and cost ratio) were considered in the 2023 survey (4.3.Annex B).

70.      To illustrate countries' progress with regards to engaging patients for patient safety, heatmaps were produced to represent the strength of patient or citizen[11] engagement in the development cycle (design, development, implementation, evaluation, re-implementation) of selected patient safety initiatives at the macro and meso levels. The strength of patient or citizen engagement was considered 'low' if they were consulted or only informed during the development cycle of a patient safety initiative; 'medium' if patients or citizens were actively involved at some stage of developing a patient safety initiative; and 'strong' if patients or citizens were partners or co-designers (i.e., had a decision-making role in the development cycle) of a patient safety initiative.

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[10] Action point 5: *"Ensure adequate governance frameworks at international and national levels, encompassing all health sectors and settings, and defining clear lines of accountability and responsibilities of relevant stakeholders at all levels (political, financial, educational, patient, public)"* Global Ministerial Patient Safety Summit 2023 – 23rd & 24th February 2023 – Montreux, Switzerland (pss2023.ch)

[11] In this chapter, the term "patient or citizen engagement" is used interchangeably with the phrase "patient, families and carers, and communities" as it appears throughout the report. This choice of terminology aligns with the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey*, which employs the notion of citizen to refer to the various roles associated with exercising citizenship and voice (Brito Fernandes, 2022). For instance, citizens may act as voters, taxpayers, active members of families, societal groups, or local communities, and in their broader participation in society, citizens may also receive care as patients or users of health care services, or assume the role of customers/clients seeking health-related products such as health insurance.

71.      Overall, patient engagement for patient safety initiatives among the 21 responding countries is heterogeneous. The heatmaps inform cross-country learning and identify areas where patient or citizen engagement in the development of patient safety initiatives could be fostered. This chapter details the results of the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey* on how countries are institutionalising patient engagement at the macro and meso levels of their healthcare systems as a lever for designing and implementing patient safety strategies.

## 3.1. Patient engagement as a lever for designing and implementing patient safety strategies

72.      Considering the patient safety initiatives at the system level, most countries identified patient or citizen engagement during the development cycle of the selected initiatives—*establishing networks of advocates and champions for patient safety, defining safety standards linked to accreditation and certification initiatives, public reporting of patient safety events and indicators, educational programmes of future or current healthcare professionals, engaging patients in health literacy initiatives, and other national initiatives based on specific safety themes* (Figure 3.1). The engagement level—*from strong to low engagement*—varied within and across countries.

73.      The level of patient or citizen engagement was considered strong among four responding countries for initiatives such as establishing networks of patient safety advocates and champions (i.e., Canada, Ireland, New Zealand, and Slovenia) and advancing national initiatives based on specific safety themes (i.e., Canada, Ireland, New Zealand, and Portugal). Among six responding countries, patient engagement in defining safety standards linked to accreditation and certification initiatives was considered strong (i.e., Canada, France, Ireland, New Zealand, Romania, and Türkiye). Two countries (Canada and Israel) identified strong engagement of patients or citizens in educational programmes of future or current healthcare professionals, and three countries (i.e., Canada, New Zealand, and Portugal) reported strong engagement for engaging patients in health literacy initiatives. None of the 21 responding countries reported strong engagement of patients in public reporting of patient safety events and indicators.

### Figure 3.1. Mapping of selected examples of patient engagement for patient safety at the system level

System (macro)-level patient engagement in patient safety strategies, programs and initiatives that are best approached and implemented across an entire system.

| | Establishing networks of advocates and champions for patient safety | Engaging patients in defining safety standards linked to accreditation and certification initiatives | Public reporting of patient safety events and indicators | Engaging patients in the education of future or current healthcare professionals | Engaging patients in health literacy initiatives | Engaging patients in national initiatives focusing on specific safety themes |
|---|---|---|---|---|---|---|
| Austria | | Not implemented | Not implemented | n.a. | n.a. | |
| Belgium | | | Not implemented | | | |
| Canada | | | | | | |
| Colombia | | | | | | |
| Costa Rica | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented |
| Czech Republic | n.a. | | n.a. | | | n.a. |
| France | | | | | | |
| Germany | | | | | | |
| Iceland | | | | | | |
| Ireland | | | Not implemented | | | |
| Israel | | | | | | |
| Japan | n.a. | n.a. | | Not implemented | | |
| Korea | | | | | | |
| Latvia | | n.a. | | n.a. | | |
| Netherlands | | | | | | |
| New Zealand | | | | | | |
| Portugal | | | | Not implemented | | |
| Romania | | | | | Not implemented | |
| Slovenia | | n.a. | | Not implemented | | |
| Switzerland | | Not implemented | Not implemented | | | |
| Türkiye | | | Not implemented | | | |

Note: Information is unknown or not available (n.a.). **Darker to lighter green**: strength of patient engagement decreases from strong to low level of engagement. **Strong**: Patients or citizens were partners or co-designers of a patient safety initiative and had a decision-making role in the development cycle of a patient safety initiative; **Medium**: Patients or citizens were involved at some stages of developing a patient safety initiative; **Low:** Patients or citizens were informed or consulted at some stage of developing a patient safety initiative.
Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey.

74.     More than half of participating countries (11 out of 21) partnered with or involved patients (medium and strong levels of engagement) in establishing networks of advocates and champions for patient safety. For example, **Korea** convened a taskforce to establish the second Comprehensive Plan for Patient Safety 2023-2027 in accordance with the Patient Safety Act. People recommended by patient and civil society organisations participated in decision-making, suggesting and advising on major policies included in this comprehensive plan. One of the priorities of this new plan is to create more opportunities for the participation of patients and families in patient safety activities. In **Ireland**, patient representatives and patient advocates make a significant contribution on an ongoing basis to the work of the Department of Health, the Health Service Executive (HSE) and health agencies with patient representation on committees. Patients are included in the HSE board and board sub-committees where topics around safety and staff well-being are addressed and inform healthcare strategies. Patients or their representatives are also included in some interview panels for senior positions at the HSE. Additionally, the Irish regulator which is known as the Health Information and Quality Authority (HIQA) routinely include patient representatives on advisory groups to inform the design of monitoring programmes concerning

quality and safety standards[12]. Another example of where patients are being engaged in defining safety standards comes from Canada. In **Canada**, the Health Standards Organization (HSO) and the Canadian Patient Safety Institute (now Healthcare Excellence Canada)—with the dedicated support of hundreds of stakeholders across Canada—recognised the need for a greater commitment to quality and safety improvement. The Canadian Quality and Patient Safety Framework aims to align the country around five shared goals for safety and quality improvement, providing a roadmap for health services regardless of their jurisdiction, and patients were engaged and involved throughout the process of developing and releasing the framework (Health Standards Organization, 2020). Patients, families, and community members are also engaged in technical committees of the HSO to develop national quality and safety standards alongside policymakers and healthcare providers. Also, Accreditation Canada together with the HSO engage patients in the role of surveyors. Patient surveyors participate in the assessment of the performance of health organisations against standards of excellence and identify opportunities to achieve improved performance.

75.      Most countries (14 out of 21) implemented patient or citizen engagement in public reporting of patient safety events and indicators, yet the majority reported a low level of engagement. For example**,** in **Türkiye**, an information system is used to report and manage undesirable events, near misses and errors causing exposure. The system allows entry both from patients and their relatives as well as healthcare professionals. As part of National Patient Safety Objectives, patients and their relatives have been engaged in various steps of the process. In **Portugal**, an information system for reporting and managing patient safety events has been developed (National Notification System—*NOTIFICA*)[13]. Both citizens and healthcare professionals can report patient safety incidents occurred within the healthcare system and linked to care delivery. The reporting is confidential and anonymous, neither the person making the report, nor the professionals involved in the incident are identified. This builds on the notion of having a system embedded in non-punitive values and that can nurture learning from previous errors and prevent incidents from recurring in the future.

76.      Among 15 responding countries, patients or citizens are being engaged to some extent in the education of future or current healthcare professionals. For example, in **Slovenia**, a working group at the Chamber of Nurses and Midwives Association prepared a manual in 2022 entitled "Violence NO![14]" for dealing with forms of violence in the workplace, in the family and against patients and residents of social welfare institutions. Embedding the voice of patients and professionals through their lived experiences supports learning opportunities to health and social care institutions be better equipped to dealing with different types of violence. More broadly, the embedding of the voice of patients, families and carers, and communities in educational programmes such as those of university schools of medicine and nursing is important to ensure they have a role in forming the next generation of health leaders and practitioners.

77.      At the organisational level, engaging patients or citizens in developing and monitoring patient safety indicators was occurring, to some extent, among slightly more than three-quarters (n=17) of responding countries (Figure 3.2). Engaging patients in prioritising funding allocation to patient safety research projects was reported by eight responding countries (e.g., Canada, Colombia, Germany, and Japan). The embedding of forms of patient engagement was implemented in patient safety initiatives such as service design or development (e.g., Czech Republic, Japan, and New Zealand), improving

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[12] Ireland has also developed a framework for public and patient involvement (PPI) with regards to clinical effectiveness processes. This framework was developed to assist guideline development and audit governance groups, and sets ground to further embed the voice of patients and citizens in decision-making processes and enhance the responsiveness and transparency of the healthcare system. Involving the public in National Clinical Guideline and National Clinical Audit processes enhances the legitimacy of the guideline or audit, from a public perspective. Also, the Quality and Patient Safety Intelligence team (which is part of the HSE's National Quality and Patient Safety Directorate) use data to generate insights on the quality and safety of care. For example, a decision-making toolkit was produced with tools, resources and guidance to develop a quality agenda for Boards, Committees and other senior leadership teams. This toolkit allows patient care experiences and stories to be brought to the attention of leadership teams, and made publicly available via reports such as the "Bringing the Board of Directors on board with Quality and Safety of Clinical care: A co-designed approach."

13 https://notifica.dgs.min-saude.pt

14 https://www.zbornica-zveza.si/publikacija/nasilje-ne-prirocnik-za-obravnavo-nasilja-v-zdravstvenih-in-socialnovarstvenih-zavodih/

clinical communication protocols and training (e.g., Colombia, the Netherlands, Switzerland), and defining the organisation's culture of transparency and accountability (e.g., France, Israel, and Slovenia).

### Figure 3.2. Mapping of selected examples of patient engagement for patient safety at the organisational level

Organisational and institutional (meso)-level patient engagement in patient safety programmes, initiatives or practices while often focused on particular clinical areas or patient types, should be implemented across an entire healthcare organisation or institution.

| | Engaging patients and the community in defining the culture of transparency and accountability within the healthcare provider | Engaging patients in service design or development | Establishing an integrated patient complaints reporting system | Developing, monitoring and reporting on patient safety indicators | Engaging patients in initiatives to improve clinical communication protocols and training | Establishing responsive patient safety systems for patients and healthcare professionals to report and deal with health care harm | Engaging patients and the community in antimicrobial stewardship | Engaging patients in prioritizing funding allocated to patient safety research projects |
|---|---|---|---|---|---|---|---|---|
| Austria | n.a. | n.a. | | n.a. | n.a. | | Not implemented | Not implemented |
| Belgium | n.a. | n.a. | n.a. | n.a. | n.a. | n.a. | n.a. | n.a. |
| Canada | | | n.a. | | | | | |
| Colombia | | | | | | | | |
| Costa Rica | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented | Not implemented |
| Czech Republic | n.a. | | n.a. | | n.a. | n.a. | n.a. | n.a. |
| France | | | | | | | | |
| Germany | Not implemented | Not implemented | | | Not implemented | | | |
| Iceland | | Not implemented | Not implemented | Not implemented | Not implemented | | | n.a. |
| Ireland | | | | | | | | n.a. |
| Israel | | | | | | | | |
| Japan | n.a. | | | | Not implemented | | n.a. | |
| Korea | | | | | | | | Not implemented |
| Latvia | n.a. | n.a. | n.a. | | n.a. | n.a. | | n.a. |
| Netherlands | Not implemented | | | | | Not implemented | | |
| New Zealand | | | | | | | | |
| Portugal | | | | | | | | Not implemented |
| Romania | Not implemented | Not implemented | | | Not implemented | Not implemented | Not implemented | n.a. |
| Slovenia | | | | | | | n.a. | Not implemented |
| Switzerland | Not implemented | Not implemented | Not implemented | | Not implemented | Not implemented | Not implemented | Not implemented |
| Türkiye | Not implemented | Not implemented | | | Not implemented | | | n.a. |

Note: Information is unknown or not available (n.a.). **Darker to lighter blue**: strength of patient engagement decreases from strong to low level of engagement. **Strong**: Patients or citizens were partners or co-designers of a patient safety initiative and had a decision-making role in the development cycle of a patient safety initiative; **Medium**: Patients or citizens were involved at some stages of developing a patient safety initiative; **Low:** Patients or citizens were informed or consulted at some stage of developing a patient safety initiative.
Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey.

78.     Engaging patients or citizens in defining the culture of transparency and accountability of healthcare providers has been identified by 10 responding countries. For example, in **Ireland**, the National Care Experience Programme—a joint initiative by the Irish regulator HIQA, the HSE and the Department of Health—seeks to improve the quality of health and social care services by asking people and their relatives or friends about their experiences and acting on their feedback.

79.     Five countries responded to partner with or involve patients (medium and strong levels of engagement, respectively) in service design or development. For example, in the **Netherlands**, all hospitals have a health service user council where, among other subjects, patient safety is one of the subjects that gets the largest attention. In most hospitals, this council is involved in the development of patient safety policy in the hospital. About half of these councils give advice to the hospital boards about patient safety, and a quarter of the councils take the lead in monitoring how the hospital board adopts patient safety policies. The engagement of patients or citizens in establishing a responsive patient safety system for patients and healthcare professionals to report and deal with healthcare harm is being pursued in 14 responding countries. For example, in **Türkiye,** there are two national reporting systems of

undesirable events. The patient safety reporting system is developed for the reporting of any adverse events by patients and their relatives during the care pathway. The health worker safety reporting system is developed for healthcare professionals to report any undesirable events, near misses and errors causing exposure. In **Germany**, one of the priorities is to strengthen healthcare professionals' training in assisting patients in submitting complaints and feedback as an essential step towards strengthening the responsiveness of a patient safety system. In **Ireland**, training is seen as an important element to enhance their patient safety systems, where patients and their representatives support training by developing training materials and learning workshops. The *Patient Safety Together*[15] is key to the patient safety programme that supports the HSE Patient Safety Strategy. It aims to support healthcare professionals in applying learning for quality and patient safety improvements at all levels and to engage with incident reporting; and patients and healthcare service users to easily access information on quality and patient safety issues and reassure that by identifying and sharing learning similar incidents are prevented from reoccurring. The initiative was co-developed using a collaborative approach with a wide representation of people who both work in and use healthcare services in Ireland. The Patient Safety Together website is a platform for 'Patient Safety Stories' which gives a voice to patients and staff who have been involved in or impacted by patient safety incidents. The outputs of the initiative are freely shared in this platform, enabling all users to access and download new and up-to-date quality and patient safety information. In addition, HSE National Patient Safety Alert (NPSA) officers receive these updates via a dedicated eAlert System. Another example is the Irish Health Service's portal for online learning (HSeLanD)[16], which is an online learning and development platform created for healthcare professionals continuous training that is also accessible to some patient advocacy groups.

## 3.2. Reducing hindrances that can affect patient engagement for patient safety is key to strengthen safety culture

80.     Patients and citizens are key to building, advancing, and nurturing a robust safety culture (see Chapter 1. ). Yet, patient engagement for patient safety is not sufficiently institutionalised across levels of healthcare systems. This has led the WHO call to action for Governments to engage patients and families as partners in building safer healthcare systems (WHO, 2021); and WHO reaffirmed commitment to this objective by assigning the theme "Engaging patients for patient safety" to World Patient Safety Day 2023. To achieve that objective, reducing hindrances that can affect patient engagement for patient safety is necessary. These hindrances can refer to individual characteristics of patients (e.g., health literacy, type of disease) and features of the healthcare system (e.g., healthcare facilities and professionals), and are conditioned by contextual factors (e.g., health information systems). When designing patient safety initiatives, it is important to recognise how these factors can affect patient engagement to ensure their participation is encouraged and meaningful. In the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey*, responding countries identified several patient safety initiatives that considered potential hindering factors to patient engagement for patient safety during the development cycle of those initiatives (see Box 3.1).

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15 https://www2.healthservice.hse.ie/organisation/nqpsd/pst/

16 https://www.hseland.ie

> **Box 3.1. Patient safety initiatives among responding countries that account for both characteristics of individuals and features of the healthcare system towards maximising patient engagement to improve safety**
>
> - **Creation of forums and other forms of networks** to support patient and citizen engagement in health decision-making as a means to strengthen their voice in the health system (e.g., the *Consumer health forum Aotearoa* in New Zealand and the *Safety Hero* patient safety communication platform in Korea);
> - **Translation and adaptation of communication materials** for people of different backgrounds, such as a migration background, different levels of health literacy, or addressing the needs of people living with a specific condition (e.g., Canada, Israel, the Netherlands, Austria, and Slovenia);
> - **Inclusion of patients in the design of national information campaigns** (e.g., *Healthy Ireland* campaign in Ireland)
> - **Development of patient safety educational programs for caregivers** (e.g., Korea)
> - **Use of patient-reported outcome and experience measures in the national survey architecture**, including necessary adaptations to different care settings and needs of people with different health literacy levels (e.g., Canada, Estonia, France, Germany, Ireland, Latvia, Poland, Portugal; see Chapter 2. ).
> - **Convening focus groups** to discuss themes specific to selected medical conditions ensuring proper representation of patient organisations (e.g., France, the Netherlands, Ireland)
> - **Engaging patients in capacity building programmes** targeted at health professionals (e.g., Canada and Israel)
> - **Engaging patients in the governing bodies** of healthcare facilities and streamline dialogue with national agencies (e.g., Korea, the Netherlands, Portugal, and Canada)
>
> Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey

## 3.3. Examples of good practices of engaging patients for patient safety

81.     In **New Zealand**, a dedicated website (*Consumer health forum Aotearoa*[17]) run by the Health Quality and Safety Commission seeks to support people being actively engaged in decision-making about their health. Through this platform, it is possible to promote and advance the voice of people in the health system by linking health system actors to diverse consumer groups. Additionally, online and in-person forums are facilitated by the Health Quality and Safety Commission focusing on different topics. In **Korea**, the *Safety Hero* website was established to foster interest and participation in patient safety not only by patients, families and carers, but also by the public, and to enhance understanding of topics related to patient safety. The information is conveyed in a manner that it is easy to understand to a wider audience to ensure people with different backgrounds can participate in patient safety. This attention to communication materials was also contemplated by other countries.

82.     In **Canada**, communication materials are translated and adapted for people of different background (such as migration, language, education, health literacy) as an effort to make these materials accessible to a broader audience. Similar approaches are followed by other countries. In **Israel**, communication materials in primary and hospital care settings are adjusted to people from different backgrounds; in **Germany**, efforts are made to ensure easy-to-understand information is available about patients' rights and their safety; and in **Austria**, the Federal Ministry of Social Affairs, Health, Care and Consumer protection website shares information adapted to people with cognitive disability. A last example comes from the **Netherlands**, where the use of artificial intelligence technology (the chatbot

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17 https://www.hqsc.govt.nz/consumer-hub/consumer-health-forum-aotearoa

*Steffie*[18]) supports people in better understanding health-related topics (among other topics) so that they can exercise citizenship to the fullest. For example, medication prescriptions are explained to older people and people with lower levels of health literacy in easy-to-understand videos.

83.      In **Ireland**, the voice of patients and citizens are accounted for in national information campaigns such as the *Healthy Ireland* programme. Although the vision of the Healthy Ireland Framework 2013-2025 is somewhat broader and goes beyond patient safety, specific initiatives focusing on patient safety could be outlined in connection with Ireland's patient safety programme and guidance from the Independent Patient Safety Council. This council provides advice and guidance to the Minister for Health from a broad range of perspectives, including patients, healthcare service users and citizens, on the development of patient safety policy.

84.      Other countries are also seeking to capture patients' and citizens' voice through the mandate of similar organisations. For example, in **France**, the steering committee dedicated to patient safety ensures that the perspective of patients and citizens is represented through France Assos Santé, which is a national union of registered associations of health system users. This steering committee will soon outline a national patient safety roadmap to be carried by the Ministry of Health and Prevention, and the participation of France Assos Santé in the development of this roadmap will support the voice and defend the interests of health system users. In **Ireland**, QPS Improvement, part of the HSE National Quality and Patient Safety Directorate, provides support, tools and resources to build quality improvement skills, knowledge and confidence. Their focus is to address 13 common causes of harm identified in the HSE's Patient Safety Strategy 2019-2024. QPS Improvement ensures stakeholder representation, including patients and healthcare professionals, when developing patient safety initiatives. Some of their work include: 1) the National Medication Safety Programme (*Safermeds*, which aims to improve the safe use of medicines); 2) the pressure ulcers to zero (*PUTZ*) short-term collaborative project aiming to reduce the number of avoidable pressure ulcers across participating teams by half and to increase the capacity and capability of clinical teams to improve the care they deliver, and; 3) the falls prevention collaborative which aims to reduce avoidable falls using evidence-based interventions.

85.      Towards fostering safer care, it is important to ensure healthcare professionals have opportunities to partner up with citizens such as in Italy (see Box 3.2). To ensure a successful partnership, healthcare professionals should hold the adequate skill-mix. It is also important to nurture the commitment of healthcare professionals to long life learning and quality and safety improvement. Capacity building programmes on patient safety topics targeted at healthcare professionals are not novel, yet these programmes can fall short on addressing topics that are important to patients. For example, in Ireland, a competency framework for patient safety and complaints advocacy service sets out the competencies required to work effectively as a Patient Safety and Complaints Advocate. Some countries, such as Canada, Germany, and Ireland, are engaging patients as partners in designing training programmes. Ireland has training programmes where patients were key in supporting their design, such as the Quality Improvement Leadership programme and the Human Factors training programmes. The former is a crucial tool for the HSE Patient Safety Strategy 2019-2024 to support healthcare teams in identifying and addressing the common causes of harm. The latter aims to introduce human factors as a new approach to safety in everyday work. It focuses on understanding the factors that impact our capabilities and limitations as humans, and how this knowledge can be used to improve well-being and performance at both individual and team levels. Lastly, the Collective Leadership and Safety Cultures (Co-Lead) is a 5-year programme in University College Dublin that aims to support quality and safety cultures through the development of a new model of leadership (collective leadership) and its impact on team performance and healthcare safety. This programme was co-designed by healthcare staff, patient representatives, researchers, and academics, and is endorsed by the National Quality and Patient Safety Directorate.

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[18] https://www.steffie.nl

> **Box 3.2. Italy implemented an innovative participatory evaluation methodology to improve person-centred care in hospitals**
>
> **The Italian National Agency for Regional Healthcare Services (Agenas)** engaged with healthcare professionals and citizens for the launch of a National Program whose objective was to improve person-centred care in hospitals through a participatory assessment methodology. As part of this collaboration, a checklist for person-centeredness enhancement has been developed and used in Italian hospitals. The checklist is composed of 142 items consisting of four areas of interest: person-oriented processes; physical accessibility and comfort; access to information and transparency; patient- professional relationship.
>
> Trained teams composed of citizens and healthcare professionals fill in the checklist during an on-site visit then the collected data are sent to Agenas; data are stored in a national database. Agenas analyses the data and sends back the results to regions, hospitals and teams for local public dissemination. Healthcare professionals at hospitals and citizens are part of the identification and implementation of improvement plans.
>
> Source: (Carinci, et al., 2018; Donaldson, Ricciardi, Sheridan, & Tartaglia, 2021; Cardinali, et al., 2021)

86.     Some responding countries have been engaging patients in the governing bodies of healthcare facilities (such as in the Netherlands) and streamline dialogue with national agencies (such as in Korea, Switzerland, and Portugal). In the **Netherlands**, many hospitals convene patient panels in a regular basis either to discuss general aspects such as patient safety and participation, or to have more focused disease-specific discussions. In addition, patient panel members receive online surveys to share their experiences and are invited to in-person meetings. In **Korea**, a multi-stakeholder group was convened to discuss how to lead the current healthcare system toward becoming a patient-centred system. This group included representatives from the government, patient and civil society organisations, and healthcare experts to discuss the expansion and role of healthcare professionals in improving the quality and safety of healthcare. In **Australia**, the Partnering with Consumers Standard[19] positions partnerships with patients and citizens as driving forces to the planning, design, delivery, measurement, and evaluation of care. The Partnering with Consumers Standard recognises the importance of involving patients, families, carers and communities in a meaningful manner for accreditation within the mandatory national accreditation scheme, but more broadly because it adds value across levels of the healthcare system and strengthens trust, accountability, and a sense of ownership of the system.

87.     In **Portugal**, formal partnerships between patient associations and national agencies, such as the Directorate-General of Health and the National Authority of Medicines and Health Products (INFARMED) have been deepened to streamline dialogue with and participation of patient associations. For example, on a regular basis the INFARMED seeks the advice of patient associations on new drugs and health technologies with particular interest in their feedback about implications to patients' safety, health outcomes and care experiences. In **Canada**, the *Patients for Patient Safety Canada*[20] platform seeks to represent the voice of patients and bring patients experiences with healthcare to the forefront to help improve patient safety at all levels in the health system. They partner up regularly with Healthcare Excellence Canada in ensuring all their programs and initiatives represent the patient perspective. Some examples are the initiatives *Patients engaging government* and *Engaging patients in patient safety*. The former is a guide for patient partners to advance patient safety which provides strategies, resources and tools to support effective communication with elected and government officials. The latter draws on the experiences of patients, providers and leaders that come together to strengthen patient safety by further embedding the voice of patients in the health system.

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[19] https://www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard

[20] https://www.healthcareexcellence.ca/en/what-we-do/all-programs/patients-for-patient-safety-canada/

88.　　In **Canada**, at least two programmes aim at providing support to individuals after a more severe patient safety incident. First, a programme designed to support patients and healthcare workers after medical error through mutual healing (Aubin, Soprovich, Carvalho, Prowse, & Eurich, 2022). When a medical error occurs, both the patient and the healthcare professional can experience trauma. Hence, to build an organisational culture that can best support both patients and healthcare professionals after a medical error throughout the incident management process is key to reduce the barriers to healing together after harm. Initial steps have been taken to the creation and piloting of a programme for healing after harm. Second, a programme designed to nurture psychological safety of healthcare professionals[21], which aims at supporting healthcare professionals recover, restore, and build resilience after patient safety incidents. This programme provides guidelines to assist healthcare organisations to support their healthcare professionals by creating peer support programs or other models of support.

89.　　In **Portugal**, psychological support to patients and healthcare professionals is available through the national support line SNS 24[22], which is available 24/7 with a team of clinical psychologists. This counselling service was created amid the profound changes in people's lives led by the COVID-19 pandemic, in their daily family and work lives. This support helpline aims to provide support in various situations, such as acute anxiety, psychological fragility, and aggravation of psychological illness, foster psychological resilience, develop a sense of security among the population and healthcare professionals, and decrease the likelihood of people developing mental health problems following the COVID-19 pandemic. In **Korea**, a *Patient Safety Incident Trauma Centre* will be established to identify the psychological status of patients and families who have experienced a patient safety incident, select groups at high-risk that require a discerned management approach, and operate a protection and support system such as counselling, treatment, and investigation.

90.　　In **Ireland**, the voice of patients is accounted for during the development of clinical guidelines. The National Clinical Effectiveness Committee requires two patient representatives to sit on the committee. Public involvement helps to develop priorities and make improvements based on public identified needs rather than assumptions. Involving the public in National Clinical Guideline and National Clinical Audit processes enhances citizens' trust on and legitimacy of guidelines and audits. Patient representatives were also involved in co-developing national policy such as the *Incident Management Framework*[23] and in service reviews and development such as the National Framework for Person-Centred Planning in Services for Persons with a Disability[24].

91.　　In **Canada**, during the summer of 2020, patients were engaged in developing policy guidance for the reintegration of caregivers as essential care partners[25]. This policy guidance for healthcare decision makers was co-developed by policy decision-makers, health system leaders who implement policy, and the people who are impacted by policy decisions—providers, administrators, patients, families and caregivers. This co-design approach brought together people with a diverse range of expertise and COVID-19 related experience to develop policy guidance to support a safe and consistent approach for reintegrating essential care partners back into healthcare facilities, long-term care and congregate care settings during the COVID-19 pandemic. The policy guidance focuses on two key areas where barriers to consistent and supportive access of caregivers have been noted: 1) identification and preparation of essential care partners and; 2) entry into the facility. This policy guidance was updated during the summer of 2021 as the context of the COVID-19 pandemic continues to change and will be considered in future recovery and resiliency plans. In 2022, Canada also released a report offering guidance on how to effectively engage patients and care partners in all aspects of measurement and monitoring of safety and providing recommendations outlining how to strengthen provider and patient partnerships in support of

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21  Creating a safe space" https://www.healthcareexcellence.ca/media/eyihzd5c/creating-a-safe-space-manuscript-final-ua.pdf

22 https://www.sns24.gov.pt/servico/aconselhamento-psicologico-no-sns-24/#o-que-e-o-servico-de-aconselhamento-psicologico-por-telefone

23 https://www.hse.ie/eng/about/who/nqpsd/qps-incident-management/incident-management/

24 https://www.hse.ie/eng/services/list/4/disability/newdirections/framework-person-centred-planning-services-for-persons-with-a-disability.pdf

25 Policy Guidance for the Reintegration of Caregivers as Essential Care Partners

safer care (Healthcare Excellence Canada, 2022). Patient partner co-authored the report and co-chaired the advisory committee who guided the research.

92.     Health information systems can support patients into becoming partners in patient safety, notably by supporting feedback mechanisms, ensuring data flows to co-create responsive patient safety alert systems, enabling patients' access to their health data using portals and electronic systems, or creating adaptive patient-centred digital experiences. Many of the responding countries seem to leverage digital technologies to some extent. For example, **France** has implemented a digital health space (*Mon Espace Santé*[26]) for all healthcare service user in France. This digital platform enables citizens to store their health-related documents and health data free of charge and securely and to share them with healthcare professionals of their choice. In **Portugal**, a dedicated electronic health system (Portal SNS 24[27]) allows patients and citizens to interact digitally with the healthcare system and access their personal health data.

93.     In **Slovenia**, a well-developed national patient portal called zVEM[28] is available as a web portal for computers and mobile app. The portal provides patients access to their eReferrals, ePrescriptions and other healthcare-related documents, which are stored in the Central Registry of Patient Data. Through the portal they can also submit various consent forms or opt-out of certain services. Patients can also access an audit trail that helps them identify potentially unauthorized access to their data. In the future, the portal will be enhanced with a safe communication module, which patients will be able to use to communicate with various healthcare practitioners for new prescriptions, referrals or appointments for primary care. The app will soon be used for sending out push notifications to inform patients about new documents, test results, and prescriptions. In **Austria** and **Romania**, the development of an electronic health record (ELGA) is ongoing. It is expected that this new system will facilitate patients' access to their health records.

94.     In **Latvia**, the use of digital technologies via smartphones is encouraged to engage patients and family members in safe care, for example for collecting patient feedback regarding care experiences. Condition-specific applications are also available such as Vigo[29], which is a digital therapy tool covering the full cycle of stroke recovery. The app is responsive to the needs of each patient in terms of their condition and therapy goals. The app includes video lessons in therapeutic exercises, speech therapy in a wide variety of difficulty levels, and tasks to regain fine motor skills. In the **Netherlands**, a digital health portal[30] allows citizens to consolidate their health data when using various health apps or interacting with the healthcare system (e.g. an appointment with a specialist in the hospital) as adoption of the system is still expanding. The portal allows users to add self-reported data, such as blood pressure or weight, and connect to other health apps or sports watch that can facilitate data collection.

95.     Countries noted the importance of engaging patients in the development cycle (design, development, implementation, evaluation, re-implementation) of patient safety initiatives at all levels of the healthcare system. However, the strength of patient or citizen engagement varies widely within a country for different patient safety initiatives as well as between countries for a given initiative. Good practice examples from existing initiatives offer opportunities for international learning to foster patient engagement in patient safety initiatives. Chapter 4 describes how patients are embedded in national patient safety and quality strategies and provides key recommendations on how to promote greater patient engagement for patient safety.

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26 https://www.monespacesante.fr
27 https://servicos.min-saude.pt/utente/
28 https://zvem.ezdrav.si/portal/gost
29 https://vigo.health
30 https://www.digitalezorggids.nl

# 4.  Embedding patient involvement in national strategies for patient safety and quality

96.        An increasing number of countries are developing their national patient safety policy or strategy following the WHO's Global Patient Safety Action Plan. Embedding the involvement of patients, families and carers, and their representatives in national strategies plays a central role in ensuring safe, integrated and people-centred care. In addition, the extent of engagement is key for meaningful patient engagement for patient safety. This chapter provides an overview of how countries engage patients in national patient safety and quality strategies and shares OECD recommendations for enhancing patient engagement for patient safety.

## 4.1. Patient involvement in national strategies for patient safety and quality

97.        Most countries responding to the *2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey* reported that patient safety has been recognised as a priority in national health policy. A few of them (4 out of 21) stated that some aspects were prioritised. For example, **Belgium** implemented a National Action Plan on antimicrobial resistance, mortality measures (e.g., maternal complications and mortality), and a safety culture assessment survey. The **Czech Republic** prioritised the implementation of patient safety from the point of view of control (audit) and qualitative accreditation of healthcare facilities, whereas in **Romania** the themes prioritised were related to hospital-associated infections, antimicrobial resistance, never-events management, safety blood transfusion, pharmacology prescription, and surgical safety.

98.        Most countries (20 out of 21) reported they had a national patient safety policy or strategy. For the majority of responding countries (15 out of 20), national patent safety policies or strategies included references to patient engagement in them and more than half (11 out of 20) engaged patients or citizens in the development cycle of the policy (see Figure 4.1). In **Canada,** the Federal Government provides funding to the provinces and Territories. Each jurisdiction (13 in total) is responsible for creating their own strategies and policies. A significant example to patient engagement in the development of national patient safety policies or strategies was the involvement of Patients for Patient Safety Canada in education and support of Vanessa's Law. Vanessa's Law underpins drug and medical device safety by strengthening the collection of data and the rapid action when a serious health risk is identified[31].

99.        In **France**, engagement of patients is currently under discussion as part of the new National RoadMap for ensuring patient safety. France Assos santé[32], a national umbrella organisation created in

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[31] Vanessa's Law: https://www.healthcareexcellence.ca/en/resources/educational-support-for-mandatory-reporting-of-serious-adrs-and-mdis-by-hospitals/what-the-public-needs-to-know-about-vanessa-s-law/

[32] https://www.france-assos-sante.org/

2017 by the initiative of 72 patient representative associations, is also part of the working group in the development of the roadmap. In **Portugal,** the National Plan for Patient Safety 2021-2026 and the technical document supporting the implementation of the plan by healthcare providers includes "patient engagement" in Pillar 1 "Patient Safety Culture" with the objective of increasing literacy and the participation of patients, families, caregivers and communities in the safety of healthcare. The National Plan includes actions on developing and implementing an awareness plan aimed at patients, families, and caregivers on the importance of safety in healthcare in full articulation with the Health Literacy Action Plan; involving patients, families, caregivers and communities in the actions of the National Plan; and carrying out communication campaigns and awareness-raising actions regarding patient safety.

100.    In **Korea,** Article 5 of the Patient Safety Act stipulates that patients and families shall participate in patient safety activities. The *1st Comprehensive Plans for Patient Safety (2018-2022)* promoted policies to raise awareness and foster a culture for patients and families to participate in patient safety activities. A *2nd Comprehensive Plan for Patient Safety* is envisaged for 2023-2027, which will expand the target audience to the general public as well as patients and families. In **Türkiye,** one of the national patient safety targets is "Patient and Patient Relatives' Engagement", which lead to a few guiding national initiatives[33].

**Figure  4.1. Existence of national patient safety policies or strategies among surveyed countries, and their characteristics**

Most countries with national patent safety policies or strategies included references to patient engagement in them and/or engaged with patients or citizens in the development of the policy.
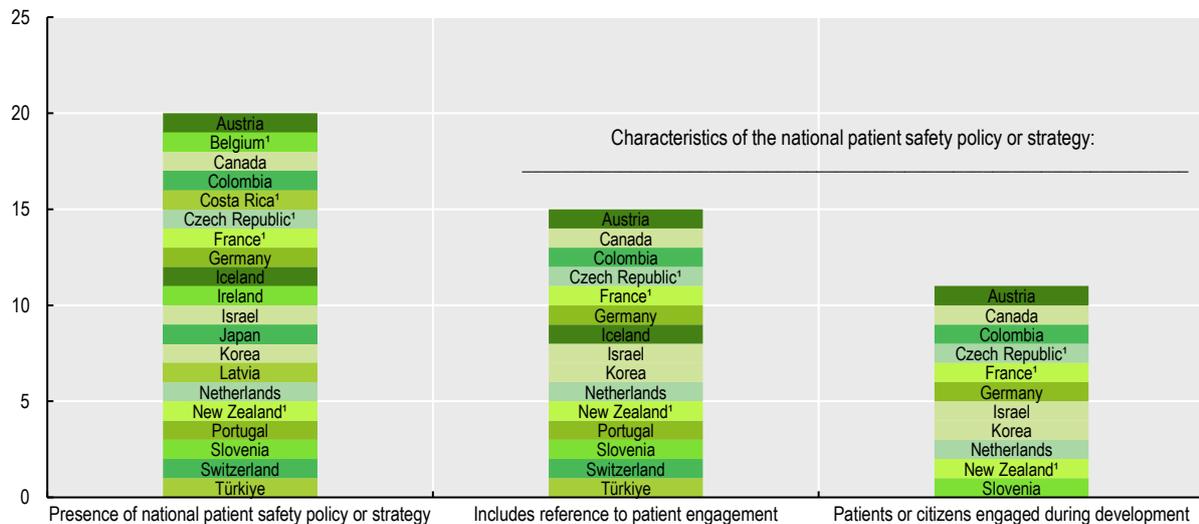


Note: 1: A patient safety policy or strategy in discussion/being considered
Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey

101.    Most surveyed countries noted that there was a legal right to safe care in the country. Just over half of countries, however, reported that there is a means for enforcement associated with this right, such as a legal recourse or alternative course of action. Promisingly, half of the countries citing a legal right to safe care indicated that there was some form of patient or citizen engagement during the development of the legal structure (see Figure 4.2).

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[33] https://stratejikplan.saglik.gov.tr/files/TC-Saglik-Bakanligi-2019-2023-Stratejik-Plan.pdf#zoom=55

### Figure 4.2. Presence of a legal right for safe care, including means for enforcement and engagement of patient and citizens in development

While most countries have a legal right to safe patient care, but just over half of countries cite that the right is associated with a means for enforcement.
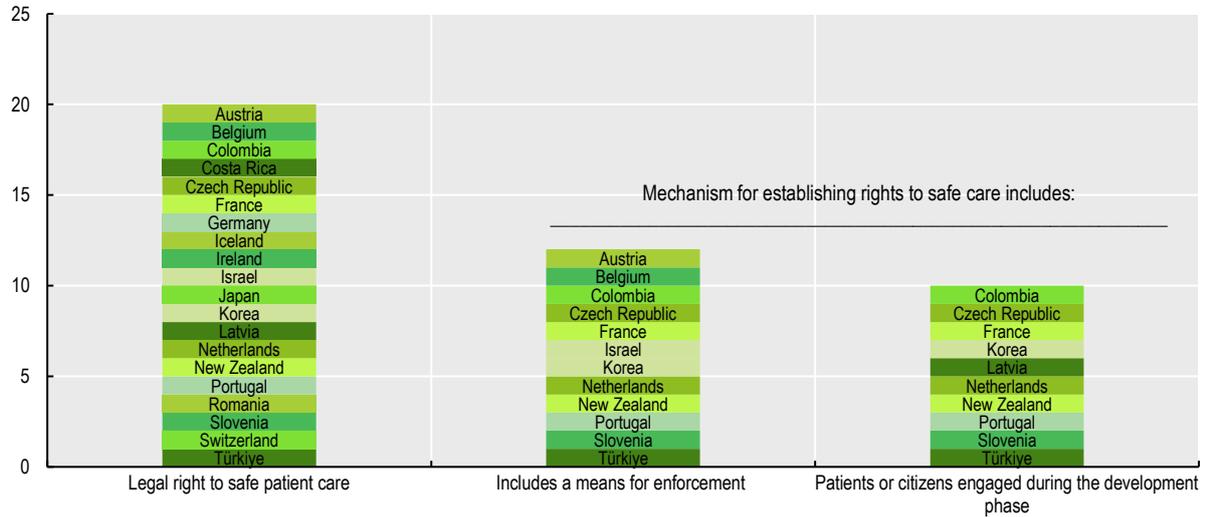


Note: N=21 countries.
Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey

102.     Duty of candour refers to the obligation of medical professionals and systems to disclose to patients the occurrence of a patient safety event. In many countries, this duty has been codified into national legislation with the objective of increasing transparency and respecting patients' right to information about the care they have received. Almost 70% (14 out of 21) of countries surveyed noted there was a duty of candour legislation present in their country or that one is currently being developed (see Figure 4.3). The scope and coverage of duty of candour legislation varies across countries. Most countries include at least an acknowledgement of the event that occurred. A minority of countries include provisions for disclosing the scope and timeline of errors, guarantees for protecting patients and families when speaking out about patient safety events, or apologies (either from the involved medical professional or organisation). Five countries include a requirement for information on actions that will be taken to prevent similar events in the future.

### Figure 4.3. The presence and scope of Duty of Candour Legislation

Sixty-seven percent of surveyed countries have a duty of candour legislation in place or under development.
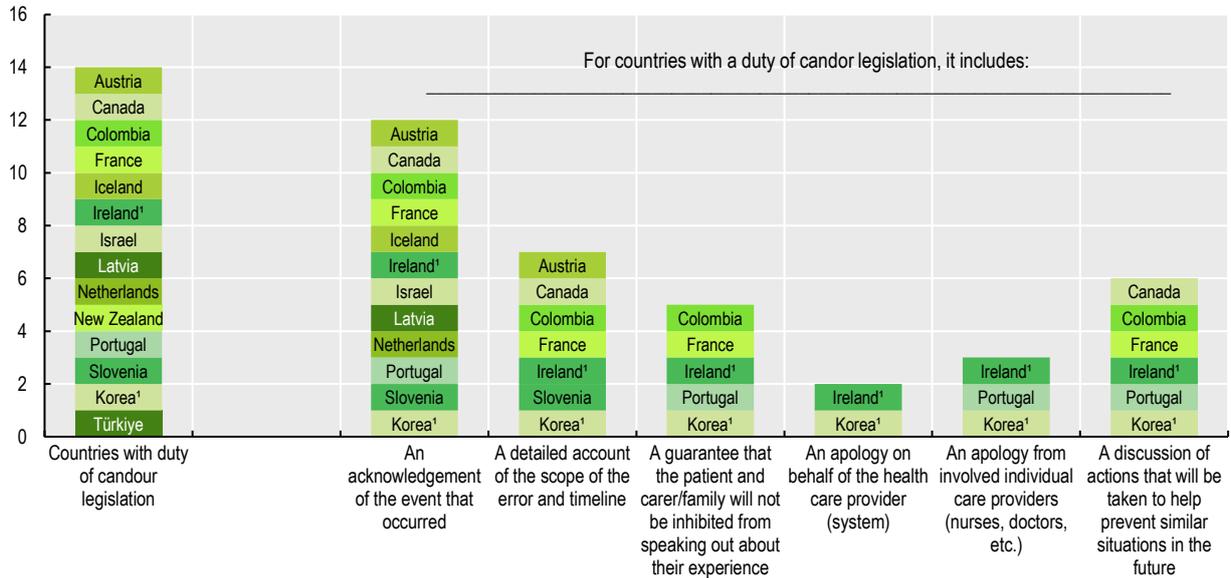


Note: One is in discussion/being considered, N=21 countries. In Canada, although apologies are not part of mandatory disclosure legislation, they are subject to apology protection legislation in all jurisdictions except for Yukon.
Source: 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey

103.    In **Canada,** Healthcare Excellence Canada developed the Comprehensive Patient Safety Incident Legislation[34] in relation to legislative requirements for mandatory reporting and mandatory disclosure of patient safety incidents, protection of quality assurance information, and apology protection. The background paper includes the key policy issues and illustrate how they have been addressed by different jurisdictions across Canada. It also provides policy recommendations for jurisdictions that are considering future legislative development. The scope and coverage of mandatory disclosure legislation (duty of candour legislation) varies within Canada (Box 4.1).

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[34] https://www.healthcareexcellence.ca/media/pjehatzi/fpt_patientsafetylegislation_summaryreport_en.pdf

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**Box 4.1. The scope and coverage of mandatory disclosure legislation varies within Canada**

In Canada, where jurisdiction over healthcare is divided between the federal, provincial and territorial governments, the scope and coverage of duty of candour legislation varies across provinces and territories, but jurisdictions with mandatory disclosure legislation usually ensure an acknowledgement of the event that occurred and support a detailed account of the scope and timeline of the error. In Manitoba, the Regional Health Authorities Act stipulates that patients must be informed of the facts of the incident, its consequences as they become known, and actions taken to address these consequences. Similarly, in Ontario, the Hospital Management Regulation requires that patients or their representatives be informed of the material facts of the incident, its consequences, and actions taken to address them. Quebec's Act Respecting Health Services and Social Services mandates the disclosure of accidents that occur during healthcare delivery, including their actual or potential consequences for the patient's health or welfare, and measures taken to correct or prevent recurrence. The province of Newfoundland and Labrador's Patient Safety Act requires regional health authorities to disclose to patients the facts of adverse health events, their consequences, details of health services provided as a result, and any recommendations from quality assurance activities. In New Brunswick, the Health Quality and Patient Safety Act mandates that healthcare organisations notify patients about relevant facts of incidents, recommendations from quality assurance committees, and steps taken to improve healthcare quality and patient safety. In Northwest Territories, the Hospital Insurance and Health and Social Services Administration Act stipulates that patients be notified of critical incidents that occur during service provision, as well as measures taken to ameliorate their consequences.

Canadian legislation also includes provisions for discussing actions that will be taken to prevent similar incidents in the future. For example, Ontario's Hospital Management Regulation requires that patients or their representatives be informed of systemic steps taken by hospitals to reduce the risk of further similar critical incidents. Similar requirements exist in Quebec, Newfoundland/Labrador, and New Brunswick. However, jurisdictions do not guarantee that patients and their families will not be inhibited from speaking out about their experiences. Although apologies are not mandated by disclosure legislation, they are subject to apology protection legislation in all Canadian jurisdictions except Yukon. This legislation does not require healthcare providers to apologize but facilitates apologies by preventing them from being used in subsequent proceedings.

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104.     In **France,** reporting harm associated with healthcare is a moral, ethical and legal obligation. Everyone has the right to be informed about their state of health. The information must be clear, fair, appropriate and provided in the context of an individual interview. It must be provided by all healthcare professionals in compliance with the professional rules applicable to them. The Code of Medical Ethics[35] also states that "*Any person who is the victim or who considers him/herself to be the victim of harm attributable to a preventive, diagnostic or healthcare activity, or his/her heirs if the person is deceased, or, where applicable, his/her legal representative if the person is a minor, must be informed by the professional, health establishment, health services or organisation concerned of the circumstances and causes of this harm.*" Similarly, the Canadian Medical Association's Code of Ethics and Professionalism states that physicians must take all reasonable steps to prevent or minimise harm to the patient; and disclose to the patient if there is a risk of harm or if harm has occurred.

105.     In **Latvia,** the Law on Rights of Patients[36] states that they have the right to receive information regarding previously unforeseen outcomes and the reasons thereof. In the **Netherlands,** within the Healthcare Quality, Complaints and Disputes Act (WKKGZ law), healthcare providers are obligated to inform patients if an incident occurred. This needs to be recorded in the patient file. It also states that healthcare providers are obligated to inform patients about the quality of the care delivered upon the patient's requests. The law also mandates that healthcare providers nurture a patient safety culture, which includes a continuous focus on improving quality of care and communication with patients.

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[35] https://www.has-sante.fr/upload/docs/application/pdf/2022-10/manuel_certification_es_qualite_des_soins.pdf

[36] https://likumi.lv/ta/en/en/id/203008

106.     In **New Zealand,** the 'healing, learning, improving policy'[37] requires open communication and ongoing engagement in the review of an event of harm. The policy requires the existence of an acknowledgement of the safety event and recognition of the harmed parties' emergent needs. This may lead to an apology being issued, the involvement of the harmed parties in providing feedback on the review report and opportunities to learn and implement an associated action plan. The Medical Director of Health and Public Health Act[38] in **Iceland** also requires mandated reporting. Healthcare facilities, self-employed healthcare practitioners and others who provide healthcare services must notify the Medical Director of Health without delay of any unforeseen incident which has caused or could have caused serious harm to a patient, such as death or grave disablement. The patient (and closest relatives, where applicable) shall also be informed of the unforeseen incident without unnecessary delay.

## 4.2. Recommendations

Insights from countries show that engaging patients, families and carers, and communities for patient safety can reduce healthcare costs by promoting safe care and reducing harm. Although costs of ongoing and follow-up care for patients who have experienced harm from unsafe care are relevant, such economic burden of patient safety incidents is not readily available. Yet, costs of litigation related to medical practice and no-fault compensation to compensate patients and families for patient-safety events reported by countries provide examples of costs relevant to patients and can subsume significant portions of healthcare budgets. While the exact economic impacts of patient engagement for patient safety remains an area that needs further research, it is evident that patients, families and carers, and communities, especially those who have experienced harm from unsafe care, are essential to learning and further developing health systems. The chapters in this report provide the basis for seven key recommendations for enhancing patient engagement for patient safety:

1.   **Building trust for safer healthcare through stronger patient and family engagement**: Trust in healthcare systems is fundamental to patient safety. Trust can be built through increased patient and family engagement during the care journey and in all patient safety improvement efforts at the national and subnational levels. Safe, high-quality healthcare that is jointly co-developed by those that demand and need care and those who design and deliver care is essential to realising patient safety.

     Trust is essential to promote safe care and improve health outcomes. To build trust in healthcare systems and professionals, adverse events to patients that have caused (or could have caused) inadvertent harm need to be disclosed. When people trust their healthcare system and healthcare providers, at the clinical level, they are more likely to seek both preventive and curative care, agree with treatments, signal and report concerns or errors, engage in their care and participate in efforts to prevent harm. Additionally, patients, families, and carers can be engaged in sharing and reporting experiences in safety through measuring and monitoring mechanisms to help prevent and minimise risks of patient safety incidents, and thus enhancing trust in healthcare providers. While increased engagement of patients, families and carers, and communities in patient safety improvement efforts can enhance trust and a sense of ownership of the healthcare system, lack of engagement of people in decision-making processes about patient safety can lead to mistrust and avoid/postpone care, which can ultimately result in a higher economic burden. In the aftermath of the COVID-19 pandemic, it has become increasingly important that countries intensify efforts to enhance trust in the healthcare system and healthcare providers. Efforts are needed at the national and subnational levels to engage patients, families and carers, and communities in decision-

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[37] https://www.hqsc.govt.nz/resources/resource-library/national-adverse-event-policy-2023/

[38] https://www.government.is/lisalib/getfile.aspx?itemid=3934b4b1-e0d8-11e8-942e-005056bc4d74

making towards high-quality safe care. This can be achieved by strengthening their voice in advisory councils, task forces and boards while ensuring accountability of these committees.

2. **Institutionalising patient engagement for patient safety**: Patient experiences related to safety events often do not get shared, reported, or integrated into the development of patient safety solutions. More efforts are needed to institutionalise the engagement of patients, families and carers, and communities in patient safety improvement initiatives, as well as learning from the first-hand experience of patients and families.

   Patient engagement for patient safety is still in silos and not institutionalised in many countries. Siloed activities can lead to inequalities in the inclusion of different perspectives, resulting in the lack of perspectives from disadvantaged groups, such as people with low health literacy levels, disability, and low socioeconomic status. Given that efforts to ensure high quality safe care need to be responsive to the needs and preferences of all people, mechanisms must be put in place to ensure that people's voice are fully exercised and there is full inclusion of diverse perspectives, including that of people categorised as vulnerable. Countries should enforce to institutionalise the role of patients, families and carers, and communities to ensure that people have the capabilities to participate meaningfully and exercise voice (for example, when participating in advisory councils, committees or boards). This allows people moving from their individual experience to consider the common good to their communities and having the ability to offer constructive insights for improvement and reflect the perspectives of diverse groups.

3. **Establishing better platforms and networks for sharing experiences and good practices in patient engagement:** Countries need to create mechanisms for patients, families and carers to systematically share and hear their stories about care experiences and health outcomes, and ensuring that such information informs the design of patient safety initiatives.

   Patient engagement platforms and networks involve patients and families in their care even when they are not in a healthcare setting, supports self-management, promotes sharing personal narratives related to safety events, and even enables interaction with healthcare providers. Efforts are needed to invest in interactive, real-time communication platforms that offer multilingual support, are integrated in electronic medical records, and provide monitoring and feedback that can be used to inform policies, education, and research. Particular attention needs to be paid to patients and family preferences, user education, healthcare providers training as well as end user acceptance of the platforms. Engaging patients and families from the onset of designing these platforms and networks can ensure that the design of patient safety programmes is useful in promoting safe care.

4. **Strengthening patient engagement for patient safety at institution and clinical levels**: Countries can further engage patients in prioritising funding allocation to patient safety research projects, embedding patient engagement in developing safety initiatives such as service design, improving clinical communication protocols and training, and defining the organisation's culture of transparency and accountability at the institution level. Countries can also promote contributions of patients, families, caregivers and citizens in developing processes and procedures to ensure delivery of safe care at the clinical level.

   To ensure successful implementation of patient safety, it is essential to have both political commitment and leadership capacity across levels of the healthcare system to guarantee patients are informed, involved and treated as partners or co-designers of patient safety initiatives. As a result, patients will have a decision-making role in the development cycle of patient safety initiatives. Patients, families and carers, and communities can contribute to making healthcare systems safer, despite of the persisting power imbalances that can lead to poor trust and accountability, and thus not conducive of a supportive environment to patient safety, not only at the macro level, but also at meso and micro levels. In support of the movement towards countries

institutionalising patient engagement for patient safety at the macro and meso levels of the healthcare system, learning from international good practices is encouraged. Regardless of cultural differences among countries and organisations, learning from countries and organisations where patient engagement for patient safety is meaningfully and further institutionalised is key to advance national efforts towards strengthening patient safety, reducing harm and the direct and indirect impacts caused by harm.

5. **Enhancing monitoring of patient safety for keeping track of progress and building accountability**: Data on patient experiences should be monitored as part of broader data collections including professional's experiences with patient safety culture and patient safety events measured through administrative data sources. Efforts could be made to classify patient safety incidents by using common terminologies in a comparable manner across data sources to maximise their use for promoting safe healthcare. Further efforts are needed to broaden data collection to other settings beyond hospitals such as primary care and long-term care.

Countries need to develop and utilise information and data collected from patients themselves, together with patient safety indicators based on administrative data sources and patient safety culture reported by healthcare professionals, to monitor the incidence of safety events and the implementation of measures to prevent them. To promote national and international monitoring of patient safety and improving safe healthcare based on multiple data sources, further work is needed to classify and code patient safety incidents systematically in a comparable manner by using common terminologies across data sources within and across countries. Commonly, countries undertaking patient surveys to measure patient experiences of safety are implementing these in the hospital setting. Efforts to monitor patient safety in other settings such as primary care and long-term care are emerging. More countries need to follow these examples since there is dearth of information on patient safety outside of the hospital setting that is not currently monitored and their occurrence implies high costs to the healthcare system. This will contribute to strengthening notions of safety culture. For example, the OECD's Patient-Reported Indicator Surveys (PaRIS) will shed light on the delivery of safe primary care from the perspectives of people living with chronic conditions such as the implementation of medication reviews.

6. **Anchoring collection and use of patient safety data to OECD's Recommendations of the Council on Health Data Governance:** Implementing OECD's Recommendations of the Council on Health Data Governance is essential for protecting privacy of individuals providing data on patient safety and promoting adequate data use (including secondary use of data).

Given the value of patient-reported experience of safety, countries use these data not only to monitor changes over time and differences across organisations within countries, but also to contribute to provider accreditation. To protect privacy of individuals providing data and to promote adequate data use (including secondary use of data), the collection and use of patient-reported experiences of safety should be anchored in the [OECD's Recommendations of the Council on Health Data Governance](#) which sets out guidance related to clear provision of information to individuals, informed consent and appropriate alternatives, review and approval procedures for the use of personal health data for research and other health-related public interest purposes, and transparency. Since data on patient safety incidents are very sensitive in nature, particular and systematic attention needs to be made to protect individual privacy while seeking ways to utilise these data for improving patient safety and healthcare quality.

7. **Improving quality of patient-reported safety indicators and systematically using them**: Measurements of patient-reported safety convey stories of patient safety events in a concise and comparative manner, leading to higher attention from policy-makers, healthcare providers, professionals and citizens to improve patient safety together. Further efforts are needed to improve the quality of patient-reported safety indicators. This can be achieved by fostering a safety culture

that encourages reporting of safety events, involving patients in survey design, enhancing survey accessibility, ensuring adequate representativeness with meaningful sample sizes, and using patient safety data in a timely manner in quality improvement cycles.

To increase the use of patient-reported data in patient safety, more efforts need to be made to improve data quality. Surveys collecting patient experiences of healthcare safety often show a low response rate. This is partly because the perceived utility of participating in these surveys and their role in preventing and minimising patient safety incidents is not well informed. To collect data which are meaningful for improving healthcare quality and patient safety from the patient perspective, patients need to be involved in survey development from the onset and their feedback during different stages of survey development need to be considered in finalising and deploying the survey. Surveys need to be designed so that they are easy to access, respond and submit. Patient-reported experience of safety data collected need to be used in a timely manner in quality improvement cycles, which also serves to strengthen accountability to patients by informing them of the importance of their inputs to healthcare quality. In turn, this can lead to increased participation rates and improved reliability of these data. Although these surveys are often started in a small scale, sample size needs to be increased to ensure adequate representativeness of the target population, and foster trust in these data for the purposes of benchmarking and informing decision-making.

## 4.3. Conclusion

107.    As countries are striving towards ensuring safe care and making health systems more people-centred, engaging patients, families and carers, and communities is essential to achieve this goal. Engaging patients and citizens requires a systematic approach across all levels of the health system. This involves institutionalising the roles of patients, families, caregivers and citizens, and ensuring the inclusion of diverse voices. International learning on patient engagement for patient safety is key for advancing national efforts to enhance trust, create a patient safety culture, and ensure safe care.

# Annex A. List of coordinating leads from participating countries

## Table A A.1. Key contacts from 21 participating countries

| Country | Contact | Affiliation |
|---|---|---|
| Austria | Patrizia Theurer | Legal Expert for Quality in Healthcare (Ministry of Health) |
| Belgium | Annemie Vlayen | Coordinator Quality and Patient Safety |
| Canada | Anne MacLaurin | Senior Program Manager at Healthcare Excellence Canada (HEC) |
| Colombia | Julio Cesar Vergel Garnica | Advisor of the Directorate of Provision of Services and Primary Care (Ministry of Health and Social Protection) |
| Costa Rica | Francisco Oviedo | Medical Officer at Ministry of Health |
| Czech Republic | Veronika Stejskalová | Official (Ministry of Health) |
| France | Caroline Bizet<br>Candice Legris | Cheffe de projet Mission Qualité et Pertinence, Sous-direction du pilotage de la performance des acteurs de l'offre de soins (SDPF) at DGOS<br>Adjointe au chef de service ; Service Évaluation et Outils pour la Qualité et la Sécurité des Soins (EvOQSS) ; Direction de l'amélioration de la qualité et de la sécurité des soins pour la Haute Autorité de Santé |
| Germany | Marco Krichelmann | Federal Ministry of Health |
| Iceland | Ólöf Elsa Bjornsdottir and Hrefna Thengilsdottir | Project manager; Senior Medical Officer at Organisation Supervision and Quality of Healthcare - Directorate of Health |
| Ireland | Mary McGeown | Head of Patient Safety Surveillance & Performance Unit (National Patient Safety Office, Department of Health) |
| Israel | Dana Arad | Head of patient safety division at Ministry of Health |
| Japan | | Ministry of Health, Labour and Welfare |
| Korea | Yunjeong Heo<br>Seunghee Lee | Central Patient Safety Center in Korean Institute for Healthcare Accreditation |
| Latvia | Irisa Zīle-Velika<br><br>Jana Lepiksone | Head of Patient Safety and Health Care Quality Improvement Unit at Centre for Disease Prevention and Control of Latvia<br>Head of Research and Health Statistics Department at Centre for Disease Prevention and Control of Latvia |
| Netherlands | Linda Daniels-van Saase | Manager at Patient Federation Netherlands |
| New Zealand | Sarah Upston | Manager, Clinical, Quality & Safety, OCCO at Ministry of Health |
| Portugal | Carla Sandra Martins Pereira | Head of the Division of Quality Design and Improvement / Department of Quality in Health of the Directorate-General of Health |
| Romania | Gratiela-Denisa Iordache Grigore-Octavian Borontis | Counselors at the National Authority for Quality Management in Health - NAQMH |
| Slovenia | Mirna Macur | Office for Control, Quality and Investments in Healthcare of the Republic of Slovenia |
| Switzerland | Martine Reymond | Head of Section Quality and Pass-on Requirement |
| Türkiye | Sule Ozturk | T.R. Ministry of Health General Directorate of Health Services |

# Annex B. 2023 OECD Assessment of Policies to Engage Patients in Patient Safety Survey

This survey examines key components of patient engagement for patient safety in OECD countries, with a focus on the state of policies and interventions to "engage and empower patients and families to help and support the journey to safer health care" (WHO GPSAP). Beyond the individual patient-clinician interaction, the patient's voice – especially of those who have experienced harm from unsafe care – can be effectively engaged as co-developers of patient safety solutions at the institution and national levels. There are lessons to be learned from sharing international good practices. Hence, patient safety can be improved through the active engagement of patients and citizens in the development of national policies to ensure and improve patient safety at the clinical (local), institutional (i.e. hospital, nursing home) and national level of health care systems.

The OECD, with the support of the Government of Germany, is conducting analysis on the economic benefits of patient engagement for patient safety and the status of initiatives being undertaken to improve patient engagement for patient safety in OECD member countries (as part of the Economics of Patient Safety Series). Enhancing the inclusiveness of development and execution of patient safety activities will not only contribute to safer care, but, as documented in the previous five reports in the series on the economics of patient safety, a better use of scarce healthcare resources.

Data from this survey will inform this forthcoming report, which will explore the advances countries have made to drive improvements in patient safety and improve people-centered care. This survey includes 34 questions.

The findings are planned to be discussed at the 10-11 May 2023 HCQO Working Party Meeting, informing a report planned to be launched on 17 September 2023, in accordance with World Patient Safety Day—the theme of which is "Engaging PatientsPatient Safety".

If you are unable to complete parts of the survey, please note that the OECD would be happy to follow up with national experts identified below. Only one response per country is expected. Please send completed questionnaires to HCQO.contact@oecd.org. Your response by **10 March 2023** would be greatly appreciated.

**Contact persons**

Please provide the name, affiliation, and email address of the **person responsible for the completion of this questionnaire**.

| | |
|---|---|
| **Country:** | |
| **Name:** | |
| **Job Title:** | |
| **Organisation:** | |
| **E-mail address** | |

Please provide the name, affiliation and email address of the **person who should be contacted for a potential follow up consultation (i.e. national expert).**

| | |
|---|---|
| **Country:** | |
| **Name:** | |
| **Job Title:** | |
| **Organisation:** | |
| **E-mail address** | |

**Glossary of terms used in this questionnaire:**

| | |
|---|---|
| **Patient Safety Incident/Event** | An event or circumstance which could have resulted, or did result, in unnecessary harm to a patient |
| **Patient engagement** | Patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care |
| **Citizen engagement** | Citizen engagement in health care is a top-down initiated mechanism that can enhance the quality of policy making by redistributing power from authority to citizens, nurturing the right of individuals in participating individually or collectively in health policy decision-making. |

## Section 1. Policy context related to patient engagement for patient safety

| 1.1 | Has patient safety been recognised as a priority in national health policy? | ☐ Yes<br>☐ Some aspects of patient safety have been considered in national health policy<br>☐ No<br>☐ Don't know<br><br>If "some aspects have been considered"<br>    *1.1.1 Which aspects of patient safety?*<br>    _____ |
|---|---|---|
| | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. | |
| 1.2 | Do you have a national patient safety policy or strategy in your country? | ☐ Yes<br>☐ One is in discussion/being considered<br>☐ No<br>☐ Don't know<br><br>If "yes" or "being considered"<br>    *1.2.1 Does the national patient safety policy or strategy reference patient engagement?* _____<br><br>    *1.2.2 Were patients or citizens engaged during the development phase?* _____ |
| | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. | |
| 1.3 | Do you have formal mechanisms to engage patients in national governance, task forces, or committees that address patient safety? | ☐ Yes<br>☐ This is in discussion/being considered<br>☐ No<br>☐ Don't know<br><br>If "yes" or "being considered"<br>    *1.4.1 Could you briefly identify which mechanisms are in place?*<br>    _____ |
| | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. | |

## Section 2. Legal context related to patient engagement for patient safety

| 2.1 | Are there mechanisms to ensure the right to safe patient care in your country (e.g., national patient rights charter)? | ☐ Yes<br>☐ One is in discussion/being considered<br>☐ No<br>☐ Don't know |
|---|---|---|

| | | If 'yes' or 'being considered'<br>*2.1.1 Do the existing mechanisms include a means to enforce its provisions?* _____<br>*2.1.2 Were patients or citizens engaged during the development phase?* _____ |
|---|---|---|
| | | Please use this box to provide additional information. Please include links to relevant documentation or send over email to <u>HCQO.contact@oecd.org.</u> |
| 2.2 | Does your country have data on the number of patient safety incidents that result in litigation or settlements annually? | ☐ Yes (litigation):<br>  Annual number of patient safety incidents that result in litigation: _____<br>☐ Yes (settlements):<br>  Annual number of patient safety incidents that result in settlements: _____<br>☐ Data not available<br>☐ Don't know |
| | | Please use this box to provide additional information. Please include links to relevant documentation or send over email to <u>HCQO.contact@oecd.org.</u> |
| 2.3 | Is there a national estimate of how much is spent annually on patient safety settlements with patients? | ☐ Yes:<br>  Estimate of national spending on patient safety settlements (and currency): _____<br>☐ Data not available<br>☐ Don't know |
| | | Please use this box to provide additional information. Please include links to relevant documentation or send over email to <u>HCQO.contact@oecd.org.</u> |
| 2.4 | Is there a *duty of candor\** legislation in your country?<br><br>*\*A requirement of disclosure of a patient safety event to a patient* | ☐ Yes<br>☐ One is in discussion/being considered<br>☐ No<br>☐ Don't know<br><br>If 'yes' or 'being considered'<br>*2.4.1 Does it involve any of the following? Tick all that apply.*<br>  ☐ An acknowledgement of the event that occurred<br>  ☐ A detailed account of the scope of the error and timeline<br>  ☐ A guarantee that the patient and carer/family will not be inhibited from speaking out about their experience<br>  ☐ An apology on behalf of the health care provider (system)<br>  ☐ An apology from involved individual care providers (nurses, doctors, etc.)<br>  ☐ A discussion of actions that will be taken to help prevent similar situations in the future. |
| | | Please use this box to provide additional information. Please include links to relevant documentation or send over email to <u>HCQO.contact@oecd.org.</u> |
| 2.5 | Is there a system of no-fault compensation to patients who have been impacted by certain safety events? | ☐ Yes<br>☐ One is in discussion/being considered<br>☐ No<br>☐ Don't know<br><br>If 'yes' or 'being considered'<br><br>*2.5.1 Please specify for which events a no-fault compensation applies and the scope of compensation.* _____ |

| | |
|---|---|
| | |
| Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. | |

## Section 3: Patient engagement as a lever for designing and implementing patient safety strategies

In the 2017 OECD report, The Economics of Patient Safety: Strengthening a value-based approach to reducing patient harm at national level, several patient safety initiatives were assessed in terms of their impact on patient safety and implementation costs by a panel of academic experts and policymakers. Many of the patient safety initiatives perceived as generating highest value (impact and cost ratio) among respondents of that initial survey are now listed below.

In this survey, we want to understand the strength of patient or citizen engagement in the development cycle (design, development, implementation, evaluation, re-implementation) of various categories of patient safety initiatives. For each patient safety initiative, please score the strength of engagement using the scale "Low" (patients or citizens were consulted or informed only), "Medium" (patients or citizens were actively involved at some stage), and "Strong" (patients or citizens were partners/co-designers).

You can also score patient safety initiatives as "Not implemented" or select "Don't know" when you have insufficient information.

| **LOW patient or citizen engagement** | Informed/Consulted | For example, patients were informed with posters about hand hygiene hanged in waiting rooms or corridors<br>Or<br>For example, patients were consulted about developing posters about hand hygiene. |
|---|---|---|
| **MEDIUM patient or citizen engagement** | Involved | For example, patients were interviewed during root-cause or hazard analyses |
| **STRONG patient or citizen engagement** | Partnered/Co-designed | For example, patients were partners/co-designers and had a decision-making role in the development cycle of a patient safety initiative |

| | **To what extent were patients or citizens engaged in the following patient safety initiatives?** | **Level of patient or citizen engagement** | | | | |
|---|---|---|---|---|---|---|
| | | Low | Medium | Strong | Not Implemented | Don't know |
| **System level initiatives** | | | | | | |
| 3.1 | Establishing networks of diverse patient advocates and champions including civil society and patient organizations for patient safety | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.2 | Engaging patients in defining safety standards linked to accreditation and certification initiatives | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.3 | Public reporting of patient safety events and indicators | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.4 | Engaging patients in the education of future or current health care professionals<br>*(For example: patient-led curriculums, patient involvement in teaching, patient sharing experiences within a faculty-directed curriculum, etc.)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.5 | Engaging patients in health literacy initiatives, such as education and training programmes for patients and hand hygiene initiatives | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.6 | Engaging patients in national initiatives based on specific safety themes<br>*(For example, communication campaigns, safety improvement programs)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Organizational level initiatives** | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| 3.7 | Engaging patients and the community in defining the culture of transparency and accountability within the healthcare provider<br>*(For example, convening citizen panels for discussing the health care provider's vision and strategy, designing mechanisms encouraging healthcare professionals to admit mistakes, etc.)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.8 | Engaging patients in service design or development<br>*(For example, co-development of a clinical incident reporting and management system, designing improvement plans, etc.)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.9 | Establishing an integrated patient complaints reporting system | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.10 | Developing, monitoring and feedback of patient safety indicators | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.11 | Engaging patients in initiatives to improve clinical communication protocols and training<br>*(For example, design bedside handover processes, discuss patient feedback among health care professionals, etc.)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.12 | Establishing responsive patient safety systems for patients and health care professionals to report and deal with health care harm | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.13 | Engaging patients and the community in antimicrobial stewardship | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.14 | Engaging patients in prioritizing funding allocated to patient safety research projects | ☐ | ☐ | ☐ | ☐ | ☐ |
| **Clinical level initiatives** | | | | | | |
| 3.15 | Processes for medication management/reconciliation<br>*(For example, engaging patients in developing processes and procedures to ensure systematic review and reconciliation)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.16 | Processes for transcribing error minimisation protocols<br>*(For example, engaging patient in developing strategies to prevent adverse drug events precipitated by failures in transcribing, labelling or misinterpretation of written orders)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.17 | Development of urinary catheter uses and insertion protocols<br>*(For example, engaging patients in developing materials about appropriate use and management of catheters)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.18 | Development of peri-operative medication protocols<br>*(For example, engaging patients in developing checklists)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.19 | Establishing mechanisms for patients to provide direct input into quality improvement cycles<br>*(For example, for establishing clinical care standards)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.20 | Conduct of root-cause or hazard analyses to create protocols, such as falls prevention and patient identification and procedure matching protocols | ☐ | ☐ | ☐ | ☐ | ☐ |
| 3.21 | Development of a patient or caregiver-activated escalation system<br>*(For example, an emergency response system that can be accessed directly by patients and carers/families to alert staff to any worrying changes in the patient's condition)* | ☐ | ☐ | ☐ | ☐ | ☐ |
| | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. | | | | | |

## Section 4: Priorities in relation to patient engagement in safety activities

There are many factors that can affect patient engagement for patient safety. Considering the type of factors below, please indicate specific activities that have been prioritized in your country to strengthen patient engagement in patient safety activities.

| | Type of factors that can affect patient engagement for patient safety | Prioritised activities to strengthen patient participation in patient safety |
|---|---|---|
| 4.1 | **Patient/population related**<br>*(For example, dedicated communication channels for people with a migration background, ensuring patient surveys are accessible and adapted to different health literacy levels, etc.)* | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. |
| 4.2 | **Health-related**<br>*(For example, convening focus groups among people with specific diseases or health conditions that make them vulnerable to patient safety events)* | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. |
| 4.3 | **Health professionals related**<br>*(For example, engaging patient advocates in designing leadership capacity building programmes, discussing with panels of patients about health care professional values, characteristics, and roles)* | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. |
| 4.4 | **Health care setting related**<br>*(For example, ensuring availability of psychological support for patients and families impacted by healthcare harm, engaging patients in the co-development of standard operation procedures)* | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. |
| 4.5 | **Technology structure related**<br>*(For example, facilitating patient education and feedback through smartphone technologies, co-creation of patient safety alert systems, enabling patients' access to their health data using portals and electronic systems)* | Please use this box to provide additional information. Please include links to relevant documentation or send over email to HCQO.contact@oecd.org. |

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