



OECD Health Working Papers No. 185

Digitalisation of public
health: Leading practices in
immunisation reporting and
respiratory disease
surveillance

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<https://dx.doi.org/10.1787/97204768-en>

Digitalisation of Public Health

Leading practices in immunisation reporting and respiratory disease surveillance

JEL classification: I10, I18, L86, O33

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Abstract

The digitalisation of public health systems offers new opportunities to strengthen health system resilience, improve population health, and enhance preparedness for future crises. Yet as countries accelerate this transformation, they continue to face persistent challenges related to fragmented data governance, limited interoperability, and unequal access to digital tools. Building on lessons from the COVID-19 pandemic, OECD countries are developing long-term strategies to embed digital public health tools, such as immunisation registries and respiratory disease surveillance systems, into routine practice.

This paper examines how Australia, Canada, New Zealand, and the United Kingdom are advancing the digitalisation of public health through reforms in governance, workforce development, technology, and policy co-creation. Drawing on desk research and interviews, it identifies leading practices in data stewardship, digital skills development, interoperable and secure systems, and the co-creation of health data policies with the public. The findings highlight shared challenges and practical opportunities to strengthen digital public health systems, reinforcing essential functions and enhancing overall resilience and performance.

Résumé

La numérisation des systèmes de santé publique offre de nouvelles opportunités pour renforcer la résilience des systèmes de santé, améliorer la santé des populations et renforcer la préparation face aux futures crises. Pourtant, à mesure que les pays accélèrent cette transformation, ils continuent de faire face à des défis persistants liés à la gouvernance fragmentée des données, à la faible interopérabilité et à l'accès inégal aux outils numériques. Tirant les leçons de la pandémie du COVID-19, les pays de l'OCDE élaborent des stratégies à long terme visant à intégrer durablement les outils numériques de santé publique, tels que les registres de vaccination et les systèmes de surveillance des maladies respiratoires, dans la pratique courante.

Ce document examine la manière dont l'Australie, le Canada, la Nouvelle-Zélande et le Royaume-Uni font progresser la numérisation de la santé publique grâce à des réformes en matière de gouvernance, de développement des compétences, de technologie et de co-crédation de politiques. S'appuyant sur des recherches documentaires et des entretiens, il identifie des pratiques exemplaires en matière de gestion des données, de développement de compétences numériques, de systèmes interopérables et sécurisés, ainsi que de co-crédation de politiques de données de santé avec le public. Les conclusions mettent en évidence les défis communs et les possibilités concrètes de renforcer les systèmes numériques de santé publique, en consolidant leurs fonctions essentielles et en améliorant leur résilience et leurs performances globales.

Acknowledgements

The authors would like to thank Canada for funding this work to analyse the digitalisation of public health and to engage in a comparative analysis across Australia, Canada, New Zealand and the United Kingdom.

The work presented here was undertaken by Katarina Vujovic and co-written by Rachel Fellner at the OECD. The authors would especially like to thank Eric Sutherland, Senior Health Economist at the OECD, for his guidance in writing this paper and providing valuable recommendations, and Viktoria Lykke for her revision of the report. The authors would also like to thank Francesca Colombo of the Employment, Labour and Social Affairs (ELS) Division of the OECD, as well as colleagues from the Science, Technology, and Innovation (STI) Directorate for their time and contribution in reviewing this work.

The authors would like to extend their gratitude to the OECD Health Committee and the many government officials, policy and technical experts across the OECD who participated in the interviews, provided recent literature and studies, and reviewed draft chapters. In addition, a special thank you goes to the country leads, Sinead Tuite, Lucy Farrell, Fiona Callaghan and Matt Thompsons for their invaluable support to this report, and to Reena Kudhail and Miranda Nonis for their commitment to bringing this work to fruition.

Table of contents

OECD Health Working Papers	2
Abstract	3
Résumé	4
Acknowledgements	5
Acronyms and abbreviations	8
Executive summary	10
1 Advancing the Digitalisation of Public Health	13
2 Background of the Digitalisation of Public Health	17
3 Policy Considerations and Leading Practices	23
4 Conclusions and Next Steps	33
References	38
Annex A. Interviewed experts across the four surveyed countries	52
Annex B. OECD Recommendation on Health Data Governance (2016)	53
Annex C. Governance and People Capacity	55
Annex D. Data and Data flows	63
Annex E. Technology	76
Annex F. Co-creation of digital public health	89

FIGURES

Figure 1. The broader digital public health (DPH) ecosystem	15
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Figure 2. Timeline of eHealth policies or strategies adoption, 1995-2015	17
Figure 3. Introduction of changes to health data governance models in response to COVID-19	20
Figure 4. Readiness assessment across four OECD member countries	34
Figure 5. Summary of findings in this report	35
Figure 6. Summary of leading practices in digitalising public health systems across four OECD member countries	37
Figure 7. Pan-Canadian health data content framework	69
Figure 8. National communicable disease surveillance dashboard	70
Figure 9. COVID-19 register data flow	74
Figure 10. UK Health Security Agency Enterprise Data and Analytics Platform applications and services	81
Figure 11. HISO 10029 health information security functional processes	84
Figure 12. HISO 10029 health information security framework strategy	85
Figure 13. Iwi-Māori partnership boards	94
Figure 14. Australian digital inclusion index: First Nations	97

TABLES

Table 1. Governance practices for digitalising public health systems	24
Table 2. Summary of governance practices across four OECD member countries	25
Table 3. Health data architecture across four OECD member countries	26
Table 4. Summary of data architecture practices across four OECD member countries	27
Table 5. Technology practices for digitalising public health system	29
Table 6. Summary of technology practices across four OECD member countries	30
Table 7. Co-creation within national public health programs across four OECD members	31
Table 8. Summary of co-creation practices across four OECD member countries	32
Table 9. Governance practices for digitalising public health systems	56
Table 10. Summary of governance practices across four OECD member countries	62
Table 11. Health data architecture across four OECD member countries	64
Table 12. Summary of data architecture practices across four OECD member countries	75
Table 13. Technology practices for digitalising public health system	77
Table 14. Summary of technology practices across four OECD member countries	88
Table 15. Co-creation within national public health programs across four OECD members	90
Table 16. Summary of co-creation practices across four OECD member countries	98

BOXES

Box 1. The definition of digital public health used in this report	14
Box 2. Canada's progress in modernising public health data governance	59
Box 3. A collaborative and patient-centric healthcare model through the establishment of standardised data content	68
Box 4. Linking multiple health-related datasets to increase public health emergencies' response	73
Box 5. United Kingdom enterprise data and analytics platform	81
Box 6. New Zealand cyber security uplift and health information security framework	84
Box 7. Canada legislation: Interoperability and prohibiting data blocking	87
Box 8. Māori-centred decision-making frameworks with recognition of Indigenous sovereignty	94
Box 9. Australian First Nations Dashboards	97

Acronyms and abbreviations

ABS	Australian Bureau of Statistics
AI	Artificial Intelligence
AIR	Australian Immunisation Register / Aotearoa Immunisation
AIHW	Australian Institute of Health and Welfare
APIs	Application Programming Interfaces
AUCDI	Australian Core Data for Interoperability
BAME	Black, Asian, and Minority Ethnic
CACDI	Canadian Core Data for Interoperability
CA Core+	Canada Health Infoway Core+
CDC	Centre for Disease Control
CIHI	Canadian Institute for Health Information
cNICS	Childhood National Immunisation Coverage Survey
DPH	Digital Public Health
DRIPA	Declaration on the Rights of Indigenous Peoples Act
DSPT	Data Security and Protection Toolkit
EDAP	Enterprise Data and Analytics Platform
EGAP	Engagement Governance, Access and Protection
EMHP	Environmental Monitoring for Health Protection
EMRs	Electronic Medical Records
ESR	Institute for Environmental Science and Research
FAIR	Findability, Accessibility, Interoperability, and Reusability
FDP	Federated Data Platform
FINM	First Nations, Inuit and Métis Nations
FPT	Federal, Provincial, and Territorial Governments
GDPR	General Data Protection Regulation
GDS	Government Digital Service
GP	General Practice
GSSO	Gender, Sex and Sexual Orientation
HDRN	Health Data Research Canada
HISO	Health Information Standards Organisation
HL7 FHIR	Fast Healthcare Interoperability Resources
ICD-10/-11	International Classification of Diseases, 10 th /11 th Edition
ICT	Information and Communications Technology
IHI	Individual Healthcare Identifier
IMPBs	Iwi-Māori Partnership Boards
IRFS	Canadian Immunisation Registry Functional Standards

ISA	Information Sharing Agreements
ISM	Information Security Manual
MBS	Medicare Benefits Schedule
NACDC	National Aged Care Data Clearinghouse
NAATSIHWP	National Association of Aboriginal and Torres Strait Islander
NDP	National Data Platform
NDI	National Death Index
NHMD	National Hospitals Morbidity Database
NHS	National Health Service
NHI	National Health Index
NIAA	National Indigenous Australians Agency
NIMS	National Immunisation Management Service
NIVS	National Immunisation and Vaccination System
NMDS	National Minimum Data Sets
NNDSS	Australian National Notifiable Diseases Surveillance System
NNAPEDCD	National Non-Admitted Patient Emergency Department Care
NIR	National Immunisation Register
NIP	National Immunisation Program
NHS	National Health Service
NZCDI	New Zealand Core Data for Interoperability
NZDep	New Zealand Index of Deprivation
NZHTS	New Zealand Health Terminology Service
NZIPS	New Zealand International Patient Summary
OECD	Organisation for Economic Co-operation and Development
OHID	Office for Health Improvement and Disparities
PCHDCF	Pan-Canadian Health Data Content Framework
PCHDS EAG	Pan-Canadian Health Data Strategy Expert Advisory Group
PHAC	Public Health Agency of Canada
PHDS	Public Health Data Strategy
PHLN	Public Health Laboratory Network
PHN	Public Health Network
PIPEDA	Personal Information Protection and Electronic Documents
RIFIC	Regional Insights for Indigenous Communities
RSV	Respiratory Syncytial Virus
RTPM	Real-Time Prescription Monitoring
SDH	Social Determinants of Health
SNOMED CT	Systematised Nomenclature of Medicine - Clinical Terms
STARVAX	Standardised Reporting on Immunisation
UK HSA	United Kingdom Health Security Agency
UNDRIP	United Nations Declaration on the Rights of Indigenous
WHO	World Health Organization

Executive summary

Digitalising public health systems has become a cornerstone for enhancing health system resilience and performance as populations and individual health needs continue to evolve in an increasingly digitalised world. Robust health data governance frameworks, supported by secure and interoperable infrastructure, are essential for enabling efficient health data sharing and secondary usage, advancing the quintuple aim of healthcare. Central to this transformation is the proactive integration of communities living in marginalised conditions. This ensures that digital health advancements can equitably benefit all populations, fostering digitally enabled health systems that ‘leave no one behind.’ By driving a holistic cultural shift, public health objectives such as immunisation and respiratory disease surveillance programs will be reinforced, enhancing countries’ preparedness and response capabilities to address public health challenges.

Before the COVID-19 pandemic, digital public health efforts primarily focused on establishing foundational health data governance frameworks and technical infrastructure. These initiatives aimed to standardise data sharing and ensure coherence across jurisdictions, particularly in the areas of immunisation reporting and respiratory disease surveillance. Despite these advances, significant fragmentation remained, further exposed during the pandemic. Critical gaps included insufficient data availability, especially among marginalised and Indigenous communities, as well as challenges in data timeliness, linkability, and reporting mechanisms. These issues were most pronounced in decentralised governance structures, where a lack of harmonisation across government levels hindered effective coordination.

During the pandemic, many countries accelerated the digitalisation of the public health systems in place to address these shortcomings. Emergency measures included investments in nearly real-time surveillance systems to facilitate faster data sharing. However, the scale and effectiveness of these expansions varied. Countries with robust pre-pandemic digital infrastructure were better positioned to *adapt* quickly, while those with underdeveloped systems relied on more ad hoc measures to meet immediate demands (OECD, 2023^[1]).

In the post-pandemic era, countries are exploring long-term strategies and action plans to integrate these advancements into routine practices, ensuring the effective, equitable, and transparent use of health data for immunisation reporting and respiratory disease surveillance.

This paper identifies **leading practices** in the post-pandemic digitalisation of public health services, focusing on immunisation and integrated respiratory disease surveillance. It aims to enhance countries’ preparedness and responsiveness to future public health emergencies. It evaluates the current capabilities of four OECD member countries (Australia, Canada, New Zealand and the United Kingdom) highlighting their progress and opportunities to ensure the sustainability of digital health initiatives.

Previously, the 2023 OECD publication *Ready for the Next Crisis? Investing in Health System Resilience* (OECD, 2023^[1]) identified three critical areas where countries should further invest to strengthen their integrated health systems. First, despite advancements in timely data reporting during the COVID-19 pandemic, many countries still face challenges with **standardised health-related datasets**, with issues persisting around inconsistent data quality, lack of interoperability, and limited linkability impeding the

efficient use of health data. Second, with insufficient **capacity building** to enhance the use and application of information within health systems, the ability of healthcare professionals and administrators remains limited in fully leveraging data and digital tools for decision-making. Third, **appropriate health data governance frameworks** are not consistently in place across the OECD countries, due to legal restrictions and policy barriers, particularly related to data sharing and usage among public health authorities. This paper utilised desk research and interviews with thirty-eight experts in the public health sector from the four OECD members between June and September 2024 to explore practices and progress across these areas.

Across governance and people capacity, data and data flows, technology, and health equity, eight leading practices emerged for the continuity in digitalising public health systems, with a specific focus on immunisation and integrated respiratory disease surveillance:

Governance and people capacity

Given the importance of timely access to quality and granular data for the digitalisation of public health, it is notable that all of the interviewees are making progress towards the adoption of data stewardship models, with **New Zealand** and the **United Kingdom** having implemented such a model for several years. Notably, **Australia** was the only country to have a defined program to build people capacity to better use data for public health professionals. Based on the analysis, leading practices would include:

Assigning accountability for developing an independent and competency-based national stewardship authority to design, oversee and ensure stewardship of health data foundation and provide advice on unified data-sharing standards.

Develop a comprehensive national program for the public health system, with clear objectives and financing, to provide end-to-end digital and data skills development for both frontline health workers and backend data professionals.

Data and data flows

In **Canada**, recent efforts to address data fragmentation included the Connected Care for Canadians Act (former Bill C-72), introduced to the Canadian House of Commons in June 2024. This bill sought to ensure interoperability by prohibiting vendor data blocking and requiring vendors to comply with data standards. While the bill did not advance due to the prorogation of Parliament and will need to be reintroduced, it promotes interoperability and bans information blocking. These measures are crucial for improving patient safety and enabling real-time public health data analysis and response. Based on the analysis, leading practices would include:

Assign accountability for developing a common set of integrated health data standards (content) and incentives for public health use cases to ensure accountability, quality, privacy, and access to health data.

Assign accountability for developing a health data framework for data collection, exchange, integration, and security, with regional monitoring processes.

Technology

A common trend across all interviewed countries is the implementation of **cloud-first** and **cloud- smart** policies, prioritising scalability, open infrastructure, and compliance with privacy and security guardrails. Procurement processes in all four countries incorporate national recommendations for privacy and cybersecurity criteria, though enforcement in federated systems is often left to regional jurisdictions, making accountability harder to achieve. Based on the analysis, leading practices would include:

Develop cost-benefit analysis framework of existing software solutions to ensure their adaptability and scalability to evolving public health needs (immunisation and surveillance).

Foster adoption of federated data architecture across (large) organisations that enable local data collection, regional data integration, and both national and regional data use.

Co-creation

In co-creation, efforts are being made to engage populations facing marginalised conditions in the development of health data policies. Fostering social license varies across the four OECD countries, reflecting their public health priorities. Federated systems like **Australia** and **Canada** emphasise regional collaboration, with initiatives focused on Indigenous data sovereignty, culturally tailored interventions, and community-based partnerships to improve co-creation. In contrast, **New Zealand** and the **United Kingdom** lead with centralised strategies, embedding accessibility standards into national health programs. Across all countries, a shared priority is to strengthen trust through transparent policies, inclusive community engagement, and culturally sensitive approaches in the digitalisation of health systems. Based on the analysis, leading practices would include:

Assign accountability for the co-creation of health data policies to foster social license for engaging populations.

Invest in information-sharing campaigns to establish common understanding of data collection and use for public health purposes to minimise perceived risks vs. actual risks.

1 Advancing the Digitalisation of Public Health

1. The COVID-19 pandemic highlighted the critical need for robust health systems and accelerated the adoption of innovative healthcare delivery models, particularly those leveraging digital technologies and advanced analytics. To protect populations and contain the transmission of the virus, countries rapidly adapted their health systems, prioritising preventive measures and leveraging technology-driven data sharing. These adaptations enhanced surveillance and immunisation systems, enabling real-time tracking, monitoring, and coordination of health data to inform targeted and effective policies. The pandemic also underscored the importance of investing in health information systems and adapting health data governance to ensure timely, accurate, and high-quality data for informed public health decision-making.

2. In 2016, long before the pandemic, the OECD adopted a Health Data Governance Recommendation as a response to a growing need for international standards to harmonise policies to health data governance (see Annex B). The Recommendation provides a roadmap toward more consistent and coherent approaches to health data governance to support the development of a modern health information system that meets the needs of the digital age (de Bienassis et al., 2022^[2]). It calls on governments to:

- Implement national health data governance frameworks and it sets out 12 principles to follow when doing so;
- Support the enhancement of the capacity of the public health sector to process personal health data for public health purposes – including data availability, quality, accessibility and privacy;
- Set out clear guidelines on review and approval procedures for personal health data use, including transparency on the processing of health-related data; and
- Engage with relevant experts and organisations to develop mechanisms that enable the efficient exchange and interoperability of health data.

3. Despite the heightened focus on digitalising public health systems for immunisation and surveillance during the pandemic, public health has not been considered at the forefront of broader digitalisation efforts (see Box 1). To increase resilience against future public health emergencies, countries need to strengthen their public health systems by devising overarching strategies that support the standardised use of health data and digital technologies in public health practices to enhance individual and population health outcomes through systems-level interventions.

Box 1. The definition of digital public health used in this report

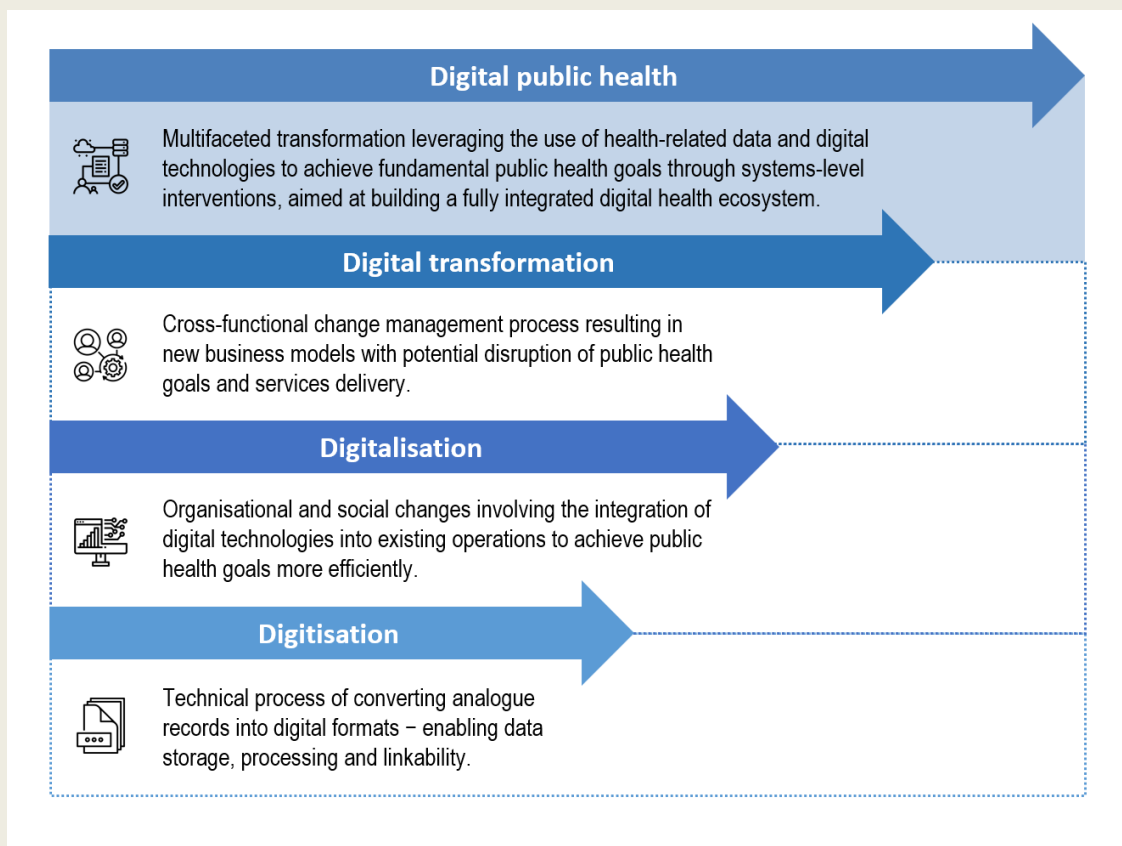
COVID-19 sparked a sharp interest in creating enabling policy environments for adopting digital technologies to achieve public health outcomes, especially in disease prevention and health surveillance, thus coining the term “digital public health (DPH)”. In 2017, the digital-first public strategy from Public Health England popularised this concept by recognising the potential of digital health technologies to improve health outcomes by adapting existing public health practice (Public Health England, 2017^[3]). With the outbreak of the pandemic, the large-scale use of digital health technologies rapidly gained popularity for data analytics and dashboards for real-time disease surveillance, evidence-based health information dissemination through social media and geo-spatial/Bluetooth-based apps for contact tracking and exposure to COVID-19 (Iyamu et al., 2024^[4]).

Digitisation involves the initial process of converting analogue information into digital formats to enable data storage, processing and linkability across databases (Verhoef et al., 2021^[5]). Conceptualising public health in relation to digitalisation considers digital technologies as an available set of *tools* integrated into existing operations to achieve public health goals more efficiently (Odone et al., 2019^[6]). However, perceiving digital technologies solely through their technical supportive role can potentially result in fragmented and siloed public health systems, with limited interoperability across health information systems. Conversely, envisioning digital public health as a *result* of digital transformation can transcend interoperability challenges, but poses threats in pursuing fundamental public health goals (Iyamu et al., 2021^[7]). In this view, health equity could be hindered since accessibility to healthcare is structured based on individuals’ socio-economic and health background, potentially worsening health inequities and deepening the ‘digital health paradox’ (van Kessel et al., 2022^[8]).

While digital technologies are now routinely used in individual and population health management, the understanding of the intersection between digital health and public health is elusive, without any clear and commonly agreed definition. Building on the WHO definition, the OECD characterises digital health as the “field of knowledge and practice associated with the development and use of health data and digital technologies to improve health. [This includes leveraging data] analytics for **health system improvement, public health preparedness**, or research and innovation” (OECD, 2023^[9]). This definition outlines the fundamental role that health data and technologies play in pursuing health goals by transforming healthcare delivery models through the effective and secure use of data for individual and population health management, consistent with an integrated digital health ecosystem. This definition applies equally in the use of digital tools and health data for individuals, communities, or the population – such as in the case of public health.

On a global level, there is no single widely accepted definition of digital public health – other than the implicit meaning that it involves the integration of digital technologies in delivering public health services. For the purposes of this report, digital public health is considered as a complementary, practice-based field aimed at achieving fundamental public health goals through the establishment of new healthcare delivery models based on interoperable, secure, and reliable health data to ensure quality, accessibility, efficiency, and equity of healthcare. While the mission and aim of public health remain unaltered, its practice is complemented by the standardised use of health data and digital technologies to improve individual and population health outcomes through efficient, effective and people-centred systems-level interventions (Iyamu et al., 2024^[4]). Throughout this report, digital public health will be used interchangeably with digitalisation of public health whenever it is not clear whether sources are referring to DPH or digitalisation of public health (see Figure 1).

Figure 1. The broader digital public health (DPH) ecosystem



Note:

1. The increasing lengths of the arrows indicate increasing complexity related to the integration and use of health-related data and digital health technologies into existing public health practice.

2. For more information regarding digital transformations in a broader context, please refer to *Going Digital: Shaping Policies, Improving Lives* (OECD, 2019^[10]).

Source: Adapted from (Iyamu et al., 2021^[7])

Objectives of this paper

4. As countries are *recovering* from the COVID-era by re-evaluating their health data foundation and policy environments (OECD, 2023^[11]), integrated surveillance and immunisation systems have proven to be a test bed for effective and timely public health decision-making. This paper will identify common barriers and highlight leading practices across Australia, Canada, New Zealand, and the United Kingdom to assess their capacity at modernising their health data infrastructure through the integration of data-driven technologies. This will be discussed across four key policy areas:

- **Governance and people capacity building:** considering the governance structure of health systems (centralised, decentralised), identify effective and forward-oriented health data governance frameworks and organisational models to address future public health needs (including stewardship and custodianship); highlight co-engagement and inclusive governance with embedded engagement process with sub-government entities to facilitate health data sharing for public health and other secondary purposes; establishing incentives and programs to sustain

and upskill the workforce (including healthcare providers, community health workers and backend data professionals) to meet evolving health system demands;

- **Technology:** assess how the development, procurement and maintenance of software solutions are organised, considering the digital health readiness of existing technical infrastructure and scalability of solutions at national and regional levels; examine how standards are adopted and updated to address the evolving needs in digital health security and privacy; examine the implementation of open-by-design solutions, ensuring transparency and consistency in data-sharing and storage guidelines; explore how parallel technical infrastructures are merged to align with immunisation and public health reporting needs.
- **Health data architecture:** assess how the data life cycle for immunisation and integrated respiratory illness surveillance is organised, considering existing technical infrastructure of (centralised, decentralised) health systems; evaluate which health-related data sharing and storage processes are effective across government levels, with adherence to semantic and operational standards at national and regional levels; analyse the inclusion of granular data (e.g., demographics, clinical, laboratory) and its availability, accessibility and timeliness for stakeholders, particularly for secondary data usage.
- **Co-creation:** evaluate the strategies put in place to ensure accessibility of data for public health surveillance and information systems to actively integrate marginalised communities; assess how digital technologies are being leveraged in terms of digital literacy, fostering a trust-oriented culture and promoting transparency in the use of health data; examine how are health-related data (including demographics) being captured to address the evolving needs of populations, with an emphasis to strengthen social license, as well as commitments and actions towards enhancing Indigenous health data sovereignty and ownership.

5. This paper will explore the topics outlined based on interviews conducted between June and September 2024 with key national administrators and stakeholders of public health system in the four OECD countries, complemented by extensive desk research to close potential regulatory and technical gaps. This method supplements the OECD publication on countries' resilience against future health emergencies, focusing on the adaptability and performance of integrated health systems to monitor immunisation and integrated respiratory diseases' surveillance.

6. The aim of the interviews is to outline key policy and infrastructure upgrades to foster shared learnings in the long-term modernisation of digital public health systems. The interviews will also discuss barriers and case-studies of success stories in modernising existing surveillance structures. Thirty-eight experts across the four surveyed countries participated in the report (see Annex A). The interviews are complemented by an extensive literature review to enhance the comprehensiveness of the insights gathered – including resources that have been shared by the interviewed countries.

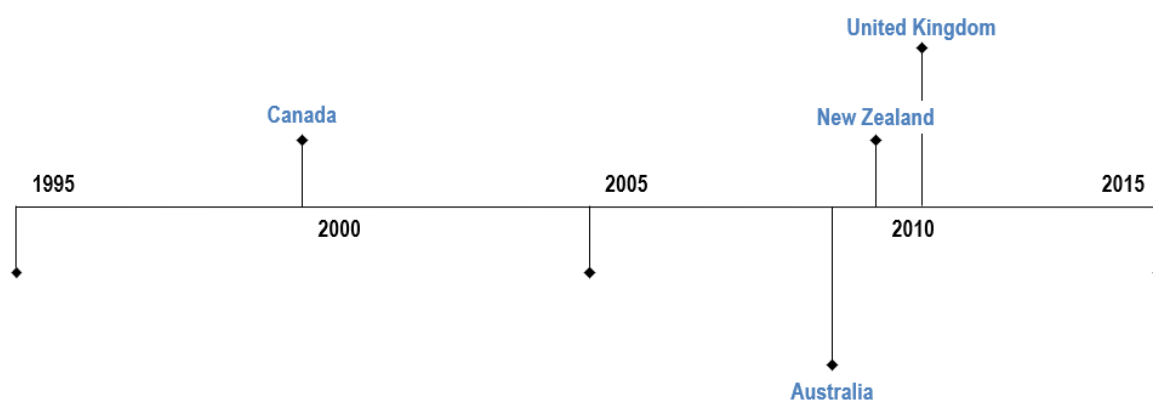
7. The objective of the paper is to provide an analysis of the ongoing digitalisation of public health systems with a focus on immunisation reporting and integrated respiratory illness surveillance. By analysing implemented strategies, this report will offer policy makers and governments practical recommendations to advance long-term, sustainable, and improved health outcomes. The outcomes of this paper will serve as a platform for sharing insights on these two specific use cases, with findings scalable to other areas of digital public health and applicable beyond national contexts, to strengthen the resilience and performance of integrated digital health ecosystem. In addition, the report will also consider the risks and lessons learnt from digitalisation thus far, providing guidance to optimise future digitalisation public health goals, reduce duplicated efforts, and strengthen sustainability in view of evolving public health needs.

2 Background of the Digitalisation of Public Health

Evolution of digitalisation of public health systems

8. In the early 2000s, countries had different levels of digital and health data capability, resulting in wide disparities in eHealth policies and strategies. A substantial increase in policy adoption occurred after 2005, coinciding with the World Health Assembly resolution on eHealth (World Health Assembly, 2005^[11]). According to the 2015 World Health Organization global survey on eHealth, 58% of responding countries reported having an eHealth strategy in place, and 66% of these adopted a health information system (HIS) strategy or policy (WHO, 2016^[12]). However, 53% of countries reported no legislation allowing access to electronic health records (EHRs), and only 13% of countries had a national policy or strategy regulating the use of big data in the health sector (WHO, 2016^[13]).

Figure 2. Timeline of eHealth policies or strategies adoption, 1995-2015



Source: (WHO, 2016^[12])

9. In the early 2000s, **Canada** established Canada Health Infoway, an independent, not-for-profit organisation, to coordinate the development of the country's digital health infrastructure in collaboration with provinces and territories. The initial focus was on building six foundational components of an EHR system: client and provider demographics, diagnostic imaging, profiles of dispensed drugs, laboratory test results, clinical reports, and immunisations (Canada Health Infoway, 2024^[14]). While some of these elements have been developed, Canada still does not have a fully integrated EHR system in place. This strategy prioritised the primary use of health data for acute care, which is still contributing to the fragmentation of the country's health data infrastructure. This issue is further compounded by the lack of

an integrated approach to support secondary data use and interoperability across the healthcare system, as well as inconsistent data governance across provinces and territories (Alberta Virtual Care, 2024^[15]).

10. In the 2008 National E-Health Strategy, **Australia** laid the foundation for the digitalisation of its e-health capabilities through four main pillars: the implementation of a national 'health information highway' to enable health data access and sharing across healthcare facilities; targeted investment in high priority IT infrastructure to deliver tangible benefits to the public and healthcare providers; the promotion of digital technology adoption; and the establishment of an e-health governance framework to ensure effective coordination across the federated infrastructure (Deloitte, 2008^[16]). Beyond improvements in interoperability and enhanced public health reporting through digitalised health records, the fragmented nature of Australian's healthcare system continues to hamper a unified adoption of e-health technologies across states and territories. In addition, the strategy left unresolved challenges in leveraging health data for secondary purposes such as for research, policy developments and broader public health initiatives.

11. To achieve its eHealth Vision, **New Zealand** adopted a five-year plan in 2010, laying the foundation for an integrated healthcare model. This whole-of-sector strategy aimed to enhance the accessibility, transmission, and quality of health information to drive greater adoption of health IT solutions across healthcare facilities. A central element of the plan was the shared care model, which integrated a multidisciplinary approach to ensure care continuity by integrating personal health records and fostering a patient-centred approach. The strategy prioritised the standardisation of data formats and terminologies to facilitate interoperability across diverse health information systems, alongside the establishment of robust health information exchanges to enable real-time data sharing. Strengthening governance models was also a core objective, aimed at streamlining coordination across stakeholders at various levels, improving accountability, and fostering collaboration within New Zealand's decentralised health system (National Health IT Board, 2010^[17]). While the plan effectively addressed primary data use for care delivery, it faced challenges in leveraging data for secondary purposes, due to persistent interoperability issues.

12. In 2012, the **United Kingdom** introduced a 10-year plan focused on enhancing access to health information across the NHS. The strategy focused on building a robust digital infrastructure by improving data sharing, integration, and data governance. It emphasised empowering both patients and healthcare professionals through the adoption of digital health tools, such as EHRs, and fostering a cultural shift toward innovation and digital adoption. A key priority was enhancing workforce digital literacy, equipping healthcare professionals with the necessary skills to leverage new technologies effectively (Naeman and Hale, 2012^[18]). Despite its ambitions, the strategy faced challenges stemming from the high decentralisation of the UK's health system, leading to data inconsistencies and limited scalability of digital solutions across all NHS entities. In addition, the strategy placed limited emphasis on integrating public health data systems, leaving gaps in aligning broader public health efforts with the evolving digital infrastructure.

COVID-19 caused shifts in the digital public health landscape

13. The 2023 OECD publication, *Ready for the Next Crisis? Investing in Health System Resilience* comprehensively discussed the regulatory, legislative, operational, financial, and technical changes that many OECD countries underwent during and after the pandemic to leverage the value of digitalised health information and surveillance systems. This rapid adaptation enabled countries to *absorb* the direct and indirect consequences of the pandemic, avoiding permanent disruptions to core healthcare services. Consequently, they *adapted* their responses and enhanced their capacity to *absorb* and *recover* from the multi-layered shocks, thus enhancing their capacity to *prepare* critical functions of their health systems to mitigate future health threats (OECD, 2023^[1]).

14. The pandemic shifted countries' motivation and capacity to develop and invest in integrated health information and surveillance systems for public health purposes, significantly enhancing their disease prevention and immunisation capabilities. As such, digital health became an "immediate necessity, rather than a potential opportunity" (Fahy et al., 2021^[19]). All countries responding to the OECD Health Data and Governance Changes during the COVID-19 Pandemic Questionnaire 2021 reported improved data reporting and almost all (over 90%) enhanced the timeliness of data. Real-time data was critical to match the needs on the ground with available resources to allocate them efficiently. For example, the **Australian** Government established the Hospital Capacity and Activity Data Sharing System (Cap & Act) which ensured availability of real-time patient flow data to monitor public hospital capacity and activity across state borders, collating daily data from every Australian public hospital. **Canada** also developed a Health System Capacity Planning Tool to support decision makers in understanding the expected health resource demands and supply shortfalls related to the pandemic (de Bienassis et al., 2022^[2]).

15. Improvements in developing near real-time data-sharing positively impacted the linkability of various datasets, including administrative, socio-economic and geolocation data, without compromising the privacy of the collected information. Countries recognised the benefits of linking and sharing data across public agencies to improve the effectiveness of their COVID-19 response efforts. **Australia**, for example, developed individual data inventories for different agencies, with common standards, which could be aggregated into a central Data Catalogue to support transparency and quick response. Complementing other testing programmes, the Environmental Monitoring for Health Protection (EMHP) wastewater programme in the **United Kingdom** cross-linked geo-localisation and wastewater data to detect the prevalence of COVID-19 in geographical sampling areas and inform localised policy responses to curb the transmission of the virus.

16. Alongside timeliness, countries actively invested in data quality, coverage and completeness through the establishment of standardised guidelines and principles to ensure that decision-making was informed by accurate and granular data (de Bienassis et al., 2022^[2]). In **Canada**, the Public Health Agency of Canada (PHAC), in consultation with the provinces and territories, developed a set of data sharing principles to guide the collection, reporting and use of COVID-19 data. To complement this, a COVID-19 case data completeness reporting dashboard was created for monitoring and ensuring high quality and accurate data on a monthly basis. As part of its plan to establish a reliable data foundation in the health sector, the **New Zealand** Ministry of Health developed a strategy focused on creating standardised protocols for data collection across all health and disability services to ensure smooth data-sharing processes. In addition, a specialised team was set up to create a centralised data catalogue, providing a comprehensive inventory of available health data at both national and local levels to facilitate the location and accessibility of relevant health information.

17. Beyond the necessity of providing timely, quality, and interoperable health data, countries recognised the importance of having an enabling regulatory framework to guarantee standardised access to large sets of health data, while ensuring privacy and security safeguards. Accordingly, a series of overarching initiatives have been launched at the national level to improve health data availability, accessibility, sharing, privacy and security to enhance the performance and resilience of health systems (see Figure 3) (OECD, 2024^[20]).

Figure 3. Introduction of changes to health data governance models in response to COVID-19

Australia	Australia	Australia	
Canada	Canada	Canada	Canada
United Kingdom	United Kingdom	United Kingdom	United Kingdom
New Zealand	New Zealand	New Zealand	New Zealand
New technologies to improve health data availability, accessibility, sharing or data privacy and security protections	Legal, regulatory, or policy reforms to improve health data availability, accessibility, or sharing	Legal, regulatory or policy reforms to improve health data privacy or security protections	Financial incentives to improve health data availability, accessibility, sharing or data privacy and security protection

Source: (de Bienassis et al., 2022^[2])

18. For many countries, this transition required comprehensive legislative adaptation to share and use health data across different levels of government agencies to ensure a coordinated and timely policy response – thus recognising data as a national asset for crisis responses. In federated countries such as **Australia**, **Canada**, and the **United Kingdom**, where public health responsibilities are shared between federal and subnational governments, these legislative changes required additional efforts to ensure coordinated responses to enable timely and protected sharing of health data across territorial jurisdictions.

- In **Australia**, the responsibility for managing national health datasets is distributed across federal and state/territorial jurisdictions, with various agencies at each level overseeing specific datasets. While the National Minimum Data Sets (NMDS) define a core set of data elements mandated for collection and reporting at the national level, these standards do not cover all public health data sources. However, all jurisdictions signed the 2020-25 National Health Reform Agreement which includes an action to scale up a national approach to data governance arrangements, structures, and processes, to facilitate clear and efficient mechanisms for sharing and developing data in a sustainable, purpose-based, and safe way. Building on these efforts, the Australian Government has committed to develop a whole-of-government Data Governance Framework to provide common rules and accountability measures across the public sector. As an example, the Department of Health and Aged Care published its own Data Governance Framework in 2024 to ensure secure, ethical and transparent management of health data to enhance system resilience and performance.
- The Government of **Canada** relied on comprehensive pan-Canadian COVID-19 case data to support evidence-informed decision-making and provide timely, accurate information to Canadians. Although reporting to the federal government is voluntary and lacks legislative authority during emergencies, the PHAC developed data-sharing principles to facilitate the collection, reporting, and use of COVID-19 data across federal, provincial, and territorial levels. In 2020, the Pan-Canadian Health Data Strategy Expert Advisory Group (PCHDS EAG) proposed high-level commitments for jurisdictions to follow to make improvements to their health systems in four key areas: public trust and data literacy, data policies, data interoperability and health data governance. These efforts built upon previous provincial-level adaptations aimed at modernising the sharing and protection of health data. In 2023, a Pan-Canadian Health Data Charter was adopted to guide collaborative efforts to modernise and improving how health information is collected, shared, used, and reported to Canadians to promote greater transparency on results and inform decisions (Government of Canada, 2023^[21]).

- In the **United Kingdom**, each national government, comprising the territories of England, Scotland, Wales, and Northern Ireland, is responsible for running its own NHS. Consequently, each national government managed its own immunisation information systems during the pandemic, with limited possibilities to link nationwide datasets prior to the pandemic. In 2020, three government agencies developed the NHS COVID-19 Data Store which functioned as a single repository of datasets to inform effective response, while adhering to strict de-identification process to ensure data anonymisation. Recognising the burden occurring in the data collection stage especially during a crisis, the Data Saves Lives strategy introduced the FAIR principles – findability, accessibility, interoperability, and reusability – aimed at streamlining data management and enhancing the usability and integration of health data across the UK.
19. Unlike federated countries, New Zealand’s centralised approach to public health responsibilities enabled a more unified response to health data governance challenges during the pandemic:
- The **New Zealand** Ministry of Health launched a comprehensive strategy in 2021 to establish a cohesive approach to health data governance across national and local health authorities. This strategy laid the foundation for the development of the National Data Platform (NDP), designed to promote efficient, effective, and consistent data sharing across the health system. This platform is aimed at supporting Te Whatu Ora (Health New Zealand) – the agency responsible for managing health services, in collaboration with the Public Health Agency – which oversees public health directions and policy oversight. Besides these improvements, the Health Information Privacy Code 2020 introduced specific amendments to facilitate data sharing, including provisions for contact tracing while maintaining high privacy safeguards.

Mitigating risks in the digitalisation of public health

20. While the digitalisation of public health holds significant potential, it also presents risks that should be pro-actively mitigated to ensure sustainable and equitable outcomes. Key challenges include vulnerabilities to cyberattacks that compromise health data security and disrupt healthcare service delivery, privacy and governance concerns arising from data-driven technologies, and the potential for exacerbating health inequities due to digital divides. In addition, failing to reconfigure existing processes to leverage the full potential of digital tools risks limiting the multi-layered impact of digitalisation.

21. While the pandemic brought rapid advancements in countries’ digital health landscape with significant benefits to individuals, communities, and the public health sector, it also increased risks from malicious activities. The growing reliance on health data for the provision of care and the use of technologies to manage health data architecture highlight technical vulnerabilities, thus exposing digitalised health systems to a higher risk of cyberattacks (Sutherland et al., 2023^[22]). Such disruptions can adversely affect health outcomes as health services that rely on digital tools become unavailable, potentially leading to a lasting decline in public trust in data-driven health services (World Economic Forum, 2022^[23]). Given the increasing vulnerability to cyber threats, the OECD has distilled lessons and made recommendations to strengthen digital security, aligning with the OECD Recommendation on Health Data Governance (2016) (OECD, 2022^[24]), (OECD, 2020^[25]).

22. Another risk is that the digital responses to the pandemic have precipitated novel data governance and privacy challenges. With unprecedented measures to track and contain COVID-19, countries harnessed the power of data to drive digital solutions such as contact-tracing technologies. When lacking transparency and public consultation, such data-driven solutions can also be used for extensive collection and sharing of personal data, mass surveillance, limiting individual freedoms and challenging democratic governance (de Bienassis et al., 2022^[2]). Recent research suggests that even with data anonymisation, a residual probability of re-identifying individuals using a limited set of data points remains (Ratra, Gulia and Gill, 2022^[26]). As a response, countries such as New Zealand and the United Kingdom have endorsed

principles for data controllers and processors about the application of privacy and security data protection laws, balanced with public health needs.

23. In addition, scaling data-driven technologies without consideration for fair availability may result in unintended consequences on underserved or hard-to-reach populations, worsening health outcomes. The pandemic underlined existing digital divides across countries with significant disparities in digital literacy and access to digital infrastructure. With the potential that socio-economic and geographical characteristics can exacerbate the ‘digital health paradox’, countries are investing in digital public health strategies to ensure inclusive health services delivery in both crisis and non-crisis contexts (OECD, 2019^[27]).

24. Another risk to be mitigated is to recognise that the full benefits of an integrated health ecosystem will only occur by creating an enabling policy environment supported by a broad consensus among all involved stakeholders. A key part of this evolutive process is recognising the importance of how attitudes and behaviours of end-users are adapting to the integration of digital technologies. In addition, failing to reconfigure underlying processes to fully leverage digitalisation poses a significant risk. For example, using digitalised health records without making them searchable or usable for secondary purposes, risks undermining the transformative potential of these solutions, maintaining a ‘check-the-box’ mentality to digital objectives. Considering digital solutions solely through their technical supportive role, without acknowledging their potential disruptive nature on current public health practice, can potentially hinder sustainable long-term benefits. It is important to establish an inclusive, nationally consented digital strategy to ensure that ‘no one is left behind’ and to invest in trust-building policies to fully harness the ‘low hanging fruit of digitalisation’.

25. Given these existing risks, countries are actively working to adapt their public health systems by harnessing data and emerging data-driven technologies in a way that ensures sustainability, fairness, resilience, and efficiency. While public health sectors differ in their levels of digital maturity, the following sections will showcase leading practices in governance, human capacity building, health data architecture, technology, and co-creation across the four OECD member countries. These examples highlight how tailored national strategies are driving the digitalisation of public health systems, with a particular focus on advancing immunisation programs and enhancing respiratory disease surveillance, ultimately demonstrating the potential for innovative solutions to address public health challenges.

3 Policy Considerations and Leading Practices

26. This report examines considerations and leading practices for digitalisation of public health in the four key areas. This chapter provides the summary findings from the analysis. Detailed findings are in the respective annexes.

- Governance and People capacity (Annex C)
- Data and data flows (Annex D)
- Technology (Annex E)
- Co-creation (Annex F)

Governance and people capacity

27. Governance for public health services delivery involves complex layers of administration, policymaking, and stakeholder engagement. In federalist systems, these complexities are further compounded by the need to coordinate and align efforts between national and subnational governments. This section examines the critical components of digitalising immunisation and surveillance governance across the four OECD member countries, including organisational structures, health data governance, policy frameworks, and the engagement of stakeholders across multiple government levels, considering the unique context of each health system.

28. The governance of immunisation and surveillance systems requires robust organisational structures with established, clear accountabilities at all government levels for ensuring seamless data monitoring and sharing, especially in federalist systems. Health data governance is particularly crucial, as it encompasses the policies and practices necessary to manage and use health data while safeguarding data privacy and security (OECD, 2016^[28]).

29. One key aspect is the organisational structure with shared responsibilities and accountabilities across different government levels. This includes the degree of co-operation and harmonisation, ensuring fit-for-purpose data sharing processes that are timely, accurate and secure, and responsive to public health needs. It also requires interoperable datasets for validating and linking data safely for effective reporting, developing, and updating standards for safe storage. While the degree of governance harmonisation varies widely across the four surveyed countries, key common elements ensure effective, timely and secure processing of health data, which are essential for public health.

30. Governance of immunisation and surveillance systems should also be inclusive and prioritise transparency, especially concerning key stakeholders, such as the public and vulnerable communities, given their related rights on data processing for public health purposes. Pro-active and inclusive engagement with these communities is essential for designing policies and services that are aligned, effective and harmonised with their evolving needs in the digital space. This approach can result in higher

immunisation coverage and thus, better health outcomes at the individual and population level (Scobie et al., 2020^[29]).

31. In addition, to sustain the efforts related to digitalising public health systems, integrating, retaining, and upskilling the workforce is a key enabler. Despite a growing health and social care workforce, concerns persist regarding professionals' shortages, further exacerbated by digital divides and insufficient training in data-driven technologies needed to optimise workflows (Socha-Dietrich, 2021^[30]). Establishing comprehensive programmes to retain and upskill health providers, IT professionals, epidemiologists and data scientists devoted to digitalising public health systems will facilitate a smooth generational transition to deliver the promised potential of digitalised public health services, while meeting evolving market demands and ensuring workforce retention in the public health sector.

Table 1. Governance practices for digitalising public health systems

Country	Jurisdictions and data liability are established across governments agencies for data lifecycle management	Legal and operational standards facilitate data collection, integration and reporting	A standardised minimum dataset is implemented nationally, facilitating interoperable sharing of health-related data	Information about primary and secondary data processing is publicly available	Guidelines on data safety and privacy are publicly available	Financing for digital public health is sufficiently available at national and sub-national levels
Australia	No	Yes	Yes	Yes	Yes	No
Canada	No	Yes	No	Yes	Yes	No
New Zealand	Yes	Yes	Yes	Yes	Yes	No
United Kingdom	Yes	Yes	No	Yes	Yes	Yes

Source: Authors

Policy considerations

32. Across all interviews, it was consistently observed that countries are actively adapting their health data governance frameworks to align with evolving public health needs. While these efforts are shaped by each country's governance context and health system infrastructure, a common trend is the shift towards a stewardship model. This approach establishes clear accountabilities and assigns specific roles to various levels of government to streamline health data sharing and utilisation, enhancing public health preparedness and response. Most countries are gravitating toward a federated data model, which balances centralised coordination with local autonomy to address region-specific public health priorities. Notably, **New Zealand** stands out with a more centralised governance structure through Te Whatu Ora and the Ministry of Health, while other countries maintain a mixed model that delegates certain responsibilities to local entities while ensuring national-level oversight.

33. While workforce development remains an underdeveloped area in health data governance, some progress has been made. Targeted programs to upskill the public health workforce are limited to **Australia**, where initiatives have begun to address critical gaps in data literacy and digital health capabilities. Other countries are gradually introducing data-driven programs to enhance workforce competencies, but these efforts are not yet sufficient to attract, retain, or sustain a skilled public health workforce capable of meeting the demands of increasingly digitalised health systems. Furthermore, no country has yet devised targeted funding mechanisms specifically dedicated to workforce planning and development, leaving a critical gap in the long-term sustainability of digital public health transformation.

Leading practices

34. While governance structures for public health systems vary across countries, there are two pillars that are essential for advancing the digitalisation efforts in immunisation and respiratory disease surveillance: (1) **clear accountability of a national stewardship authority**, particularly in light of coordination of health data infrastructure and strategic guidance on unified data-sharing standards and (2) **comprehensive people-capacity building programme in the public health sector**, through a national strategy to drive holistic cultural change across the public, and dedicated financing schemes.

Table 2. Summary of governance practices across four OECD member countries

Country	Establishment of a national model for health data stewardship	Comprehensive people-capacity building program in the public health sector
Australia	In development	Yes
Canada	Yes	No
New Zealand	Yes	No
United Kingdom	Yes	No

Source: Authors

Data and data flows

35. Building on robust health data governance, data architecture serves as the backbone of an integrated health system, enabling the standardised, secure, and interoperable management of health data across multiple systems. It involves the design, organisation, and processes necessary to collect, store, integrate, and share data efficiently. A reliable data architecture is critical to ensuring seamless health data flows, which promote consistency, accessibility, and utility for public health applications such as immunisation tracking and respiratory disease surveillance. Achieving this requires collaboration across various government entities to align processes, streamline data management, and foster interoperability within and across systems (OECD, 2023^[1]).

36. This section examines the critical components of developing a robust health data infrastructure, including standardised data collection methods, shared semantic and operational standards, and comprehensive security and privacy protocols. The OECD's 2022 review of the Health Data Governance Recommendation OECD revealed that many member countries continue to face significant challenges in establishing these foundational elements, particularly regarding data privacy protections, legal barriers to data linkage and sharing among public authorities, and difficulties implementing standards for clinical terminology and interoperability (OECD, 2022^[56]). Addressing these implementation gaps through robust foundational infrastructure enables countries to ensure data integrity throughout its lifecycle while achieving timely and efficient reporting for the likes of immunisation and respiratory disease surveillance. Such an infrastructure not only enhances responsiveness to public health demands but also strengthens overall health system resilience.

37. Data collection is the initial pillar to ensure a strong data architecture. Public health data comes from diverse sources, including demographic records, EHRs, laboratory results, and disease registries. However, the granularity and scope of collected data often vary between jurisdictions, creating challenges for uniform reporting and analysis. To address this, immunisation registries have been established in many countries to centralise and standardise data collection to help monitor vaccination coverage, identify gaps, and track disease trends. Despite these efforts, data collection processes remain fragmented in many countries, hindering timely and efficient reporting mechanisms.

38. To support reliable data flows, countries must adopt semantic and operational standards, which are integral to ensuring the consistency and usability of health data. Semantic standards define the content and structure of data, ensuring consistent labelling, classification, and interpretation across health information systems. Operational standards, on the other hand, address the processes, protocols, and technical requirements for data collection, storage, and sharing. Together, these standards create the foundation for interoperability, allowing health data to flow seamlessly and reliably across systems for public health use.

39. With standardised data and processes in place, achieving interoperability ensures that health information systems – ranging from local healthcare facilities to national public health platforms – can communicate and exchange data effectively. From an international perspective, establishing trusted health data networks creates simplified collaboration pathways by providing clear points of contact with transparent standards and controls. These networks offer particular advantages through reduced bilateral agreements, consistent privacy safeguards, and pooled resources that eliminate duplicate data assets. From an international perspective, such networks could even connect at a global level, with national networks linking together through standardised approaches, an approach consistent with the EHDS framework (OECD, 2025^[31]). This reduces fragmentation and supports cohesive data management across facilities, organisations, and jurisdictions. Interoperability also enables real-time access to health data, enhancing decision-making and enabling a prompter response to public health challenges, such as outbreaks or vaccination coverage gaps (OECD, 2022^[56]).

40. Another key component is the implementation and regular updating of privacy and security protocols to protect sensitive health information. These protocols are designed to ensure the responsible handling of data throughout its lifecycle, from collection and storage to transmission and sharing, including cross-border exchanges. Measures such as encryption, multi-factor authentication, and audit trails safeguard data against unauthorised access and maintain its integrity. However, significant challenges remain, including balancing privacy with usability, harmonising standards across jurisdictions, and addressing cybersecurity threats (Sutherland et al., 2023^[22]). Addressing these challenges is essential to building trust in health data systems while enabling their effective use for public health purposes.

Table 3. Health data architecture across four OECD member countries

Country	National and subnational availability of health and health-related datasets (e.g., demographics, immunisations, surveillance etc.)	National and subnational linkability of health-related datasets (through unique identifiers)	State-level immunisation and surveillance health registries	National immunisation and surveillance health registries	Developing public application programming interfaces (APIs) for data access and innovation	Adopting HL7 Fast Health care Interoperability Resource (FHIR) standard for interoperability	Usage of SMART on FHIR standards for application integration
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Canada	Yes	In development	No	No	Yes	Yes	Yes
New Zealand	Yes	Yes	No	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	Yes	No	Yes	Yes	Yes

Source: Authors

Policy considerations

41. Across all interviews, it was consistently observed that countries are actively advancing their health data architectures to enhance national and subnational data sharing, interoperability, and

scalability. While these efforts are shaped by each country's governance context and technical infrastructure, a common trend is the adoption of open data-sharing principles underpinned by international standards such as HL7 FHIR, SNOMED CT, and ICD-10. These shared frameworks provide consistency and efficiency, though the maturity of implementation varies significantly across countries due to factors such as regional autonomy and the absence of unified national frameworks.

42. Federated nations such as **Canada** and **Australia** are working to align diverse regional systems with national frameworks to address fragmentation. Canada leverages initiatives like the Pan-Canadian Health Data Content Framework (PCHDCF) and its subset focused on bi-directional exchange the CACDI to standardise data elements and terminology. Similarly, Australia relies on systems such as the NNDSS and the Australian Immunisation Register (AIR) to promote interoperability, though cross-jurisdictional integration remains a challenge.

43. In contrast, the United Kingdom and New Zealand lead with more centralised approaches. New Zealand demonstrates best practices with its New Zealand Core Data for Interoperability (NZCDI), supported by integrated systems like the Aotearoa Immunisation Register (AIR) and EpiSurv, as well as the NHI, which enables seamless data integration and lifecycle management. The United Kingdom aligns its systems with global standards through initiatives like the NIMS, the Big Rocks Transformation Program, and the EDAP, providing a robust foundation for interoperability and scalability.

44. A shared priority across all countries is the development of transparent documentation for APIs, privacy and security protocols, and integration standards to support technical consistency. Countries like **New Zealand**, the **United Kingdom**, and **Canada** stand out for their comprehensive frameworks, which balance the need for integration with regional autonomy. These initiatives offer valuable lessons for federated nations like Australia where achieving seamless interoperability across diverse jurisdictions remains a more significant challenge.

Leading practices

45. During the interviews, there were two leading practices that were identified: (1) **establishing a common set of semantic health data standards** to enhance interoperability across health information systems and (2) **devise a comprehensive health data framework** with well-established data collection, integration, and security procedures, integrated in regional monitoring. The findings from the interviews, as aligned to leading practices are summarised below:

Table 4. Summary of data architecture practices across four OECD member countries

Country	Common set of integrated health data standards with incentives for public health use cases	Comprehensive health data framework for data collection, integration and security including regional monitoring
Australia	In development	In development
Canada	In development	In development
New Zealand	Yes	Yes
United Kingdom	Yes	In development

Source: Authors

Technology

46. Technology infrastructure is a key enabler to the effective use of health data to enable evidence-based decision making. Each of the four OECD countries, Australia, Canada, New Zealand, and the United Kingdom, saw their public health technology infrastructure accelerate with the needs of the COVID-19 pandemic, often done by jumping past regulatory hurdles to meet the needs of the countries. As countries settle into the post-pandemic environment, the technologies which were deployed during COVID-19 are being reviewed and understood for the best approach moving forward. This section will examine the technical foundation for national immunisation and surveillance programs, including immunisation registers, notifiable disease surveillance systems, cyber security, open by design systems, application programming interfaces to enable the interoperable exchange of data, cloud, enterprise data platforms and relevant privacy, security, and technical standards to be put in place.

47. In all four OECD countries, different layers of technology exist between the national and regional levels, especially in countries with a federated model, where the states, territories, and/or provinces maintain control over their data but share it nationally for analysis and public health management. Each region has their own health legislation and approach to providing health services to its citizens, often with different systems, implementation of the same technologies, standards, and individual data sharing agreements with the federal level. This fragmentation leads to an increasing need for semantic interoperability, with consistent standards and data exchanges. In countries with an amalgamated model, or in the process of moving to an amalgamated model, this work remains, along with updating or retiring existing systems to create enterprise-wide solutions.

48. Reaching semantic interoperability faces several barriers, such as vendors blocking data from the electronic medical records (EMRs), EHRs, and public health immunisation and surveillance systems being implemented at regional and state levels. In this, OECD countries are introducing new legislation to ensure that vendors comply to set specifications of data standards and data sharing to deploy their systems within the countries and/or states. Without these legislation or direction from the national level, states will continue implementing fragmented vendor systems and introducing additional technical tools and expertise to reach semantic interoperability.

49. Digital health tools have been in use for decades such as immunisation registries and disease surveillance systems dating back to the 1990's. Legacy systems add an additional layer to the complicated technical ecosystem in use today. When these systems were first implemented, the focus was often on collecting data at a site, regional or state level, and not focused on sharing the data to provide a comprehensive health record outside of the intended site. The legacy systems often host data on-premises rather than cloud based, and as a result pose higher risks to maintaining data security.

50. Countries are at different stages of retiring and/or updating legacy systems to the current standards to enable the centralising of primary use data into enterprise data and analytics platforms, which subsequently enable the secondary use of health data after de-anonymisation and de-identification into separate secure research environments. As some OECD, such as the **United Kingdom**, amalgamate their health service and technical infrastructures, legacy systems and the associated data are required to be transitioned to enable continuation of the records and reducing duplication of systems and data.

51. Another opportunity arising from this work is to understand the value proposition for future and ongoing investment in public digital health systems. With the COVID-19 pandemic, a huge influx of funding came to public health to provide timely tracking of diseases surveillance and immunisation tracking, but now countries are facing a challenge to demonstrate the long-term cost-benefits of maintaining such health information systems and introducing new technologies as technological innovations arise. For those countries needing to update their existing technical infrastructure, the value proposition needs to be made for the benefits of open-by design and scalable solutions which can easily integrate with the infrastructure and enable more timely and reliable sharing of public health data.

52. In public health surveillance and immunisation, the COVID-19 pandemic was an exceptional case which brought the focus of the whole world to vaccine rollouts, respiratory disease tracing, and hospital capacity, however the everyday business of public health focuses on the health of the population and preventive measures to prevent, detect, and respond to epidemic and pandemic level incidents. COVID-19 offered the opportunity for countries to reinforce the value of investment and maintenance of public health infrastructure, similarly to what the severe acute respiratory syndrome outbreak of 2003 offered to the **Canadian** public health system (Infection Prevention and Control Canada, 2024^[98]).

53. An essential piece of the public health technical infrastructure are frameworks and supportive measures to maintain the privacy and security of its data. Security measures are needed in the procurement, implementation, and maintenance of information technology system to ensure the data is secure. Key mitigation strategies, identified by **Australia's** Essential Eight principles for data security include the patching of applications and operating systems, multi-factor authentication, and limiting administrator privileges (Australian Signals Directorate, 2023^[99]). Responsibility for ensuring secure data also lies with the users of the data, so training on the safe handling and use of public health data is essential (UK Data Service, 2024^[43]). These principles have been brought into the procurement processes for new technologies in all the OECD countries, ensuring that privacy and security are built into any new solution.

54. To build towards a federated data architecture in public health and solutions which are scalable to the changing technology landscape in healthcare, open by design systems with cloud-based storage solutions and built in security and privacy frameworks are key. Countries are actively working to remove barriers, such as **Canada** who has been working on legislation to ensure vendors cannot block data from its clients, allowing public health systems to gain timely access to the data it needs to monitor, prevent, and report on public health crises (Government of Canada, 2024^[100]). These measures, along with transitioning from on-premises, local data storage to integrated data infrastructure with API are some examples of how countries can digitalise the technical infrastructure of their public health systems.

Table 5. Technology practices for digitalising public health system

Country	Use of cloud-based storage solutions for public health data infrastructure	Security and privacy standards for the transfer, access, and storage of public health data	Established procurement processes with privacy and security components	Scalability of public health solutions at a national/regional level	Use of open by design solutions with built-in interoperability, integration, and existing standards	Legislation to counteract vendor blocking which can limit the data sharing between systems
Australia	Yes	Yes	Yes	Yes	Yes	No
Canada	In development	Yes	Yes	In development	In development	No
New Zealand	Yes	Yes	Yes	Yes	Yes	No
United Kingdom	Yes	Yes	Yes	Yes	Yes	No

Source: Authors

Policy Considerations

55. The interviews with the four OECD countries demonstrate varied steps towards the adoption of a federated data architecture which is open by design, scalable, and supports privacy and security measures. These variations stem from the nature of each countries health systems, with differing levels of federal authority over the practices of their jurisdictions. Leading practices have emerged to reach a federated data architecture, including the use of cloud first and cloud smart policies, a focus on the scalability and compliance with privacy and safety during procurement, and an open infrastructure for application programming interfaces. Some countries, such as **Canada** and **Australia**, face challenges

with the regional data integration to a common national platform due to the structure of their respective health systems. The **United Kingdom** and **New Zealand** are leading the way with ongoing development of cloud based national data platforms and clear standards for integration with the national technical infrastructure. All countries demonstrate national procurement recommendations which encompass privacy and cyber security criteria, however in federated countries these practices are often left to the jurisdictions to action, and accountability is difficult to enforce.

56. Preparing transparent documentation on standards, privacy and security requirements, APIs and integration approaches set public health systems up the future integration into a federated data architecture. All of the four OECD countries have adopted some level of scalable and open by design practices, though at different states of maturity. **Canada** is leading the way in its recent efforts to legislate vendors to be compliant with standards with the recent legislation prohibiting vendor data blocking and also provides technical assistance for its jurisdiction when procuring new technology solutions. All countries have national practices to set transparent national data standards, though some are further along with establishing a unified framework for the country. The **United Kingdom** and **New Zealand** are leading the way with extensive national health information standards, application programming interfaces, and privacy and security.

Leading Practices

57. Throughout the interviews, two leading practices were identified to support the technical infrastructure requirements for the digitalisation of public health systems: (1) develop **cost-benefit analysis framework** of existing software solutions to ensure their adaptability and scalability to evolving public health needs (immunisations and surveillance) and (2) foster the adoption of **federated data architecture** across (large) organisations that enable local data collection, regional data integration, and both national and regional data use. The findings from the interviews, as aligned to leading practices are summarised below:

Table 6. Summary of technology practices across four OECD member countries

Country	Establishment of a national federated data architecture	Cost-benefit analysis framework and strategy for public health technical infrastructure
Australia	In development	In development
Canada	No	In development
New Zealand	In development	Yes
United Kingdom	Yes	Yes

Source: Authors

Co-creation

58. Co-creation with the public, jurisdictions, and stakeholders is an emerging trend in public health strategies, particularly in immunisation and respiratory disease surveillance. Diseases such as influenza, COVID-19, and respiratory syncytial virus (RSV) disproportionately impact communities facing marginalised conditions, highlighting the need to address these disparities to achieve universal healthcare goals. Co-creation of public health strategies understand stakeholders' perspectives on the use and protection of their health data to enable the collection, analysis, and reporting of sociodemographic and health-related data to identify gaps and inform targeted interventions. By implementing culturally sensitive measures and optimising data management processes, these efforts strive to ensure that 'no one is left behind'.

59. This section explores how digitalised health infrastructure supports co-creation of DPH by enhancing the entire data lifecycle. Digital communication channels play a critical role in fostering a shared understanding of how health data is used for public health purposes, while collaborative frameworks emphasise people-centered policies. In addition, initiatives aimed at co-creating health data policies, with a focus on data sovereignty, are helping to address the unique needs of specific national contexts.

60. Comprehensive data collection remains a fundamental enabler for developing health policies (Oderkirk, 2021^[145]). This is particularly important in settings where there is a deep-seated lack of trust in public institutions due to historical instances of systemic data misuse and exclusion. In many cases, these issues are legacies of colonialism that have disproportionality harmed Indigenous populations and other marginalised communities. Increasingly, countries are collecting data not only to better understand the health outcomes of marginalised and Indigenous populations but also to design policies that actively include them in national health programs. Incorporating variables such as Indigenous status, gender, and socioeconomic factors enriches the understanding of diverse healthcare needs. The pandemic underscored the effects of misinformation and mistrust, which often resulted in poorer health outcomes (OECD, 2024^[146]).

61. Building and maintaining public trust is critical when using health data for secondary purposes, such as research, policy development, and public health monitoring. Fostering public acceptance of these uses requires transparency, accountability, and active engagement (Muller et al., 2021^[147]). Clear, transparent, and active communication about data collection, storage, and use, combined with robust privacy and security safeguards, helps reassure the public. Involving local communities in decision-making processes ensures their voices, values and approaches shape data governance policies. In addition, demonstrating the tangible benefits of health data use, such as improved health outcomes, strengthens trust over time.

62. Effectively sharing health information with underserved communities is equally vital. Many groups facing marginalised conditions face barriers to understanding the importance of immunisation and disease tracking, often leading to worse health outcomes for those communities. To address this, countries are investing in culturally tailored information-sharing campaigns through both digital and traditional channels. Collaborating with local stakeholders further strengthens these efforts, as their established trust and relationships within communities by bridge gaps between local needs and national public health strategies.

63. Reliable connectivity to digital healthcare infrastructure facilitates the use of tools like EHRs systems, which are essential to integrated healthcare systems. Addressing regional disparities in digital infrastructure is crucial to ensuring that all communities benefit from advancements in health technology and are fully integrated into a unified, data-driven public health framework.

Table 7. Co-creation within national public health programs across four OECD members

Country	Strategies to address existing gaps in public health data collection and reporting	Strategies to increase health data literacy	Communication channels to promote and share common understanding of data use for public health purposes	Strategies to engage with hard-to-reach communities and actively include them into the co-creation of health data policies
Australia	In development	Yes	In development	Yes
Canada	In development	Yes	In development	In development
New Zealand	In development	Yes	In development	Yes
United Kingdom	In development	Yes	Yes	Yes

Source: Authors

Policy Considerations

64. The interviews with the four OECD countries reveal diverse approaches to engaging hard-to-reach populations and fostering social license for the equitable use of health data. Common practices include the co-creation of health data policies with marginalised communities, targeted information-sharing campaigns to improve trust and counter misinformation, and efforts to ensure data collection processes respect cultural norms and address inequities.

65. Countries like **Canada** and **Australia** face challenges due to the decentralised nature of their health systems, requiring regional engagement to ensure the inclusion of Indigenous peoples and communities facing marginalised conditions. However, this approach also yields positive outcomes, as the collection of data requires localised efforts to address specific needs and build trust within communities. Canada, for instance, emphasises Indigenous data sovereignty through national standards for race-based and Indigenous data collection, complemented by initiatives like the Immunisation Partnership Fund to address vaccine disparities. Similarly, Australia supports its Aboriginal and Torres Strait Islander communities through partnerships that embed Indigenous values into data governance and tools like the First Nations Disease Dashboard to track disparities.

66. In contrast, **New Zealand** and the **United Kingdom** are leading efforts to integrate marginalised communities through national frameworks. New Zealand's Te Mana Raraunga and Iwi-Māori Partnership Boards ensure Māori self-determination in data governance, while the Whakamaua Māori Health Action Plan embeds equity in health policies. The United Kingdom combines statutory guidance for community engagement with initiatives like the Community Champions Programme and the Immunisation Inequalities Strategy to reduce barriers for underserved populations. Both countries are also advancing accessibility through strategies that prioritise community involvement and culturally sensitive approaches to data use.

Leading practices

67. Through the interviews with the four OECD countries, two leading practices emerged regarding co-creation: (1) the adoption of **co-creation principles** within health data policies to foster **social license** and (2) investing in information-sharing campaigns to establish common understanding of data collection and use for public health purposes to **minimise perceived risks vs. actual risks**. The findings from the interviews, as aligned to leading practices are summarised below:

Table 8. Summary of co-creation practices across four OECD member countries

Country	Adoption of co-creation principles within health data policies to foster social license	Information sharing campaigns to establish common understanding of data collection and use for public health purposes
Australia	Yes	No
Canada	Yes	In development
New Zealand	Yes	No
United Kingdom	Yes	Yes

Source: Authors

4 Conclusions and Next Steps

68. The potential for digitalising public health systems, particularly for immunisation and respiratory disease surveillance, is immense. As this report has explored, digitalisation has become a critical determinant in enabling the effective, interoperable, ethical, and secure use of health data to advance the quintuple aim of healthcare during and after the COVID-19 pandemic. Despite this transformative cultural shift in leveraging data and digital technologies to adapt and create new healthcare delivery models, surveyed countries face persistent challenges in ensuring the timeliness, quality, comprehensiveness, and interoperability of their health data architectures. These challenges vary depending on the structure of the health system, with decentralised models requiring particular effort to adopt federated data approaches that enable national collaboration while preserving local autonomy. Although progress has been made in fostering cross-jurisdictional initiatives, the effectiveness of these strategies depends strongly on their successful long-term implementation.

69. In the post-pandemic era, the digitalisation of public health systems is about building integrated, resilient, and sustainable health systems supported by adequate human resources, reliable and secure infrastructure, and robust health data governance. This approach must be complemented by public policies that support co-creation in the digitalisation of public health. Critical to this transformation is an understanding of how existing models can be adapted to national contexts, drawing on cross-border knowledge-sharing practices to identify and scale leading practices. While progress has been made, OECD countries have yet to fully harness the potential of data and digital technologies to comprehensively enhance public health services, particularly in improving immunisation coverage and respiratory disease surveillance. This adaptation is crucial in preparing for future public health emergencies, and early lessons from the COVID-19 pandemic provide valuable insights. The key question remains how to implement these changes sustainably over the long term, ensuring sufficient funding and prioritisation of public health digitalisation within national health programs.

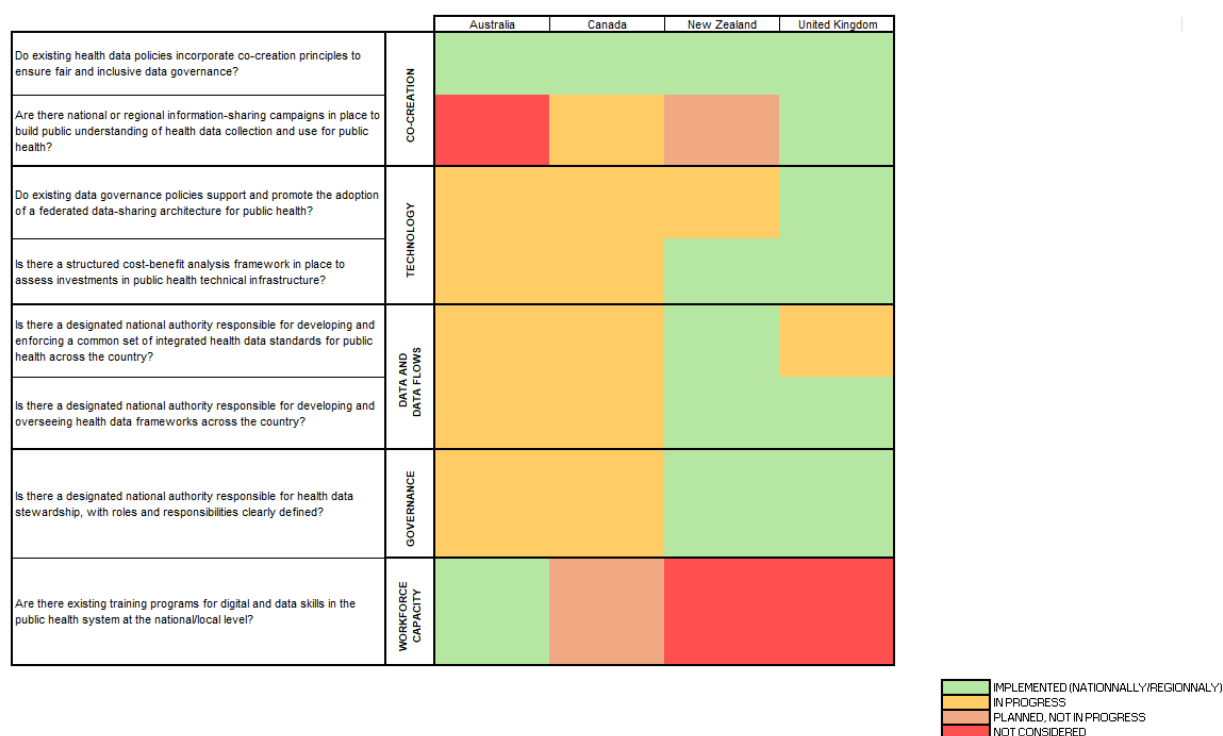
70. Prior to analysing countries' alignment with the identified leading practices, a readiness assessment was conducted to evaluate performance across the five analysed areas: governance and people capacity building, data and data flows architecture, technology, and co-creation. The results revealed divergent readiness across all areas, with the **United Kingdom** and **New Zealand** demonstrating the highest levels (see Figure 4).

71. The **United Kingdom** showed high performance across all areas, although there are opportunities for improvement in data and data flows and, more significantly, in workforce capacity building, as existing programs do not cater specifically to public health servants. Similarly, **New Zealand** performed well in most areas but fell short in health equity and people capacity building, primarily due to the absence of data-driven public health programs and a strategic implementation plan to enhance the understanding of health data collection among communities living in marginalised conditions.

72. **Australia** is undergoing significant changes with the establishment of the Australian CDC, influencing current performance across governance, data and data flows, and technology. These ongoing developments contribute to the observed variability in its readiness level. In **Canada**, early-stage initiatives are focusing on stewardship, including the exploration of federated data architecture and common data

standards across jurisdictions. However, these initiatives remain in the exploratory phase without any concrete plans for implementation.

Figure 4. Readiness assessment across four OECD member countries



Source: Authors

73. Interviews with national stakeholders revealed leading practices across all four OECD member countries, with significant potential to further evolve, expand, and integrate digitalised public health services into broader healthcare systems. These advancements must be driven by a focus on resilience, sustainability, and efficiency to address current gaps and meet future challenges.

Governance and people capacity

- Assigning accountability for developing an independent and competency-based national data stewardship authority to design, oversee and ensure stewardship of health data foundations and provide advice on unified data-sharing standards.
- Develop a comprehensive national program to provide end-to-end digital and data skills development for both frontline health workers and backend data professionals to support the digitalisation of public health.

Data and data flows

- Assign accountability for developing a common set of integrated health data standards (content) and incentives for public health use cases to ensure accountability, quality, privacy, and access to health data.
- Assign accountability for developing a health data framework for data collection, integration, and security, with regional monitoring processes.

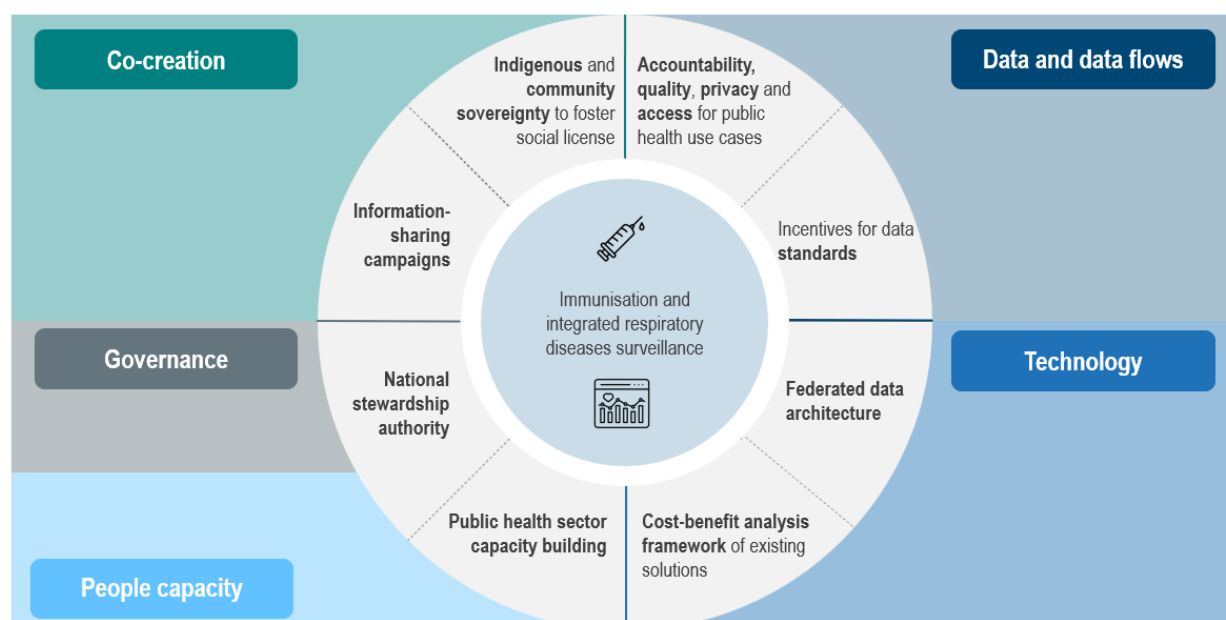
Technology

- Develop cost-benefit analysis framework of existing software solutions to ensure their adaptability and scalability to evolving public health needs (immunisation and surveillance).
- Foster adoption of federated data architecture across (large) organisations that enable local data collection, regional data integration, and both national and regional data use.

Co-creation

- Assign accountability for the co-creation of health data policies to foster social license for engaging populations.
- Invest in information-sharing campaigns to establish common understanding of data collection and use for public health purposes to minimise perceived risks vs. actual risks.

Figure 5. Summary of findings in this report



Source: Authors

74. The leading practice with the least achievement was the investment in information-sharing campaigns to establish common understanding of health data collection and use for public health purposes, while the practice with the highest achievement was the development of a common set of integrated health data standard with incentives for public health uses cases, and the adoption of co-creation principles within health data policies. The **United Kingdom** and **New Zealand** were the highest achievers, achieving at least 6 out of 8 leading practices.

75. For **governance**, member states are actively adapting their health data governance frameworks to address evolving public health needs, reflecting each country's unique governance context and health system infrastructure. A common trend is the adoption of a stewardship model, which clarifies accountabilities and assigns specific roles across government levels to streamline health data sharing and usage, thereby strengthening public health preparedness and response. In **Canada**, collaborative work is being explored with sub-national governments (provinces and territories) to transition from a data custodianship model to a health data stewardship model, with new Federal-Provincial-Territorial

governance tables guiding work towards pan-Canadian objectives. **New Zealand** employs a centralised governance structure under Te Whatu Ora (Health New Zealand) and Manatū Hauora (the Ministry of Health), which together form a national governance structure, while **Australia** combines centralised oversight through the upcoming establishment of the Australian CDC with local implementation. The **United Kingdom** adopts a hybrid approach, leveraging the National Health Service (NHS) for centralised oversight while enabling regional entities to tailor data collection and utilisation to meet local needs.

76. Despite these advancements, **people capacity building** remains a critical challenge. Only **Australia** have initiated targeted programs in the public health sector to address data literacy and digital health skills, while others are gradually introducing training programs. However, no country has established dedicated funding mechanisms for workforce planning and development in public health, leaving a critical gap in ensuring the long-term sustainability of digital public health transformation.

77. For **data and data flows**, the approaches adopted by the four OECD countries reflect diverse strategies for building integrated health data architectures that facilitate seamless national and subnational data sharing, interoperability, and scalability. A shared commitment to open data-sharing principles forms the foundation of these efforts, with all countries employing international interoperability standards such as HL7 FHIR, SNOMED CT, and ICD-10. The **United Kingdom** is also transitioning to ICD-11, while **Canada** is considering undertaking this transition and **Australia** has established a taskforce to lead work to inform a decision on ICD-11 implementation. However, the maturity of these efforts varies based on regional autonomy, technical infrastructure, and the availability of unified frameworks.

78. Notably, both **Australia** and **New Zealand** employ identifiers to facilitate the linkage of health data sets. Australia, however, does not utilise a single unique identifier for linkage as there has not been widespread adoption of Individual Healthcare Identifiers across healthcare programs and services; instead, it relies on various identifiers, such as the Medicare Consumer Directory and Tax File Number, which are adapted from administrative services and lack full population coverage. To mitigate these limitations, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare have developed the ABS Person Linkage Spine to enhance data integration capabilities. Meanwhile, **Australia**, **Canada** and **New Zealand** are advancing their Core Data for Interoperability initiatives.

79. Differences in the adoption of **technology** to support scalable, secure, and federated data architectures across the four OECD countries mirror the structure and governance of their health systems. Federated systems, such as those in **Canada** and **Australia**, face challenges in integrating regional data into a unified national platform due to varying jurisdictional practices. In contrast, **New Zealand** and the **United Kingdom** lead in developing cloud-based national data platforms supported by clear standards for integration and alignment with national technical infrastructure.

Figure 6. Summary of leading practices in digitalising public health systems across four OECD member countries

		Australia	Canada	New Zealand	United Kingdom
Assign accountability for the co-creation of health data policies to foster social license for engaging populations.	CO-CREATION	YES			
Investment in information-sharing campaigns to establish common understanding of health data collection and use for public health purposes		NO	IN DEVELOPMENT / PARTIAL	NO	YES
Establishment of a national federated data architecture	TECHNOLOGY	IN DEVELOPMENT / PARTIAL	NO	IN DEVELOPMENT / PARTIAL	YES
Development of a cost-benefit analysis framework and strategy for public health technical infrastructure		IN DEVELOPMENT / PARTIAL	IN DEVELOPMENT / PARTIAL	YES	YES
Development of common set of integrated health data standards with incentives for public health use cases	DATA AND DATA FLOWS	YES	IN DEVELOPMENT / PARTIAL	YES	YES
Adoption of comprehensive health data framework for data collection, integration and security, including regional monitoring		YES	IN DEVELOPMENT / PARTIAL	YES	IN DEVELOPMENT / PARTIAL
Establishment of an independent and competency-based national data stewardship authority	GOVERNANCE	IN DEVELOPMENT / PARTIAL	IN DEVELOPMENT / PARTIAL	YES	YES
Establishment of end-to-end digital and data skills program in the public health sector	WORKFORCE CAPACITY	NO	NO	NO	YES

YES
 NO
 IN DEVELOPMENT / PARTIAL

Source: Authors

80. It is notable that these leading practices are aligned with the OECD Recommendation on Health Data Governance (OECD, 2016^[28]). The Recommendation emphasises the need for coherent and standardised approaches to enhance data interoperability, foster stakeholder engagement and participation in processing health data for the public interest, ensure robust data protection measures, regularly evaluate the capacity of public health sector data systems, and implement comprehensive training and skills development programs for managing personal health data responsibly.

81. Every responding country had areas of excellence and areas for improvement. Working together, the four OECD countries can share their leading practices and improve cross-border public health collaboration, to strengthen cooperation considering future public health challenges.

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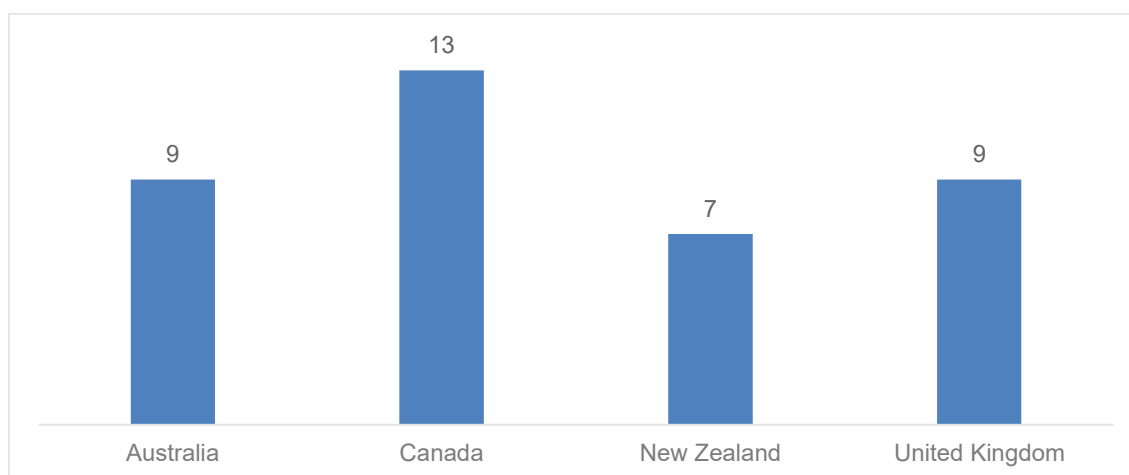
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Annex A. Interviewed experts across the four surveyed countries



Note: The interviews were conducted between June and September 2024.

Source: Authors

Annex B. OECD Recommendation on Health Data Governance (2016)

The OECD recommends that governments establish and implement a national health data governance framework to encourage availability and use of personal health data to serve the health-related public interest, while promoting the protection of privacy, personal health data and data security. The 12 key principles that health data governance frameworks should provide for are summarised as follows:

1. Engagement and participation, notably through public consultation, of a wide range of stakeholders to ensure the framework serves the public interest and is consistent with societal values.
2. Government co-ordination and promotion of co-operation among organisations processing personal health data, whether in the public or private sectors, to encourage common data terminology and interoperability standards, and common procedures to minimise barriers to sharing data.
3. Review of the capacity of the public sector to process personal health data for research, statistical and other uses within the public interest – including data availability, quality, accessibility, privacy protection, and data security.
4. Clear provision of information to individuals regarding processing of their personal health data with associated legal basis and timely notification of data breach or other misuse of their personal health data through individual notification or public communication.
5. Processing of personal health data by informed consent or a lawful alternative; and, when processing is not based on consent, the ability for individuals to object to the processing (to opt out) is granted, or if opt-out is not possible then to be provided with the reason why and the legal authorisation for it.
6. Review and approval procedures for the uses of personal health data that assess whether the uses are within the public interest, which should be objective, fair, timely and transparent to the public that is supported by those who have expertise in assessing the risk and benefits for individual and society.
7. Provision of transparent public information about the purpose of processing of personal health data and served public interests, the procedure, and criteria to approve data processing and a summary of approval decisions taken, and the implementation of the health data governance framework and its effectiveness.
8. Maximising the potential of new technologies to support data use and re-use, protect privacy and manage digital security risks, and support individuals' control of the uses of their own data.
9. Monitoring and evaluating whether the uses of personal health data served the public interest and brought the benefits that were expected and whether any negative consequences have occurred through periodic review and assessment of the availability of personal data, policy, and technology.

10. Establishment of appropriate training and skills development in privacy and security measures for those processing personal health data that are in line with prevailing standards and data processing techniques.
11. Implementing controls and safeguards to:
 - a. Provide accountability for personal health data processing and mechanisms for audit.
 - b. Provide privacy, data protection and security training for staff members processing personal health data.
 - c. Designate a data protection officer to be accountable for the organisation's information security programme.
 - d. Undertake risk assessment processes that include the risk of unauthorised data linkages and breaches.
 - e. Take technical, physical, and organisational measures to protect privacy and data security, including:
 - i. Mechanisms that limit the identification of individuals while allowing data re-use (linkage).
 - ii. Data sharing agreements that specify data security requirements and sanction noncompliance.
 - iii. Alternatives to data transfers, such as secure data access centres and remote data access.
 - iv. Identity verification and authentication of individuals accessing personal health data.
12. Requiring organisations processing personal health data to demonstrate that they meet national expectations for health data governance, which can include certifications or accreditations.

Source: (OECD, 2016^[28])

Annex C. Governance and People Capacity

82. Governance for public health services delivery involves complex layers of administration, policymaking, and stakeholder engagement. In federalist systems, these complexities are further compounded by the need to coordinate and align efforts between national and subnational governments. This section examines the critical components of digitalising immunisation and surveillance governance across the four OECD member countries, including organisational structures, health data governance, policy frameworks, and the engagement of stakeholders across multiple government levels, considering the unique context of each health system.

83. The governance of immunisation and surveillance systems requires robust organisational structures with established, clear accountabilities at all government levels for ensuring seamless data monitoring and sharing, especially in federalist systems. Health data governance is particularly crucial, as it encompasses the policies and practices necessary to manage and use health data while safeguarding data privacy and security (OECD, 2016^[28]).

84. One key aspect is the organisational structure with shared responsibilities and accountabilities across different government levels. This includes the degree of co-operation and harmonisation, ensuring fit-for-purpose data sharing processes that are timely, accurate and secure, and responsive to public health needs. It also requires interoperable datasets for validating and linking data safely for effective reporting, developing, and updating standards for safe storage. While the degree of governance harmonisation varies widely across the four surveyed countries, key common elements ensure effective, timely and secure processing of health data, which are essential for public health.

85. Governance of immunisation and surveillance systems should also be inclusive and prioritise transparency, especially concerning key stakeholders, such as the public and vulnerable communities, given their related rights on data processing for public health purposes. Pro-active and inclusive engagement with these communities is essential for designing policies and services that are aligned, effective and harmonised with their evolving needs in the digital space. This approach can result in higher immunisation coverage and thus, better health outcomes at the individual and population level (Scobie et al., 2020^[29]).

86. In addition, to sustain the efforts related to digitalising public health systems, integrating, retaining, and upskilling the workforce is a key enabler. Despite a growing health and social care workforce, concerns persist regarding professionals' shortages, further exacerbated by digital divides and insufficient training in data-driven technologies needed to optimise workflows (Socha-Dietrich, 2021^[30]). Establishing comprehensive programmes to retain and upskill health providers, IT professionals, epidemiologists and data scientists devoted to digitalising public health systems will facilitate a smooth generational transition to deliver the promised potential of digitalised public health services, while meeting evolving market demands and ensuring workforce retention in the public health sector.

Table 9. Governance practices for digitalising public health systems

Country	Jurisdictions and data liability are established across governments agencies for data lifecycle management	Legal and operational standards facilitate data collection, integration and reporting	A standardised minimum dataset is implemented nationally, facilitating interoperable sharing of health-related data	Information about primary and secondary data processing is publicly available	Guidelines on data safety and privacy are publicly available	Financing for digital public health is sufficiently available at national and sub-national levels
Australia	No	Yes	Yes	Yes	Yes	No
Canada	No	Yes	No	Yes	Yes	No
New Zealand	Yes	Yes	Yes	Yes	Yes	No
United Kingdom	Yes	Yes	No	Yes	Yes	Yes

Source: Authors

87. Organisational models of public health systems vary across the four surveyed countries, shaped by their specific governance structures and contexts. In recent years, these models have undergone notable changes, driven by the dual pressures of the pandemic and the growing need for coordinated and harmonised processes to streamline health data management. These efforts aim to foster robust collaboration across government entities. Despite progress, common challenges have been highlighted throughout the interviews:

- The high degree of decentralisation within federalist systems, coupled with variations in legislation, policies, procedures, and accountability across sub-national entities, continues to impede cross-country harmonisation and unilateral cooperation. This fragmentation not only exacerbates interoperability but also weakens the ability to respond effectively to shared public health challenges affecting both the primary and secondary use of health data. These variations extend to fundamental legal concepts such as definitions of "public interest" and "research," creating additional uncertainty for data-sharing initiatives (OECD, 2025^[31]).
- As the use of secondary data evolves, emerging requirements for stewardship and custodianship roles reveal gaps in existing policies, which are often misaligned or insufficiently adaptable for implementation across different levels of government.
- Workforce shortages, worsened by the lasting effect of the pandemic, strain the public health sector's ability to harness data-driven technologies. Limited expertise in data analysis and advanced technology management, combined with competition from the private sector, exacerbates reliance on external contractors, complicating long-term workforce planning and capacity-building.

88. In light of these challenges, countries have initiated efforts to adopt unified approaches to managing health data and establishing sustainable organisational models that support such initiatives. A coordinated approach not only enhances governance structures but also reinforces the foundations for robust health data systems, enabling better collaboration and more resilient public health preparedness and responses.

Evolving health data governance frameworks to strengthening stewardship for responding to cross-country public health needs

89. The COVID-19 pandemic highlighted critical gaps in health data governance frameworks across OECD member countries, prompting the need for substantial reforms. These reforms reflect a growing demand to establish clear data stewardship roles responsible for setting robust data standards and improving interoperability, while integrating custodianship practices to address evolving public health challenges. Despite variation in governance structures, all four OECD members have or are in the momentum to progressively adopted their policies to foster cross-jurisdictional collaboration and align data governance practices while upholding secure, ethical, and transparent data usage.

90. Delivering national functions under the **Australian** National Health Security Act (2007) throughout the pandemic revealed limitations in real-time data sharing and coordination. These and other challenges led to the introduction of the Data Availability and Transparency Act (2022). While the Act was not specifically designed for health data, it was introduced to address the evolving needs of multilateral data governance by establishing a framework for the safe, efficient, and purpose-driven sharing of data across government entities. The Act specifically detailed the roles and responsibilities of data custodians, mandating their oversight in handling sensitive data, ensuring compliance with privacy safeguards, and facilitating its use for secondary purposes including research and policymaking (Australian Government, 2024^[32]).

91. Drawing on lessons from recent public health emergencies, including the COVID-19 pandemic, the Japanese encephalitis virus outbreak, the emergence of monkeypox, and the 2019-20 bushfires alongside other natural disasters, the Australian government announced its intention to establish the Australian Centre for Disease Control (CDC) during the 2022 federal election campaign. Following the election, an interim Australian CDC was established within the Department of Health and Aged Care in January 2024, with a budget allocation of \$251.7 million over four years (Department of Health and Aged Care, 2024^[33]), (Department of Health and Aged Care, 2024^[34]). The Australian Centre for Disease Control Bill 2025 and the Australian Centre for Disease Control (Consequential Amendments and Transitional Provisions) Bill 2025 have been introduced to Parliament, establishing an authorising framework for data sharing across the Commonwealth, States and Territories. Subject to passage of this legislation, the standalone Australian CDC will commence from 1 January 2026, formalising its governance, roles, and responsibilities as Australia's central authority for health data stewardship through intergovernmental agreements (Department of Health and Aged Care, 2025^[35]).

92. With the intention to establish a **Canadian** learning health system, the PCHDS EAG has recommended to set a comprehensive framework to strengthen the country's health data governance, aiming to improve the collection, use, and sharing of health data across provincial, territorial, and federal levels. The PCHDS EAG advised to focus on establishing clear accountability mechanisms to define roles and responsibilities, ensuring transparency and accountability in health data management. It also recommended the promotion of shared stewardship to align health data practices and policies across jurisdictions, enhancing interoperability through the development of standards and systems that facilitate seamless data exchange between different health information systems. Moreover, the PCHDS EAG recommended the prioritisation of data privacy and security by implementing robust measures to protect personal health information while enabling its use for public health purposes. By supporting evidence-informed decision-making through high-quality health data, the EAG recommends the fostering of a collaborative approach to bridge jurisdictional fragmentation inherent in Canada's decentralised health system, ensuring that public health data is effectively utilised to address national health priorities and support informed policy development (Government of Canada, 2022^[36]).

93. The EAG's work has informed the priorities on health data and digital health through the *Working Together to Improve Health Care for Canadians* plan. This is supported by a \$200 billion, ten-year

investment including \$25 billion allocated through bilateral agreements to support provinces and territories.

94. As part of the *Working Together to Improve Health Care for Canadians* plan, the Shared Pan-Canadian Interoperability Roadmap, developed by Canada Health Infoway in collaboration with Federal, Provincial, and Territorial stakeholders, provides a detailed blueprint to address the technical aspects of health data governance and establish interoperable health information systems nationwide. The roadmap sets forth actionable steps to break down data silos, enhance data portability, and standardise the exchange of health information across provincial, territorial, and federal jurisdictions. It clearly delineates the roles and responsibilities of data custodians, ensuring the protection of sensitive health information while enabling its secure and ethical use for research, innovation, and evidence-based public health responses (Canada Health Infoway, 2023^[37]).

95. Building on lessons from the pandemic to improve the timeliness and quality of health data transmission, federal, provincial, and territorial (FPT) governments are collaborating to develop a world-class health data system. Under the *Working Together to Improve Health Care for Canadians* plan, the Joint FPT Action Plan on Health Data and Digital Health and the Pan-Canadian Health Data Charter, an FPT Working Group on Health Data Stewardship was established in August 2023. This work aims to clearly define roles and responsibilities for health data management and oversight. It also seeks to harmonise data stewardship practices and operational procedures across the country, ensuring a consistent approach to the creation, collection, storage, and use of health data. The FPT Health Data Stewardship Working Group has concluded its work in 2024 and the continued advancement of pan-Canadian data stewardship by the Canadian Institute for Health Information (CIHI). CIHI engaged broadly with stakeholders to validate the proposed framework and governance put forward by the FPT Working Group (see **Error! Reference source not found.**). Canada's Conference of Deputy Ministers of Health (CDMH) endorsed the CIHI Pan-Canadian Health Data Stewardship Framework in September 2025.

Box 2. Canada's progress in modernising public health data governance

Timely and reliable public health data is essential for strengthening Canada's ability to detect, prevent, and respond to public health threats. High-quality data enables evidence-based decision-making, improves health equity, and enhances disease surveillance. By leveraging modern data systems, public health authorities can better monitor health trends, support outbreak response efforts, and guide policy interventions. However, challenges remain due to fragmented data collection methods, interoperability gaps, and jurisdictional differences across provinces and territories. These limitations hinder the seamless sharing of critical public health information, affecting the ability to implement timely interventions and allocate resources effectively.

To address these challenges, the Government of Canada is working with partners at all levels to modernise public health data systems through FPT collaboration. This includes the establishment of new governance structures that includes the Public Health Data Steering Committee, the FPT Table on Digital Health and Health Data Priorities and dedicated working groups focused on key themes, including data literacy, public trust, and data stewardship. The mandate of the Working Group on Health Data Stewardship was to explore a framework and governance that align data policies, procedures, and standards across jurisdictions, ensuring greater consistency and interoperability while maintaining regional autonomy over public health data management. The Working Group recommendations were advanced by the Canadian Institute for Health Information (CIHI) and received formal endorsement from the Conference of Deputy Ministers of Health (CDMH) in September 2025.

Source: (Government of Canada, 2025^[38])

96. Privacy and data protection have long been central to **New Zealand's** health data governance landscape, laying the foundation for its modern approach to public health data. The Health Information Privacy Code (2020) (Office of the Privacy Commissioner, 2020^[39]), supported by the Privacy Act (2020) (Office of the Privacy Commissioner, 2020^[40]), provides robust safeguards for managing sensitive health data, balancing accessibility with stringent privacy protections. These regulations ensure that health data can be used ethically for research and policymaking while maintaining public trust.

97. Building on this strong regulatory foundation, New Zealand experienced a transformative shift in 2022 with the establishment of Te Whatu Ora – Health New Zealand, which unified the country's previously fragmented health system under a centralised governance model. By integrating 20 district health boards and local entities, Te Whatu Ora aims to streamline health data management, improve accountability, and ensure a cohesive national approach to public health data usage. This restructuring has enabled more efficient coordination across government levels and fostered trust in public health data practices. It also laid the groundwork for a stronger stewardship model with the Ministry of Health, supporting the integration and alignment of health data systems nationwide (Health New Zealand | Te Whatu Ora, 2024^[41]). As part of this transition, the Health Information Standards Organisation (HISO) has played a critical role in advancing interoperability across New Zealand's healthcare ecosystem. HISO develops and maintains standards that enable seamless data sharing among healthcare providers and systems (Health New Zealand | Te Whatu Ora, 2024^[42]).

98. The **United Kingdom** has made substantial progress in health data governance to meet the evolving demands of its public health sector. Central to these efforts is the Five Safes Framework, developed by the Office for National Statistics (UK Data Service, 2024^[43]). This framework ensures secure and ethical data sharing by establishing controlled environments for data access and defining rigorous protocols for privacy and data stewardship. By safeguarding data access, use, and outputs, the framework

fosters public trust and facilitates collaboration with academic researchers, government bodies, and international health organisations.

99. Building on this foundation, the Better, Broader, Safer Initiative, guided by the recommendations of the Goldacre Report, focuses on maximising the utility of the UK's extensive health data assets (Department of Health and Social Care, 2022^[44]). This initiative promotes transparency, accountability, and secure data use to drive impactful research on vaccine efficacy, disease transmission, and health inequalities (Department of Health and Social Care, 2022^[45]). Systems, such as the National Immunisation and Vaccination System (NIVS) and public health surveillance platforms, play a critical role in these efforts by enabling robust data analysis to inform policy and improve public health outcomes (NHS England, 2022^[46]).

100. In addition, the UK Health Security Agency (UK HSA) plays a central role in managing public health data, supporting compliance with privacy regulations such as the General Data Protection Regulation (GDPR), while promoting a consistent and coordinated approach to data governance. Through the establishment of national standards for data integration and interoperability, the UK HSA facilitates seamless collaboration among government and regional agencies. This coordination is pivotal for immunisation programs and disease surveillance efforts, enabling timely, evidence-based decision-making. Further enhancing these capabilities, the Digital, Data & Technology Assurance Board and the Architecture Forums oversees the adoption of advanced, secure, and scalable technologies such as the Enterprise Data and Analytics Platform (EDAP), as part of this data strategy (UK Health Security Agency, 2025^[47]). These tools will be instrumental in tracking vaccination progress, monitoring disease trends in real-time, and responding rapidly to public health threats (Sudlow, 2024^[48]).

Data-driven upskilling programs for workforce retention in the public health sector

101. Given the necessity to equip the health workforce with the right tools and capabilities to fully support the digitalisation efforts of public health systems, Australia, Canada, and the United Kingdom have initiated efforts in that space. These efforts are integrated into broader digital health and data-driven strategies, where health workforce is recognised as a cornerstone of the required holistic change. While New Zealand has not directly established specific workforce upskilling initiatives, it is addressing this need indirectly through the active integration of frontline and back-office workforce in the adoption process of health information standards.

102. In **Australia**, the National Digital Health Strategy identifies workforce upskilling as a cornerstone for improving workflow efficiencies, healthcare quality, and coordination, benefiting both patients and healthcare providers. The strategy extends beyond frontline healthcare workers to include a wide range of roles critical for a holistic data-driven culture, such as health data and systems developers, analysts, researchers, IT programmers, software professionals, and business and administrative staff. It also recognises the importance of social service providers, including those in housing, justice, child and family support, policy, and education sectors, as integral enablers of this transformation (Australian Digital Health Agency, 2023^[49]). To operationalise this vision, the National Digital Health Capability Action Plan – initiated in 2024 as a two-year program – sets out priority actions to enhance workforce digital literacy to equip the workforce with the skills needed to navigate and sustain the digital transformation of Australia's healthcare ecosystem (Australian Digital Health Agency, 2024^[50]).

103. Beyond healthcare, the Australian Government's Data and Digital Government Strategy reinforces the importance of capacity building in the public sector by improving data competency, including in the health sector. This strategy aligns with broader initiatives such as the Australian Government Data Profession, which supports specialised training and development to enhance data skills across

government agencies, though it is not exclusive to public health (Australian Government, 2025^[51]), (Australian Public Service Commission, 2025^[52]).

104. While not specific to the health sector, **Canada** and the **United Kingdom** have developed data competency frameworks to equip public servants with the necessary skills to integrate data-driven practices and enhance digital literacy. Canada's Data Competency Framework outlines a set of 13 competencies and skills spanning the data life cycle, including areas such as data governance, quality assurance, analysis, visualisation, and ethical use of data, many of which are directly applicable to the health sector. The structured framework creates a unified approach to bridging data gaps across Canada's federal public service, while incorporating relevant legislation and policies from across the country (Government of Canada, 2023^[53]). Similarly, the United Kingdom's Government Digital and Data Profession Capability Framework, managed by the Central Digital and Data Office, provides a comprehensive list of skills required to evolve in data-oriented professions across four proficiency levels i.e., awareness, working, practitioner and expert. This framework allows to identify skill gaps in public servants' teams and forecast workforce needs, fostering a data-literate public service (Gov.UK, 2024^[54]).

105. **New Zealand** has not yet included specific measures to increase the digital literacy of the public health workforce. However, through the HISO, which is the entity in charge of establishing data standards within the health sector, it indirectly supports upskilling for health providers by providing guidance and educational training in health data management (Health New Zealand | Te Whatu Ora, 2024^[42]). For example, the adoption of the New Zealand International Patient Summary (NZIPS) includes a collaborative process involving health professionals, software developers, and consumer representatives. This process is supported by educational tools and materials to ensure successful implementation, indirectly fostering workforce readiness in health data management (Health New Zealand, 2022^[55]).

Policy considerations

106. Across all interviews, it has been consistently observed that countries are actively adapting their health data governance frameworks to align with evolving public health needs. While these efforts are shaped by each country's governance context and health system infrastructure, a common trend is the shift towards a stewardship model. This approach establishes clear accountabilities and assigns specific roles to various levels of government to streamline health data sharing and utilisation, enhancing public health preparedness and response. Most countries are gravitating toward a federated data model, which balances centralised coordination with local autonomy to address region-specific public health priorities. Notably, **New Zealand** stands out with a more centralised governance structure through Te Whatu Ora and the Ministry of Health, while other countries maintain a mixed model that delegates certain responsibilities to local entities while ensuring national-level oversight.

107. While workforce development remains an underdeveloped area in health data governance, some progress has been made. Targeted programs to upskill the public health workforce are limited to **Australia**, where initiatives have begun to address critical gaps in data literacy and digital health capabilities. Other countries are gradually introducing data-driven programs to enhance workforce competencies, but these efforts are not yet sufficient to attract, retain, or sustain a skilled public health workforce capable of meeting the demands of increasingly digitalised health systems. Furthermore, no country has yet devised targeted funding mechanisms specifically dedicated to workforce planning and development, leaving a critical gap in the long-term sustainability of digital public health transformation.

Leading practices

108. While governance structures for public health systems vary across countries, there are two pillars that are essential for advancing the digitalisation efforts in immunisation and respiratory disease surveillance: (1) **clear accountability of a national stewardship authority**, particularly in light of

coordination of health data infrastructure and strategic guidance on unified data-sharing standards and (2) **comprehensive people-capacity building programme in the public health sector**, through a national strategy to drive holistic cultural change across the public, and dedicated financing schemes.

Table 10. Summary of governance practices across four OECD member countries

Country	Establishment of a national model for health data stewardship	Comprehensive people-capacity building program in the public health sector
Australia	In development	Yes
Canada	Yes	No
New Zealand	Yes	No
United Kingdom	Yes	No

Source: Authors

Annex D. Data and Data flows

109. Building on robust health data governance, data architecture serves as the backbone of an integrated health system, enabling the standardised, secure, and interoperable management of health data across multiple systems. It involves the design, organisation, and processes necessary to collect, store, integrate, and share data efficiently. A reliable data architecture is critical to ensuring seamless health data flows, which promote consistency, accessibility, and utility for public health applications such as immunisation tracking and respiratory disease surveillance. Achieving this requires collaboration across various government entities to align processes, streamline data management, and foster interoperability within and across systems (OECD, 2023^[1]).

110. This section examines the critical components of developing a robust health data infrastructure, including standardised data collection methods, shared semantic and operational standards, and comprehensive security and privacy protocols. The OECD's 2022 review of the Health Data Governance Recommendation OECD revealed that many member countries continue to face significant challenges in establishing these foundational elements, particularly regarding data privacy protections, legal barriers to data linkage and sharing among public authorities, and difficulties implementing standards for clinical terminology and interoperability (OECD, 2022^[56]). Addressing these implementation gaps through robust foundational infrastructure enables countries to ensure data integrity throughout its lifecycle while achieving timely and efficient reporting for the likes of immunisation and respiratory disease surveillance. Such an infrastructure not only enhances responsiveness to public health demands but also strengthens overall health system resilience.

111. Data collection is the initial pillar to ensure a strong data architecture. Public health data comes from diverse sources, including demographic records, EHRs, laboratory results, and disease registries. However, the granularity and scope of collected data often vary between jurisdictions, creating challenges for uniform reporting and analysis. To address this, immunisation registries have been established in many countries to centralise and standardise data collection to help monitor vaccination coverage, identify gaps, and track disease trends. Despite these efforts, data collection processes remain fragmented in many countries, hindering timely and efficient reporting mechanisms.

112. To support reliable data flows, countries must adopt semantic and operational standards, which are integral to ensuring the consistency and usability of health data. Semantic standards define the content and structure of data, ensuring consistent labelling, classification, and interpretation across health information systems. Operational standards, on the other hand, address the processes, protocols, and technical requirements for data collection, storage, and sharing. Together, these standards create the foundation for interoperability, allowing health data to flow seamlessly and reliably across systems for public health use.

113. With standardised data and processes in place, achieving interoperability ensures that health information systems – ranging from local healthcare facilities to national public health platforms – can communicate and exchange data effectively. From an international perspective, establishing trusted health data networks creates simplified collaboration pathways by providing clear points of contact with

transparent standards and controls. These networks offer particular advantages through reduced bilateral agreements, consistent privacy safeguards, and pooled resources that eliminate duplicate data assets. From an international perspective, such networks could even connect at a global level, with national networks linking together through standardised approaches, an approach consistent with the EHDS framework (OECD, 2025^[31]). This reduces fragmentation and supports cohesive data management across facilities, organisations, and jurisdictions. Interoperability also enables real-time access to health data, enhancing decision-making and enabling a prompter response to public health challenges, such as outbreaks or vaccination coverage gaps (OECD, 2022^[56]).

114. Another key component is the implementation and regular updating of privacy and security protocols to protect sensitive health information. These protocols are designed to ensure the responsible handling of data throughout its lifecycle, from collection and storage to transmission and sharing, including cross-border exchanges. Measures such as encryption, multi-factor authentication, and audit trails safeguard data against unauthorised access and maintain its integrity. However, significant challenges remain, including balancing privacy with usability, harmonising standards across jurisdictions, and addressing cybersecurity threats (Sutherland et al., 2023^[22]). Addressing these challenges is essential to building trust in health data systems while enabling their effective use for public health purposes.

Table 11. Health data architecture across four OECD member countries

Country	National and subnational availability of health and health-related datasets (e.g., demographics, immunisations, surveillance etc.)	National and subnational linkability of health-related datasets (through unique identifiers)	State-level immunisation and surveillance health registries	National immunisation and surveillance health registries	Developing public application programming interfaces (APIs) for data access and innovation	Adopting HL7 Fast Health care Interoperability Resource (FHIR) standard for interoperability	Usage of SMART on FHIR standards for application integration
Australia	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Canada	Yes	In development	No	No	Yes	Yes	Yes
New Zealand	Yes	Yes	No	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	Yes	No	Yes	Yes	Yes

Source: Authors

115. Given the complexity of developing health data architecture, countries have been working since the 1990s to establish surveillance systems aimed at tracking public health trends and informing policy decisions. These systems were originally designed to monitor disease patterns, assess health risks, and provide actionable insights for public health interventions. The COVID-19 pandemic acted as a catalyst, driving significant enhancements in these systems by incorporating additional, comprehensive data from across jurisdictions. This temporary improvement boosted data availability and integration, enabling more timely and effective public health responses. However, interviews revealed persistent shortcomings that have hindered the full potential in the post-pandemic era:

- Following the pandemic, countries faced a backslide in data availability, particularly in decentralised systems, which resulted in a lack of integration of case-level data to inform localised policy-decision making and public healthcare service delivery.
- The lack of semantic and operational standards has impaired data linkability across diverse datasets within and between regional health information systems. This, coupled with divergent data domains collected at the local level, has resulted in extensive back-and-forth validation and

integration processes – slowing down data-sharing mechanisms, hindering compatibility, and disrupting timely reporting.

- Disparities in the allocation of technical and financial resources have left many regional health information systems outdated and underfunded. This not only compromises their functionality but also poses significant security risks and weakens data protection safeguards.

116. In response to these challenges, countries are increasingly investing in adapting their health data architecture. Efforts are focused on standardising health data-sharing processes and enhancing security and privacy protocols to protect data integrity. While the task of harmonising semantic and operational standards across diverse systems is immense, a coordinated approach can yield transformative benefits. Such an approach will ensure the reliability, interoperability, and security of health data flows, enabling more effective public health monitoring that aligns with both population and individual health needs – particularly in the face of emerging public health emergencies.

A set of common integrated health data standards to facilitate data-sharing within and across government levels

117. Developing a standardised approach to health data is essential to ensure seamless data-sharing within and across government levels, especially in decentralised countries. A well-designed set of standards promotes data interoperability, quality, and accountability. Across all four OECD countries, there is a shared focus on adopting common standards such as HL7 FHIR (Fast Healthcare Interoperability Resources), SNOMED CT (Systematised Nomenclature of Medicine - Clinical Terms), and ICD-10 (International Classification of Diseases) for semantic and operational consistency. Efforts to harmonise data through national frameworks, which have been adopted by all surveyed countries, emphasise the importance of interoperability. These efforts underscore the necessity of linking immunisation and respiratory diseases data with broader disease surveillance systems to strengthen public health resilience.

118. In **Australia**, a robust framework of health data standards has been implemented to ensure consistent, interoperable, and efficient data-sharing across government levels and health systems. Core standards such as HL7 FHIR, SNOMED CT, and ICD-10 form the foundation of this framework, standardising data coding, reporting, and exchange. A taskforce has been established to lead efforts to inform a decision on ICD-11 implementation (Australian Institute of Health and Welfare, 2025^[57]). These standards are central to public health systems, including the Australian National Notifiable Diseases Surveillance System (NNDSS) (Department of Health and Aged Care, 2024^[58]) which coordinates surveillance data for over 70 notifiable diseases presenting a risk to public health. The Australian NNDSS collects standardised and de-identified data from states and territory health authorities, which collate data from clinicians, laboratories, and hospitals, incorporating data content spanning across patient demographics, clinical outcomes, and disease-specific information into a unified, interoperable system.

119. The Individual Healthcare Identifier (IHI) is a unique 16-digit number assigned to each Australian resident through the Healthcare Identifiers Service. It enables healthcare providers to accurately match health records to the correct individual, helping to reduce medical errors and ensure the integrity of patient information. However, for public health surveillance and research purposes, data linkage currently relies on person-level spines derived from the Medicare Consumer Directory, which is managed by the Australian Institute of Health and Welfare (AIHW) (Services Australia, 2023^[59]). While the IHI is used in the Australian Immunisation Register (AIR) and linked to the My Health Record (MHR) platforms, its application to broader cross-jurisdictional linkage, such as for the Australian NNDSS is not currently implemented (Department of Health and Aged Care, 2024^[60]). Efforts to strengthen national health data exchange and linkage are ongoing, including through the development of a national health information exchange platform (Australian Digital Health Agency, 2025^[61]). These initiatives may be further shaped by

the establishment of the Australian CDC, which is expected to play a central role in coordinating public health surveillance, data integration and the adoption of health data standards (Australian Digital Health Agency, 2024^[62]).

120. **Canada** has made significant strides toward establishing a cohesive framework for health data standardisation to ensure seamless data-sharing across jurisdictions. The Pan-Canadian Health Data Content Framework, recently published by CIHI, provides a harmonised approach by defining standardised data elements and formats across provinces and territories. This framework fosters data accountability and quality, enhancing interoperability across Canada's fragmented health data systems and facilitating consistent public health responses (see **Error! Reference source not found.**). Complementing this effort, the Shared Pan-Canadian Interoperability Roadmap, developed by Canada Health Infoway, outlines a strategic vision for improving interoperability by establishing common standards, fostering seamless data exchange, and enhancing connectivity across Canada's healthcare ecosystem. By addressing technical, governance, and policy-related challenges, the roadmap supports a more integrated and patient-centered approach to health data management (Canada Health Infoway, 2023^[37]).

121. Central to the objectives of the Roadmap is the use of international standards such as HL7 and SNOWMED CT, which underpin interoperability and enable consistent coding, sharing, and analysis of health information (Canada Health Infoway, 2024^[63]), (CIHI, 2024^[64]). A key component of Canada's health data standardisation efforts is the Canadian Core Data for Interoperability (CACDI), which specifies a minimum set of essential health data elements and value sets to support information capture and meaningful exchange across the health care ecosystem (Canadian Institute for Health Information, 2024^[65]), operating within the broader Pan-Canadian framework.

122. Supporting this overarching framework, the Canadian Immunisation Registry Functional Standards (IRFS) serve as foundational guidelines for immunisation registries. The IRFS establish minimum functional standards required to support healthcare providers, programs, and other stakeholders while promoting a cohesive national immunisation network (Government of Canada, 2021^[66]). The National Vaccine Catalogue complements these efforts by providing a publicly accessible repository of vaccines authorised for use in Canada, including standardised terminology for domestic and select international vaccines. This ensures consistent recording of vaccines received abroad and promotes interoperability within and across immunisation registries (Government of Canada, 2024^[67]).

123. Central to **New Zealand's** efforts in devising integrated health data standards is the NZCDI, which standardises critical health data elements such as immunisation records, medications, allergies, and demographic information. Inspired by best practices from the Australian Core Data for Interoperability (AUCDI), the NZCDI ensures consistent data representation across health information systems, enhancing interoperability and improving data quality. To sustain and expand the NZCDI, work is underway to develop a New Zealand Core FHIR Implementation Guide, which will support the technical interoperability of standardised data. As part of this modernisation, the SNOMED CT terminology standard will replace the outdated Read code system, becoming the mandatory source for coding the main data elements. This approach is designed to specify commonly exchanged health data elements while remaining agnostic of specific use cases or implementations, fostering a flexible and inclusive framework (Health New Zealand I Te Whatu Ora, 2024^[68]).

124. Supporting the NZCDI is the National Health Index (NHI), a unique identifier assigned to all individuals accessing New Zealand's health services, including overseas visitors, work permit holders, non-residents, and foreign diplomats. This system ensures equitable access to healthcare and enhances data tracking capabilities (Health New Zealand I Te Whatu Ora, 2024^[69]). The NHI encompasses seven data domains, including ethnicity, enabling consistent identification across health and disability systems. In addition, the NHI integrates with the Medical Warning System, alerting healthcare providers to potential risk factors that could influence clinical decisions.

125. In the **United Kingdom**, the National Immunisation Management Service (NIMS), central to tracking immunisation efforts, employs standards such as SNOMED CT and ICD-10 to ensure consistent coding and classification of vaccination data (NHS England, 2022^[46]). With plans to transition to ICD-11, the system is poised to further enhance diagnostic and treatment data standardisation. The use of FHIR standards aligns immunisation and public health platforms with global interoperability benchmarks, enabling efficient data exchange between clinical systems, EHRs, and surveillance systems.

126. Emerging API standards developed under the Big Rocks Transformation Program are driving real-time interoperability across public health platforms. These APIs streamline data flows between the NHS, the UK HSA, and other stakeholders, ensuring that vaccination and disease surveillance data can be accessed and integrated promptly (UK Health Security Agency, 2023^[70]). For instance, the NIVS records immunisation details for both patients and healthcare workers, demonstrating how standardised data-sharing supports operational and clinical decisions (NHS England, 2022^[46]).

127. The Patient Demographic Services (PDS), which links the NHS number with demographic data, including age, ethnicity, and geography, further strengthens data integration. By enabling comprehensive patient tracking across systems, the PDS supports targeted public health interventions and holistic monitoring of immunisation efforts (NHS England, 2024^[71]). Complementary tools like the Unique Property Reference Number (UPRN) facilitate geo-spatial analyses, improving environmental health surveillance and ensuring precision in health policy planning (Central Digital & Data Office, 2022^[72]).

Box 3. A collaborative and patient-centric healthcare model through the establishment of standardised data content

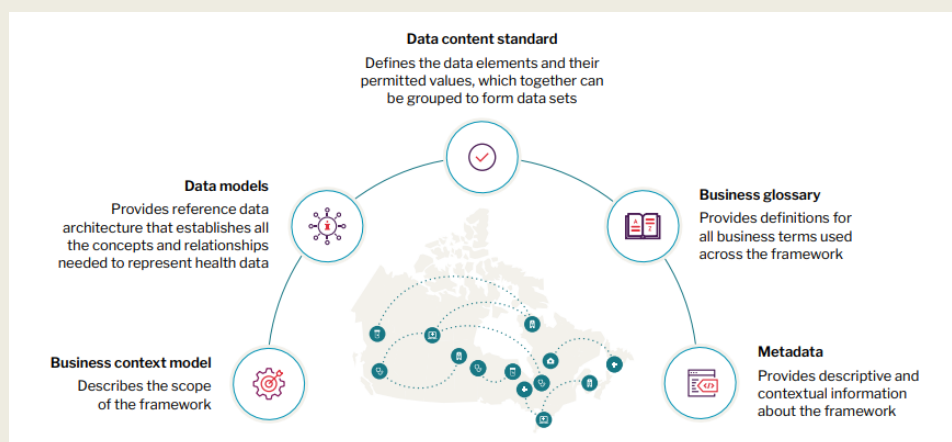
Given the complexity and fragmentation of the **Canadian** health data landscape, with limited data-sharing across jurisdictions, the CIHI developed standardised health data content to prompt the connectivity of health information systems across the country. As part of the **Shared Pan-Canadian Interoperability Roadmap** developed and executed by Infoway, with support from CIHI, Canada is advancing the digitalisation of the country's health data infrastructure with three key objectives: (a) ensuring uninterrupted, timely, and accessible health data (b) establishing commonly shared semantic standards across jurisdictions and provinces and (c) delivering direct, tangible benefits to the public.

In September 2024, CIHI introduced the **Pan-Canadian Health Data Content Framework** (see Figure 7), is a key component identified in Canada Health Infoway's roadmap. It details a collaborative and patient-centric healthcare model that standardises data content for alignment with technical solutions. This framework aims to support a cohesive approach to data stewardship, facilitating seamless data integration across existing systems while ensuring the responsible and effective management of health data throughout its lifecycle. By embedding this framework within Canada's broader health data governance strategy, CIHI seeks to promote interoperability and strengthen the national health ecosystem. A key subset of this framework, the CACDI, plays a critical role in enabling standardised data exchange across jurisdictions and health systems, by establishing harmonised semantic and technical data standards.

The standardisation process leverages insights from international best practices, including the International Patient Summary (ISO 27269), the USCDI, Australia's Core Data Sets, and the United Kingdom's Professional Record Standards Body. As a first step, six core data content standards have been defined: Person Information, Allergies and Intolerances, Immunisations, Medications, Social Determinants of Health (SDOH), and Health Concerns. CIHI plans to expand these standards in the next phase to include additional data categories, further broadening the scope of standardisation.

This foundational effort represents a major step forward in improving the linkability of health datasets across various health information systems, notably by incorporating standardised person identifier types. It also addresses the long-standing fragmentation of Canada's health data architecture by fostering collaboration among stakeholders to establish a common set of semantic standards. By building consensus and driving interoperability, the Pan-Canadian Health Data Content Framework lays the groundwork for a more integrated, effective, and equitable health data ecosystem in Canada.

Figure 7. Pan-Canadian health data content framework



Source: (CIHI, 2024^[73])

A well-established health data architecture to streamline data lifecycle across country monitoring processes

128. A robust health data architecture supports the entire lifecycle of data – from collection to integration, analysis, and sharing – ensuring efficient and secure monitoring processes. By leveraging advanced technologies such as real-time data exchange, cloud-based platforms, and AI-driven analytics, well-designed architectures enable comprehensive surveillance for immunisation coverage and respiratory disease trends. Leading practices across the four surveyed countries demonstrate how these architectures integrate diverse data sources to provide actionable insights for public health decision-making.

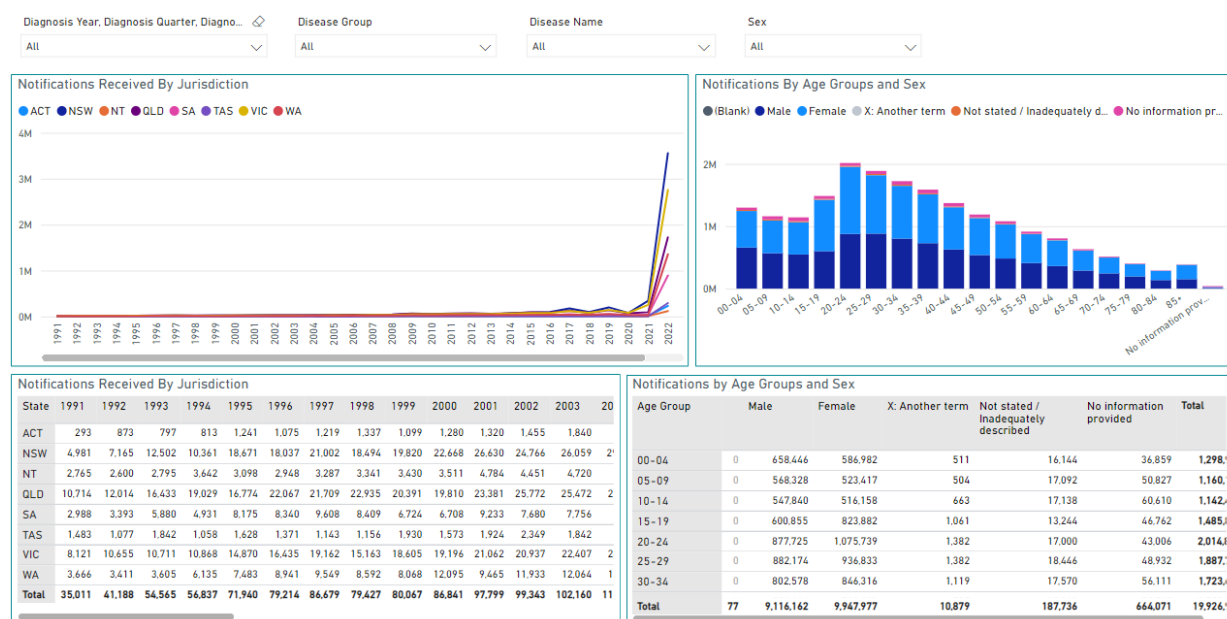
129. Mandated by the AIR Act (2015), the Australian Immunisation Register (AIR) is a vital data collection within **Australia's** advanced health data architecture (Australian Government, 2021^[74]). It provides a unified, national system for integrating and monitoring immunisation data across jurisdictions. The AIR captures comprehensive records for individuals of all ages, encompassing vaccines delivered under the National Immunisation Program (NIP) as well as privately administered immunisations, such as seasonal influenza and travel vaccines (Australian Government, 2023^[75]). Each record includes critical details such as vaccine type, dose, administration date, provider information, and patient demographics. This data is systematically linked to other healthcare systems via the Individual Healthcare Identifier (IHI), enabling seamless integration with providers, laboratories, and clinical registries. The AIR's architecture supports informed public health planning, near real-time surveillance, and timely interventions to safeguard population health (Services Australia, 2024^[76]). These records are de-identified for reporting purposes.

130. To ensure seamless interoperability, the AIR leverages HL7 FHIR standards, facilitating real-time data exchange with healthcare providers. Data from laboratories and healthcare providers directly feed into the AIR, minimising manual intervention while enhancing the timeliness and accuracy of immunisation information. While the Australian NNDSS does not currently integrate with other platforms, its data can be brought together with information from other datasets, such as the AIR, to support correlation analysis and provide a more comprehensive understanding of respiratory disease trends. The development of the

new National Public Health Surveillance System by the Australian CDC aims to address existing gaps in integration and digitalisation of public health data, including those in the Australian NNDSS (Department of Health and Aged Care, 2024^[58]).

131. Established in 1991, the NNDSS serves as the backbone of Australia's national disease surveillance framework which aims to standardise data collection across states and territories, using a minimum dataset that captures essential demographic and clinical details such as disease name, patient age, gender, Indigenous status, and geographic location. The system also has the ability to collect enhanced data on a number of conditions where further information is needed for more detailed epidemiological analysis. Updated daily, the NNDSS data visualisation tool (see Figure 8), can be used to identify trends in diseases, and assess the impact of disease control programs (Department of Health and Aged Care, 2024^[58]).

Figure 8. National communicable disease surveillance dashboard



Source: (Australian Government, 2024^[77])

132. While the integration of the AIR and the Australian NNDSS is currently not possible in real-time, efforts are underway to enhance data linkages. For example, the COVID-19 Register developed by the AIHW links datasets from both data collections, although it relies on retrospective data and is primarily used for research rather than real-time surveillance (Australian Institute of Health and Welfare, 2025^[78]). However, the development of the Australian CDC aims to address these data integration limitations by enabling the real-time linkage of immunisation data from the AIR with communicable disease notification data in the NNDSS, ultimately enhancing Australia's ability to monitor and respond to disease threats more effectively. In addition, initiatives like the National Healthcare Interoperability Plan 2023-2028 (Australian Digital Health Agency, 2023^[79]) provide the framework for advancing interoperability in public health data systems. In the future, these advancements will support predictive modelling, optimise

resource allocation, and facilitate a more cohesive approach to monitoring vaccination effectiveness and disease trends.

133. While **Canada** does not have a national immunisation registry, its health data architecture is characterised by a strategic framework that supports the integration, management, and analysis of health data across provinces and territories. The IRFS provide a cohesive foundation for registries, enabling healthcare providers, public health programs, and other stakeholders to accurately record and manage vaccination data (Wilson et al., 2017^[80]), (Government of Canada, 2021^[66]). These standards establish minimum functional requirements that ensure interoperability, data consistency, and the capacity to generate real-time insights. Supporting this, the National Vaccine Catalogue serves as a centralised repository of vaccines authorised for use in Canada (Government of Canada, 2024^[67]). By incorporating standardised terminologies such as SNOMED CT and leveraging frameworks like HL7 FHIR, the catalogue ensures compatibility across registries and facilitates seamless data-sharing for both domestic and internationally administered vaccines.

134. Canada's health data architecture also emphasises comprehensive surveillance and monitoring using immunisation coverage surveys and other population health tools. The Childhood National Immunisation Coverage Survey (cNICS), conducted biennially since 1994, plays a critical role in monitoring vaccination rates, identifying disparities, and assessing vaccine uptake trends over time (Government of Canada, 2022^[81]). Expanding on this approach, initiatives like the Childhood Immunisation Coverage Survey in Key Populations (KPCICS) address vaccine access and equity among underserved communities, including urban First Nations, Métis, and Inuit populations, newcomers, and 2SLGBTQ+ families (Leger, 2024^[82]). These targeted efforts are complemented by the integration of advanced analytics platforms that utilise anonymised, aggregated data to identify trends and forecast potential public health challenges.

135. A critical aspect of Canada's health data ecosystem is the emphasis on streamlined data lifecycles that support near real-time decision-making. This is achieved through national coordination mechanisms such as the Joint Data Action Plan, which fosters harmonised frameworks for data integration, security, and oversight. By aligning regional and national public health authorities, the plan enhances data accountability and quality while promoting interoperability (Government of Canada, 2023^[83]). Canada's efforts in this area are further strengthened by the Canadian Health Data Platform (formerly the SPOR Health Data Platform), managed by Health Data Research Canada (HDRN) in collaboration with CIHI and provincial and territorial health data agencies. This platform enables the secure linking and analysis of large health datasets across jurisdictions, supporting evidence-based health responses and reducing operational inefficiencies. Key partners, including Ontario's health data agency, play an integral role in advancing this national initiative (Health Data Research Network Canada, 2025^[84]).

136. In **New Zealand**, the EpiSurv national notifiable diseases surveillance database, operated by the Institute for Environmental Science and Research (ESR), and the Notifiable Disease Management System (NDMS) form the backbone of the country's public health data lifecycle management (Institute for Environmental Science and Research, 2024^[85]), (Health New Zealand I Te Whatu Ora, 2024^[86]). These interconnected platforms work seamlessly to streamline the reporting, management, and analysis of communicable diseases. Healthcare providers input data on notifiable diseases into NDMS, a front-end system designed for recording notifications, which then transmits de-identified data in real-time to EpiSurv. Within EpiSurv, this data is aggregated and analysed to produce actionable insights that inform public health responses, ensuring timely interventions and resource allocation.

137. The Aotearoa Immunisation Register (AIR) complements this system by serving as a comprehensive and modernised platform for tracking vaccination records across the population (Health New Zealand I Te Whatu Ora, 2024^[87]). Building on its predecessor, the National Immunisation Register (NIR), AIR captures a broader range of data, including decisions not to vaccinate, providing a holistic view of immunisation coverage. Through its integration with EpiSurv, AIR facilitates real-time cross-referencing

of immunisation data with disease surveillance metrics, enhancing New Zealand's capacity for targeted interventions and policymaking. This integration allows public health authorities to monitor vaccination gaps and correlate them with disease incidence, ensuring a more proactive approach to public health management.

138. In addition, the Respiratory Illness Dashboard provides real-time insights into acute respiratory infections, consolidating data on hospitalisations, virus detection, and test positivity rates (Institute for Environmental Science and Research, 2024^[88]). By drawing from EpiSurv and other surveillance systems, this dashboard presents both national and community-level trends. It supports timely and informed decision-making by offering a comprehensive overview of respiratory disease patterns, enabling public health authorities to anticipate outbreaks, allocate resources efficiently, and implement targeted interventions.

139. The **United Kingdom** has established a robust health data architecture designed to streamline the lifecycle of data across country-wide monitoring processes, enhancing both efficiency and responsiveness in public health management. While the UK has not developed a unified architecture for data linkage across its constituent countries, each nation has implemented tailored systems for managing COVID-19 vaccination data (Farmer, Marchildon and Allin, 2022^[89]). At the core of these efforts is the Linor X Architecture Tool, which maps relationships between data assets, applications, and technical components. This tool provides comprehensive oversight, improves governance of health data, and enables a holistic view of the health data ecosystem, ensuring streamlined workflows and well-coordinated data management across diverse systems.

140. In England, a cornerstone of this architecture is the NIMS, a centralised platform that tracks immunisations, including COVID-19 and other vaccination programs (UK Health Security Agency, 2024^[90]). NIMS integrates with related public health systems to enable real-time tracking of vaccine coverage, schedules, and adverse effects, providing a comprehensive nationwide perspective on immunisation efforts. The system consolidates vaccination data from sources such as Outcomes4Health (EMIS), previously known as Pinnacle, and the NIVS while integrating with general practice (GP) records, creating a unified and accessible dataset (NHS England, 2024^[91]), (NHS England, 2022^[46]). Similarly, other devolved nations have developed tailored solutions: Northern Ireland's Vaccination Management System replaced manual reporting (Department of Health Northern Ireland, 2024^[92]), Scotland's TURAS Vaccine Management Tool was introduced during the pandemic (NHS Education for Scotland, 2024^[93]), and Wales uses the Welsh Immunisation System, which integrates with GP records to provide detailed vaccination insights (Digital Health and Care Wales, 2024^[94]).

141. For respiratory disease surveillance, the Respiratory DataMart Sentinel System plays a pivotal role by collecting high-quality data from selected health sites. This system enables the UK Health Security Agency (UK HSA) to effectively monitor diseases such as influenza and COVID-19. The integration of these platforms supports early detection of outbreaks, informs targeted public health interventions, and enhances the overall responsiveness of the health system (UK Health Security Agency, 2024^[95]).

142. The UK is also advancing its data-sharing capabilities through the Big Rocks Transformation Program, which focuses on the adoption of API standards to improve data flows between health systems (UK Health Security Agency, 2025^[47]). This initiative enhances interoperability and facilitates real-time data exchange, supporting critical public health initiatives. In addition, the transition to the EDAP represents a significant step forward in unifying data-sharing agreements. By consolidating data-sharing into a single feed with NHS England, the UK reduces the administrative burden of negotiating individual agreements for each dataset. This approach accelerates access to critical health data while maintaining transparency, regulatory compliance, and a commitment to efficient health system operations (UK Health Security Agency, 2025^[47]).

Box 4. Linking multiple health-related datasets to increase public health emergencies' response

Despite Australia's robust health data infrastructure, no single system provides a complete picture of the epidemiology of COVID-19, influenza or respiratory syncytial virus (RSV). Understanding the dynamics of these acute respiratory infections requires integrating data from diverse sources, including community health settings, primary care, hospitals, laboratories, and notifiable disease datasets. This comprehensive approach enables the measurement of disease activity, severity and identification of at-risk populations (Australian Government, 2024^[96]).

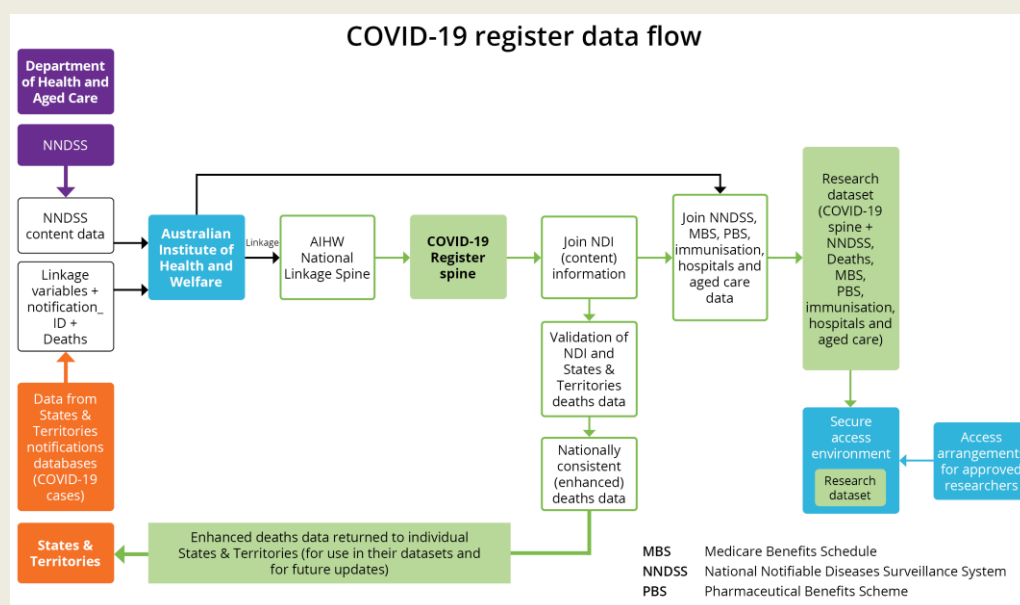
In response to the COVID-19 pandemic and associated timeliness challenges, the AIHW established a cross-jurisdictional COVID-19 Register in 2022. Funded with \$3 million AUD from the Medical Research Future Fund, this initiative leveraged existing health datasets to strengthen evidence-based public health and health system planning, improve management strategies for future pandemics, and enhance the quality of COVID-19 case data by returning linked data to state and territory custodians.

The project involved rigorous ethical approvals and alignment with jurisdictional requirements for data usage. Using probabilistic record linkage, personal identifiers such as name, sex, address and date of birth were linked with AIHW's linkage spine, including the National Death Index (NDI) and the Australian Immunisation Register (AIR). This approach combined COVID-19 case data from states and territories with information from the Australian NNDSS, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS, including the Repatriation PBS), National Hospitals Morbidity Database (NHMD), National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD), National Aged Care Data Clearinghouse (NACDC), National Disability Insurance Scheme (NDIS), Australian New Zealand Intensive Care Survey (ANZICS) Adult Patient Database (APD) and Australian and New Zealand Paediatric Intensive Care Registry (ANZPICR), creating a comprehensive de-identified research dataset.

The linked data was designed to enhance local notifiable disease systems by providing states and territories with updated information, including date and cause of death data from the NDI. While the COVID-19 Register has not yet impacted the Australian NNDSS, future improvements are expected through the development of the National Public Health Surveillance System, currently being scoped by the Australian CDC. This system will aim to improve the completeness and utility of national notifiable conditions data, facilitating faster and more effective data linkage for public health planning and response activities.

In the latest iteration of this project, seven out of eight jurisdictions provided data for linkage, achieving a total linkage rate of over 90%. To maximise value and efficiency, the AIHW research team is exploring advancements in data linkage technologies and aligning with emerging cloud-based platforms to improve data sharing, linking, and accessibility. The platform's interoperability ensures compatibility with existing national datasets, such as the Census, further enhancing its utility during public health emergencies.

Figure 9. COVID-19 register data flow



Source: (Australian Institute of Health and Welfare, 2024^[97])

Policy considerations

143. Across all interviews, it has been consistently observed that countries are actively advancing their health data architectures to enhance national and subnational data sharing, interoperability, and scalability. While these efforts are shaped by each country's governance context and technical infrastructure, a common trend is the adoption of open data-sharing principles underpinned by international standards such as HL7 FHIR, SNOMED CT, and ICD-10. These shared frameworks provide consistency and efficiency, though the maturity of implementation varies significantly across countries due to factors such as regional autonomy and the absence of unified national frameworks.

144. Federated nations such as **Canada** and **Australia** are working to align diverse regional systems with national frameworks to address fragmentation. Canada leverages initiatives like the Pan-Canadian Health Data Content Framework (PCHDCF) and its subset focused on bi-directional exchange the CACDI to standardise data elements and terminology. Similarly, Australia relies on systems such as the NNDSS and the Australian Immunisation Register (AIR) to promote interoperability, though cross-jurisdictional integration remains a challenge.

145. In contrast, the United Kingdom and New Zealand lead with more centralised approaches. New Zealand demonstrates best practices with its New Zealand Core Data for Interoperability (NZCDI), supported by integrated systems like the Aotearoa Immunisation Register (AIR) and EpiSurv, as well as the NHI, which enables seamless data integration and lifecycle management. The United Kingdom aligns its systems with global standards through initiatives like the NIMS, the Big Rocks Transformation Program, and the EDAP, providing a robust foundation for interoperability and scalability.

146. A shared priority across all countries is the development of transparent documentation for APIs, privacy and security protocols, and integration standards to support technical consistency. Countries like **New Zealand**, the **United Kingdom**, and **Canada** stand out for their comprehensive frameworks, which balance the need for integration with regional autonomy. These initiatives offer valuable lessons for federated nations like Australia where achieving seamless interoperability across diverse jurisdictions remains a more significant challenge.

Leading practices

147. During the interviews, there were two leading practices that were identified: (1) **establishing a common set of semantic health data standards** to enhance interoperability across health information systems and (2) **devise a comprehensive health data framework** with well-established data collection, integration, and security procedures, integrated in regional monitoring. The findings from the interviews, as aligned to leading practices are summarised below:

Table 12. Summary of data architecture practices across four OECD member countries

Country	Common set of integrated health data standards with incentives for public health use cases	Comprehensive health data framework for data collection, integration and security including regional monitoring
Australia	In development	In development
Canada	In development	In development
New Zealand	Yes	Yes
United Kingdom	Yes	In development

Source: Authors

Annex E. Technology

148. Technology infrastructure is a key enabler to the effective use of health data to enable evidence-based decision making. Each of the four OECD countries, Australia, Canada, New Zealand, and the United Kingdom, saw their public health technology infrastructure accelerate with the needs of the COVID-19 pandemic, often done by jumping past regulatory hurdles to meet the needs of the countries. As countries settle into the post-pandemic environment, the technologies which were deployed during COVID-19 are being reviewed and understood for the best approach moving forward. This section will examine the technical foundation for national immunisation and surveillance programs, including immunisation registers, notifiable disease surveillance systems, cyber security, open by design systems, application programming interfaces to enable the interoperable exchange of data, cloud, enterprise data platforms and relevant privacy, security, and technical standards to be put in place.

149. In all four OECD countries, different layers of technology exist between the national and regional levels, especially in countries with a federated model, where the states, territories, and/or provinces maintain control over their data but share it nationally for analysis and public health management. Each region has their own health legislation and approach to providing health services to its citizens, often with different systems, implementation of the same technologies, standards, and individual data sharing agreements with the federal level. This fragmentation leads to an increasing need for semantic interoperability, with consistent standards and data exchanges. In countries with an amalgamated model, or in the process of moving to an amalgamated model, this work remains, along with updating or retiring existing systems to create enterprise-wide solutions.

150. Reaching semantic interoperability faces several barriers, such as vendors blocking data from the electronic medical records (EMRs), EHRs, and public health immunisation and surveillance systems being implemented at regional and state levels. In this, OECD countries are introducing new legislation to ensure that vendors comply to set specifications of data standards and data sharing to deploy their systems within the countries and/or states. Without these legislation or direction from the national level, states will continue implementing fragmented vendor systems and introducing additional technical tools and expertise to reach semantic interoperability.

151. Digital health tools have been in use for decades such as immunisation registries and disease surveillance systems dating back to the 1990's. Legacy systems add an additional layer to the complicated technical ecosystem in use today. When these systems were first implemented, the focus was often on collecting data at a site, regional or state level, and not focused on sharing the data to provide a comprehensive health record outside of the intended site. The legacy systems often host data on-premises rather than cloud based, and as a result pose higher risks to maintaining data security.

152. Countries are at different stages of retiring and/or updating legacy systems to the current standards to enable the centralising of primary use data into enterprise data and analytics platforms, which subsequently enable the secondary use of health data after de-anonymisation and de-identification into separate secure research environments. As some OECD, such as the **United Kingdom**, amalgamate

their health service and technical infrastructures, legacy systems and the associated data are required to be transitioned to enable continuation of the records and reducing duplication of systems and data.

153. Another opportunity arising from this work is to understand the value proposition for future and ongoing investment in public digital health systems. With the COVID-19 pandemic, a huge influx of funding came to public health to provide timely tracking of diseases surveillance and immunisation tracking, but now countries are facing a challenge to demonstrate the long-term cost-benefits of maintaining such health information systems and introducing new technologies as technological innovations arise. For those countries needing to update their existing technical infrastructure, the value proposition needs to be made for the benefits of open-by design and scalable solutions which can easily integrate with the infrastructure and enable more timely and reliable sharing of public health data.

154. In public health surveillance and immunisation, the COVID-19 pandemic was an exceptional case which brought the focus of the whole world to vaccine rollouts, respiratory disease tracing, and hospital capacity, however the everyday business of public health focuses on the health of the population and preventive measures to prevent, detect, and respond to epidemic and pandemic level incidents. COVID-19 offered the opportunity for countries to reinforce the value of investment and maintenance of public health infrastructure, similarly to what the severe acute respiratory syndrome outbreak of 2003 offered to the **Canadian** public health system (Infection Prevention and Control Canada, 2024^[98]).

155. An essential piece of the public health technical infrastructure are frameworks and supportive measures to maintain the privacy and security of its data. Security measures are needed in the procurement, implementation, and maintenance of information technology system to ensure the data is secure. Key mitigation strategies, identified by **Australia's** Essential Eight principles for data security include the patching of applications and operating systems, multi-factor authentication, and limiting administrator privileges (Australian Signals Directorate, 2023^[99]). Responsibility for ensuring secure data also lies with the users of the data, so training on the safe handling and use of public health data is essential (UK Data Service, 2024^[43]). These principles have been brought into the procurement processes for new technologies in all the OECD countries, ensuring that privacy and security are built into any new solution.

156. To build towards a federated data architecture in public health and solutions which are scalable to the changing technology landscape in healthcare, open by design systems with cloud-based storage solutions and built in security and privacy frameworks are key. Countries are actively working to remove barriers, such as **Canada** who has been working on legislation to ensure vendors cannot block data from its clients, allowing public health systems to gain timely access to the data it needs to monitor, prevent, and report on public health crises (Government of Canada, 2024^[100]). These measures, along with transitioning from on-premises, local data storage to integrated data infrastructure with API are some examples of how countries can digitalise the technical infrastructure of their public health systems.

Table 13. Technology practices for digitalising public health system

Country	Use of cloud-based storage solutions for public health data infrastructure	Security and privacy standards for the transfer, access, and storage of public health data	Established procurement processes with privacy and security components	Scalability of public health solutions at a national/regional level	Use of open by design solutions with built-in interoperability, integration, and existing standards	Legislation to counteract vendor blocking which can limit the data sharing between systems
Australia	Yes	Yes	Yes	Yes	Yes	No
Canada	In development	Yes	Yes	In development	In development	No
New Zealand	Yes	Yes	Yes	Yes	Yes	No
United Kingdom	Yes	Yes	Yes	Yes	Yes	No

Source: Authors

157. The need for more integrated and scalable technical infrastructure has evolved for countries, as the need for more rapid and actionable data became apparent during the COVID-19 pandemic. Public health has evolved from an initial practice of deploying technologies at a local site or region level, to an interconnected and federated data architecture. Key components of this work are to enable open by design solutions with a foundation of data interoperability, data sharing, transparency, and accessibility from their inception. A number of key challenges are present which limit country's ability to move forward with this leading practice:

- There is a high degree of fragmentation in current public health technical infrastructures, especially in those with a federated model. For example, in **Canada** there are 53 surveillance systems with data sharing agreements for national reporting. Each region which provides health services has their own technical infrastructure in place to store and report on public health data. These systems are a mixture of on-premises locally implemented systems and cloud-based systems, with varies levels of integration to national public health reporting.
- In the fragmented nature of the system, data standards are frequently inconsistent between different regions, provinces, territories and/or states. With different understandings and representations of key data points, the integration of disparate data sources is a challenge.
- Software vendors attempt to block data leading to limiting or restricting interoperability and sharing of health data with other health systems.
- Countries strive to demonstrate the value proposition of continued investment in preventative-based technologies, but there is a lack of understanding of the cost-benefits of both procuring and operationally maintaining software solutions.

158. These challenges are being addressed through several co-ordinated actions as discussed in the following sections.

Transition to open by design systems with transparent, consistent data-sharing/storing guidelines

159. One key area of focus for countries is to have an infrastructure of technologies which can easily integrate with both new and existing solutions to support the timely and safe transfer of public health data. As demonstrated with COVID-19, when monitoring a public health event, having access to timely, quality, and accurate data is key to enable evidence-based decision making by public health leaders. This data can also aid in the tracking and implementation of preventive measures such as immunisations. Countries have all shown advances in implementing open by design systems with developments in cloud-based storage to enable a more resilient and scalable public health technology infrastructure, though with varying degrees of implementation.

160. The **United Kingdom** is setting a leading practice in the development of national data platforms, first with the federated data platform (FDP) which brings together all its operational day-to-day health data from the NHS and across the local NHS trusts to support more efficient and quality patient care (NHS England, 2024^[101]). This new initiative has already demonstrated some impact locally (Department of Health and Social Care, 2024^[102]). Under the direction of the UK HSA and its 2023 Data Strategy, the United Kingdom is also establishing a cloud-based EDAP to provide a common platform to integrate data for public health purposes (UK Health Security Agency, 2025^[47]). These platforms are pulling in data from multiple partners, including from across the NHS, and leading to a concurrent process to review the legacy on-premises data storage and registry systems in use to be either decommissioned or, if applicable, transitioned to the EDAP; this was well demonstrated by the decommissioning and transferring of

capabilities of three key COVID-19 data platforms post pandemic. The EDAP represents a leading practice in enhancing the accessibility and usability of public health data, enabling real-time analysis of data related to immunisations, disease outbreaks, and other public health threats, on the foundations of open by design and cloud principles (see Box 5). In addition, the United Kingdom has the NIMS which integrates with the EDAP, enabling the UK HSA to better monitor immunisation efforts across the country.

161. In the United Kingdom, a number of key supportive services, with the backing of an API and cloud first mentality, have been put in place to set the foundations for a transparent and consistent open by design system. In late 2024, the already piloted Application Programming Interface Management (APIM) system is targeted to be implemented to provide a central hub for integration for the United Kingdom NHS. The APIM system includes a catalogue of all APIs in use across the organisation, and support for the key standards if creating a new API. This information is also available to external partners and will enable the NHS to more easily integrate new solutions into the ecosystem. The Information Management and Privacy Division is responsible for setting metadata standards which are to be adopted by the whole organisation which is key foundational element to the EDAP. A core set of common standards, such as SNOMED CT and ICD-10 codes are also available, and to support developers within the NHS, data coding standards repositories and license are made available.

162. All countries are working towards a cloud-based infrastructure, with cloud first approaches and in some cases, specific cloud first policies. In **New Zealand** in 2023, the government updated the countries Cloud First policy which requires all government organisations to use cloud services for its information systems whenever possible and uniquely mentioned Māori data sovereignty and sustainability in the policy (New Zealand Government, 2024^[103]). The **United Kingdom**, which published a cloud first policy in 2013, approach focused on simplified procurement methods and **Australia** followed not long after with its policy in 2014 (GOV.UK, 2017^[104]) (Australian Government, 2014^[105]). The **United Kingdom** relies on a private cloud infrastructure in its health system to ensure that sensitive health data is protected. **Canada** includes a cloud first policy and being cloud smart in its Cloud Adoption Strategy (Government of Canada, 2023^[106]). A key policy for all countries is that data must reside within the countries boarder when using cloud. Cloud offers several benefits related to public health, including the security and timely availability of the data, reducing the risk of cyber security threats, and a reduction of operational resources required by the government to support ongoing database management if enlisting a provider like Amazon Web Service or Microsoft Azure for cloud services.

163. **New Zealand** has a big data transformation project underway to move data to Snowflake, which is a cloud-based data warehouse. The country also has a National Data Platform which integrates data from a number of sources to support public health analysis (Health New Zealand I Te Whatu Ora, 2024^[107]). It was noted the cloud offers a heightened level of cyber security and responded with the cloud first policy, as in the past, it was the on-premise system which were compromised from cyber security attacks (New Zealand Government, 2024^[103]). The country has also set the foundations for transparent and openly designed systems with the Hira programme, which as of June 2024 set up the building blocks for digital health services in New Zealand, with the Health New Zealand Digital Services Hub which supports developers to create and securely implement APIs following a set of standards, including those for the Aotearoa Immunisation Register, and the New Zealand Health Terminology Service (NZHTS) (Health New Zealand I Te Whatu Ora, 2024^[108]). Health New Zealand also published the minimum requirements for health care organisation to meet for digital solutions which are updated annually, including key areas like cyber security, and APIs (Health New Zealand I Te Whatu Ora, 2024^[109]).

164. **Australia** uses a federated data model that allows state and territory health departments to maintain local data sovereignty while sharing it nationally for analysis and public health management, which allows for cross-jurisdictional collaboration. One example of this is the Real-Time Prescription Monitoring (RTPM) system, a national initiative that enables real-time access to prescription data for healthcare providers, including medical practitioners and pharmacists to prevent prescription misuse and

improve patient safety (Department of Health and Aged Care, 2024^[110]). In terms of cloud systems, the Australian Department of Health and Aged Care has adopted cloud platforms (such as Microsoft Azure) to securely store, manage, exchange and process the data in real-time from the AIR, the NNDSS and the My Health Record, improving data accessibility across healthcare providers (Department of Health and Aged Care, 2024^[111]), (Services Australia, 2024^[76]), (Australian Digital Health Agency, 2024^[112]). A key differentiation for Australia is that data needs to be stored within the country, in compliance with data privacy laws and security standards (Australian Digital Health Agency, 2020^[113]).

165. **Canada**, also a federated country, has seen much of its healthcare infrastructure developed locally within their 13 jurisdictions (ten provinces and three territories) and federal health service organisations (Correctional Service Canada, Canadian Armed Forces, Indigenous Services Canada, Royal Canadian Mounted Police, and Global Affairs Canada). One such technology is Panorama Software which aimed to enable national collection and analysis for public health surveillance and management system developed as a response to the SARS epidemic in 2003. This software is in use across 8 of the 13 jurisdictions in Canada, but with some variance in functionality across jurisdictions and data standards. Through the Pan-Canadian Interoperability Roadmap, the Canadian Institute for Health Information and Canada Health Infoway are collaborating to develop a common data content framework, exchange standards, and a unified architecture to support health data exchange across Canada (CIHI, 2024^[114]). These set the foundations for open by design systems, but Canada still has considerable work to do.

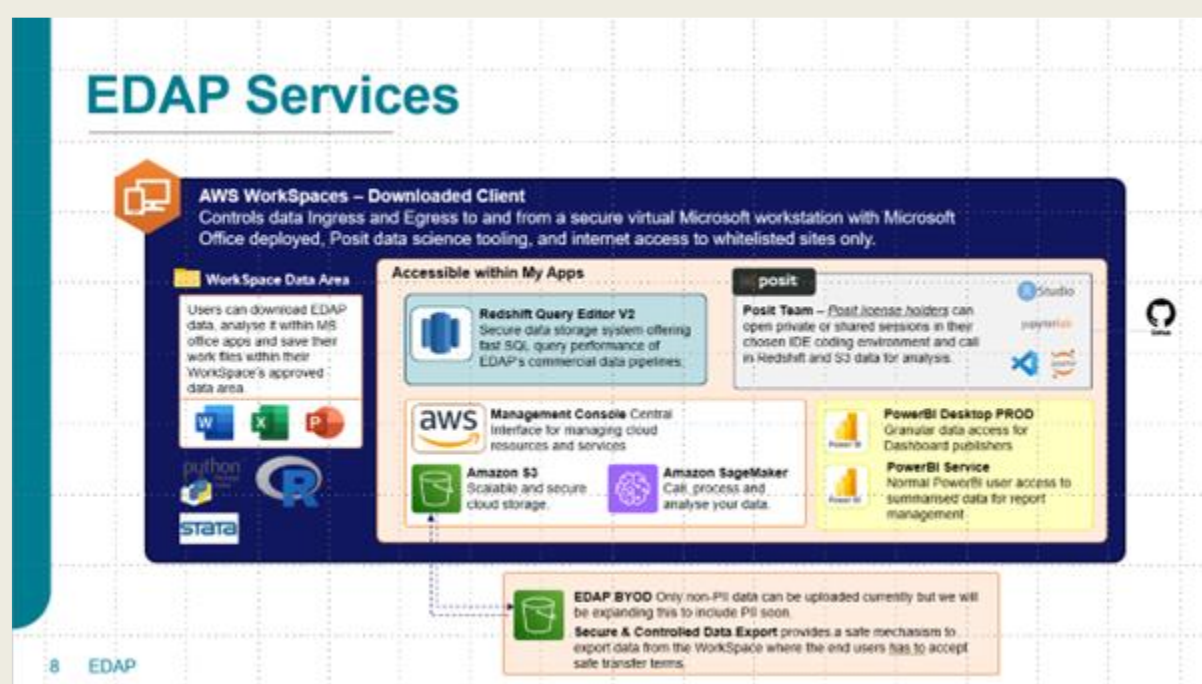
166. There are 64 surveillance systems which require data sharing agreements to contribute to national reporting, and this data often is delayed. The data originates from fragmented Health Information Systems used across jurisdictions. There is federal direction to cloud-based platforms in Canada, but this work is done on a jurisdictional and regional level.

167. Regarding immunisation surveillance, the Public Health Agency of Canada collaborates with provinces and territories on the Standardised Reporting on Immunisation (STARVAX) initiative. STARVAX is a system designed to collect standardised vaccination reports from the provinces and territories. Each jurisdiction uses its own immunisation registry to produce these reports, which are then submitted to STARVAX for national monitoring purposes. Participation in STARVAX varies, as not all jurisdictions currently contribute to the system (Government of Canada, 2024^[115]). While there are many challenges, Canada is proactively working on policies and national health data sharing and interoperability strategies. This includes efforts related to Bill C-72, which although aimed at setting standards for interoperability and preventing health technology vendors from blocking data being produced by their systems from healthcare providers, has not yet been passed due to the prorogation of Parliament (Government of Canada, 2024^[100]).

Box 5. United Kingdom enterprise data and analytics platform

In the United Kingdom, in response to the need to consolidate various data platforms, including those for COVID-19, the UK Health Security Agency (UK HSA) developed a data strategy (UK Health Security Agency, 2025^[47]). Central to this strategy is the creation of the Enterprise Data and Analytics Platform (EDAP), which serves as the central repository for health data. The EDAP integrates multiple data sources, including the National Immunisation Management service, and is intended to support real-time analysis of critical information such as vaccination coverage and disease outbreaks. It is designed to standardise data transfer and exchange processes, enabling public health decision-makers to manage large volumes of data efficiently during emergencies, such as pandemics or seasonal flu outbreaks. The platform is scalable, allowing rapid responses during high-volume periods, and aims to enhance the use of AI and predictive analytics to anticipate disease spread and adjust vaccination strategies. By providing centralised access to key health data, the EDAP exemplifies a leading practice in integrating data to support quicker, more informed responses to health threats. Full functionality is expected to be operational by later in 2025, enabling public health authorities to effectively manage vaccination campaigns and track infectious diseases.

Figure 10. UK Health Security Agency Enterprise Data and Analytics Platform applications and services



Source: (UK Health Security Agency, 2025^[47])

Regular assessment of security and privacy standards with links to adherence to leading practices

168. In developing an integrated technical infrastructure for public health, a key consideration is how to maintain the privacy and security of the information as it is stored and exchanged across jurisdictions. When operationally maintaining, procuring, and deploying new technologies, it is key to have cyber security and privacy standards embedded into each step of the process. The industry has transitioned from security by design to a focus on cyber security, as the technical infrastructures for countries have evolved from on-premises locally sourced solutions to the use of cloud and health information exchanges. Cyber security has become a priority, with all countries facing frequent threats and attempted breaches of their health data infrastructure. To reinforce security principles, all countries have developed privacy and security frameworks to support their jurisdictions in the proper handling of health data.

169. In the **United Kingdom**, security standards and frameworks are in place and internal agencies, such as the Technical Assurance and Compliance Board, are responsible for insuring digital tools meet the necessary privacy and security standards prior to implementation (Central Digital and Data Office, 2024^[116]). A key standard organisations adhere to is the ISO 27001 to ensure the digital health technologies in use comply with international information security standards (GOV.UK, 2022^[117]). NHS Digital also offers cyber security services, assistance, and frameworks, such as the Cyber Assessment Framework aligned Data Security and Protection Toolkit (DSPT) across the NHS and social care (NHS Digital, 2024^[118]). These supports align with the recommendations from the 2023 policy paper on how to build cyber resilient health (GOV.UK, 2023^[119]). Additionally, the five safes framework sets the best practices for maintaining data protection while using health data for research, allowing data to be safely accessed for secondary purposes (UK Data Service, 2024^[43]). Building on the EDAP, the United Kingdom is also setting up EDAPxX, a secure data environment following the Five Safes principles for secure intergovernmental collaboration on public health data, all with the foundations of security.

170. Cyber security and maintaining data privacy are key issues for **New Zealand**, and after some significant ransomware attacks in 2021, the country established the Cyber Security Uplift Programme in 2022 (Health Informatics New Zealand, 2024^[120]). This work is closely tied to the Cloud First Policy, due to the security risks of on-premises infrastructure (New Zealand Government, 2023^[121]). As part of this programme, the HISO published an updated Health Information Security Framework. The framework provides a common set of standards to enable a more interconnected and secure health system including regular assessments and security testing. The key principles addressed in the framework are to plan, identify, protect, detect, and respond to any cyber security incident and guide health organisation on how to do so (Health New Zealand I Te Whatu Ora, 2022^[122]). The security of health information is also protected by legislation, including the Privacy Act 2020, the Health Information Privacy Code 2020, and the Health Act of 1956 (Health New Zealand I Te Whatu Ora, 2024^[123]). New Zealand also has established data sharing processes with Privacy Impact Assessments (PIA) and Information Sharing Agreements (ISA), as per the New Zealand Privacy Act (New Zealand Legislation, 2024^[124]).

171. In **Australia**, the nationally recognised Information Security Manual (ISM) provides a cyber security framework that organisations can apply to manage risk and protect their technical infrastructure from cyber security threats (Australian Signals Directorate, 2024^[125]). To support risk mitigation across organisations using information technology, the Australian Signals Directorate also published the Essential Eight: patch applications, patch operating systems, multi-factor authentication, restrict administrative privileges, application control, restrict Microsoft Office macros, user application hardening, and regular backups (Australian Signals Directorate, 2023^[99]). In addition to supportive frameworks, there are legislative and technical assessments in place to ensure data is accessed, transferred and stored securely, such as the annual reporting on physical and cyber security using the Protective Security Policy Framework (Department of Home Affairs, 2024^[126]). It is also ensured that public health data is stored within Australia and sensitive information, such as that concerning public health, is only accessed by Australian citizens. Furthermore, Australia applies the Five Safes Framework across its National Statistical Agencies, including the AIHW and the Australian Bureau of Statistics (ABS). This framework ensures secure management of linked health data, balancing data privacy, access, and protection while enabling

responsible data use for statistical and research purposes (Australian Institute of Health and Welfare, 2023^[127]).

172. In **Canada**, the Personal Information Protection and Electronic Documents Act (PIPEDA) governs how private-sector organisations collect, use, and disclose personal information in the course of for-profit, commercial activities across Canada (Government of Canada, 2024^[128]). Additionally, the Privacy Act regulates how the federal government collects, uses, and discloses personal information when providing public services. It applies to all personal information handled by federal government institutions. Each province and territory have its own health information legislation to govern the handling of personal health data. The Canadian Institute for Health Information (CIHI), which collects public health data for secondary use, maintains the ISO 27001 certification, conducts regular audits and has an established Information Security Policy, which reflects common practices for organisations handling health data in Canada (CIHI, 2024^[129]). The Canadian government has also taken legislative action with proposing bill C-26, an act focused on cyber security and preventing cyber-attacks (House Government Bill, 2021^[130]). However, the bill was not passed into law due to the prorogation of the Parliament in January 2025.

Box 6. New Zealand cyber security uplift and health information security framework

In 2022, in response to significant ransomware attacks, the **New Zealand** Government reinforced its focus on Cyber Security. These efforts included a significant focus on cyber security in health, with \$75 million allocated to improving the existing technical infrastructure, establishing new security standards, and, building on the cloud first policy with a cyber security focus, and improving the testing and risk management processes (Health Informatics New Zealand, 2022^[131]). These focuses were developed in response to the weaknesses identified in the current infrastructure, such as the use of on-premises rather than cloud solutions.

Working within the Cyber Security Uplift, the HISO, which sets the standards for the secure, safe, and equitable use of health information in New Zealand, updated its Health Information Security Framework. The HISO 10029 framework was updated in 2022 to set new security requirements, and in 2023 to provide detailed guidelines for suppliers of services and new technical solutions (Health New Zealand I Te Whatu Ora, 2022^[122]). The goals of the framework and its associated strategy for 2023-2024 are to: improve the security of New Zealand's health information, enable improved data sharing, and build the trust in the health systems ability to maintain the privacy and security of health information (Health New Zealand I Te Whatu Ora, 2022^[122]). Within the framework, five key functional processes were defined (see Figure 11, which provided the foundation for the detailed guidelines suppliers must follow. These comprehensive, and transparent practices offer a best practice of ensuring the security of public health information is maintained and to maintain the trust of the general public in the security of their personal information.

Figure 11. HISO 10029 health information security functional processes

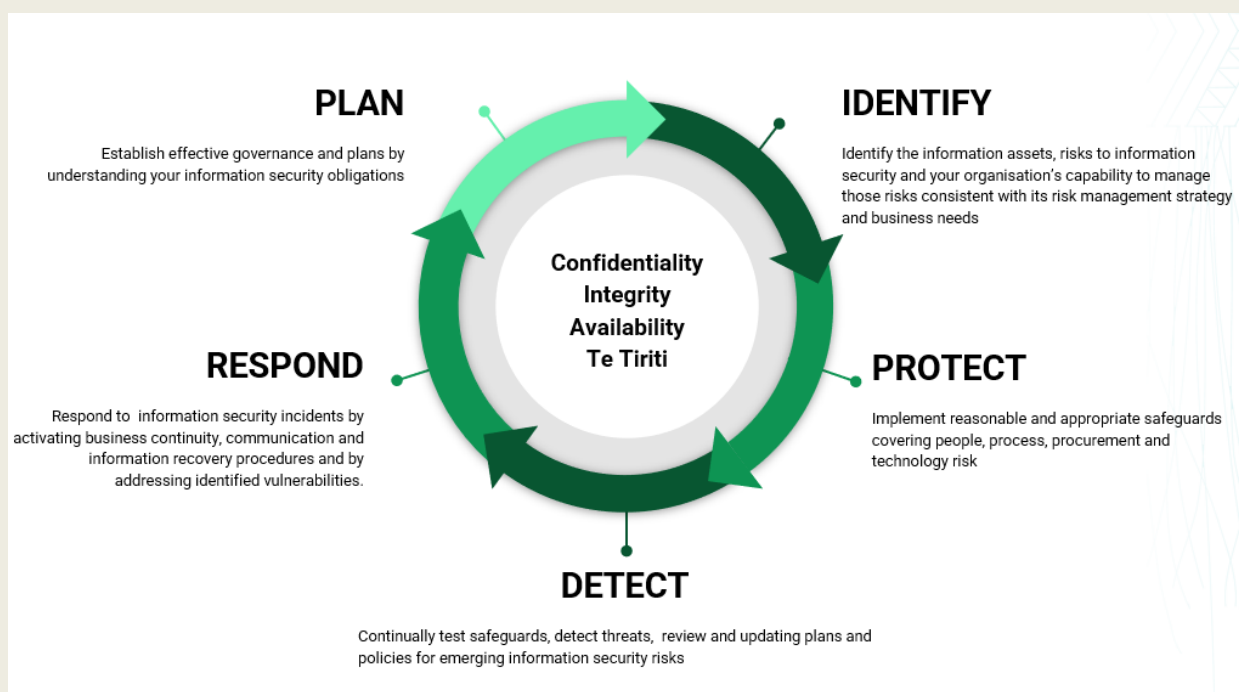
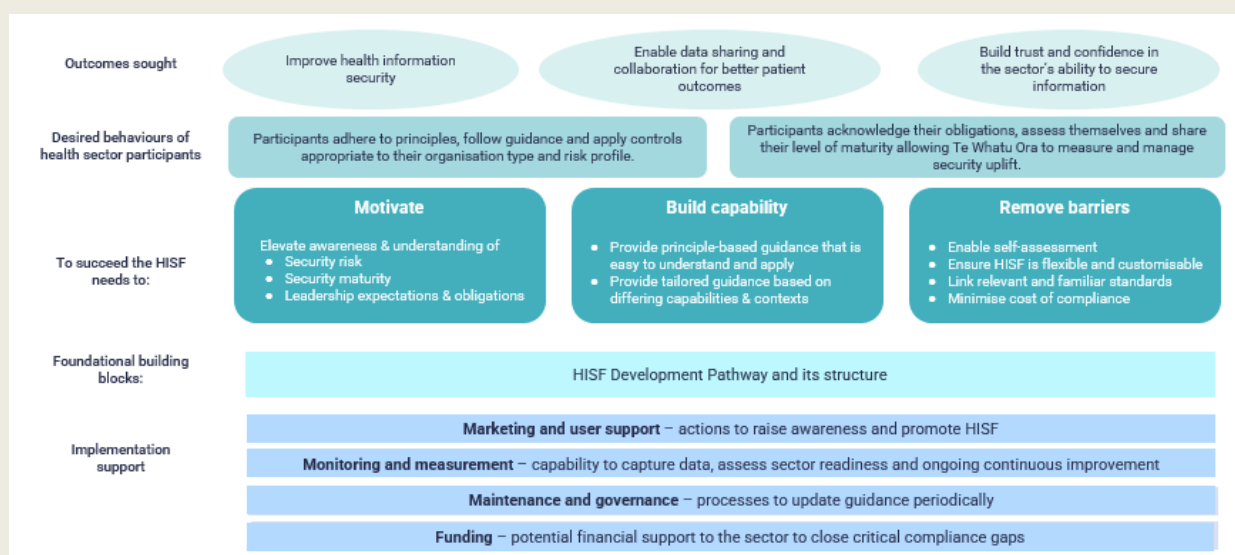


Figure 12. HISO 10029 health information security framework strategy



Source: (Health New Zealand | Te Whatu Ora, 2022^[122])

Procurement and scalable solutions

173. A key procedure to include privacy and security protocols in the development of a technical infrastructure is through the procurement process. Procurement, which is the process where a country and/or organisation procures goods or services from a third party, is a key process within public health organisations to introduce new technologies (OECD, 2025^[132]). Developing standard practices and engrained protocols into the procurement process can enable more scalable systems that meet long term needs and potentially reducing duplication and waste. Engaging with key privacy and security stakeholders within the organisation, along with requiring certain standards and API capabilities sets countries up to have transparent and secure open by design solutions. The financial framework is also a key component of procurement processes, which provide an opportunity for countries to build in cost benefit analysis frameworks when evaluating proponents. Each of the four OECD have established procurement processes for procuring new technology solutions with various levels of standards tied to scalability and at different levels of government.

174. In **Canada**, procurement is often done at the jurisdictional level. However Canada Health Infoway is setting up a national conformance service as part of the pan-Canadian Interoperability Roadmap, including the testing and validation vendors are required to conform to and meet the standards (Canada Health Infoway, 2024^[133]), (Canada Health Infoway, 2023^[134]). In addition, it is also developing national guidelines for security, cybersecurity, and data exchange requirements for digital health solutions vendors. In specific areas such as AI scribes, it is also leading efforts to quality vendors at a pan-Canadian level to support primary care providers in selecting appropriate solutions.

175. This is a key step to address the fragmented nature of public health technology procurement, where the provinces and territories develop their own requirements and criteria for choosing a proponent

(Competition Bureau Canada, 2022^[135]). In Canada, procurement cycles are lengthy, where vendors respond to a Request for Proposals with their ability to meet the needs and criteria dictated by the requesting organisation and the response is evaluated, often with key elements of privacy and security along with functionality. To support the scalability and utility of procured systems, Canada worked to introduce Bill C-72 which prevents vendors from blocking any data from the purchasing organisation (Government of Canada, 2024^[100]). However, the bill has not passed due to the Prorogation. In general, national efforts are trying to support the fragmented procurement system in Canada to develop more scalable solutions which can integrate to a common dataset nationally.

176. On a governmental level in **New Zealand**, a new digital procurement programme was introduced in 2021 to support more open understanding of what solutions have been procured with a procurement catalogue system, and share common capabilities with potential buyers (New Zealand Government Procurement, 2021^[136]). Additionally, New Zealand's Government Procurement Rules ensure scalable, privacy-conscious, and secure procurement in new solutions, enabling the selection of innovative, equitable, and resilient healthcare solutions (New Zealand Government Procurement, 2024^[137]). Focused solely on Digital Health, the Hira Programme connects health information across the country and provides core frameworks to support the procurement of new solutions (Health New Zealand I Te Whatu Ora, 2024^[108]). The Hira program is part of the 2023 New Zealand Health Strategy, which prioritised implementing existing technologies at scale to develop a more resilient and sustainable health system (New Zealand Government, 2023^[138])

177. In the **United Kingdom**, there are national foundations for procurement standards, which focus on scalability, usability, and transparent open by design systems. The Government Digital Service (GDS) sets the standard for the procurement of digital services and technology across the public sector, including healthcare (Government Digital Service, 2024^[139]). The GDS design principles set the standards of which vendors must meet in terms of security, usability and interoperability (Government Digital Service, 2024^[140]). Public health systems, such as health surveillance systems procured by the UK HSA and the NIMS must comply with the GDS standards to meet the requirements for secure data handling and sharing, as well as user needs. The Technical Assurance and Compliance Board oversees the compliance of digital projects, including public health systems, ensuring that they meet technical, security, and privacy standards before being implemented. This board conducts technical audits, reviews project designs, and ensures that procurement aligns with national and international standards (such as ISO 27001) (Central Digital and Data Office, 2024^[116]). The United Kingdom has a long-term procurement plan focused on longevity, sustainability, and portability of digital solutions with a foundation of enterprise and data architecture principles to ensure data portability and scalability.

178. In **Australia**, the Digital and ICT (Information and Communications Technology) Investment Oversight Framework (IOF) provides a comprehensive approach for managing digital and ICT-enabled investments across federal government agencies, including the Department of Health and Aged Care (Australian Government, 2025^[141]). This framework, encompassing six key stages, ensures that digital health solutions including cloud-based systems and digital tools comply with national security standards during procurement and implementation. These arrangements ensure that digital health solutions, such as cloud-based systems and digital tools, comply with national security standards during the procurement process including the ISO27001 standard, data encryption, access controls, and audit logs (Department of Health and Aged Care, 2024^[142]). During procurement, vendors must demonstrate that data centres used for storing or processing sensitive health data comply with Australian laws and data localisation requirements and that their technologies have sufficient cybersecurity maturity including end-to-end security (Australian Signals Directorate, 2024^[143]). When procuring cloud services (e.g., for AIR and My Health Record and the future National Public Health Surveillance System), the Department of Health and Aged Care with support and advice from the Digital Transformation Agency ensures that providers meet the security standards set, guaranteeing the protection of sensitive data during storage and transmission (Department of Health and Aged Care, 2024^[142]). The Digital Transformation Agency (DTA) collaborates

with agencies to provide strategic advice, ensuring that digital investments align with government objectives and comply with the IOF's security and procurement guidelines. This collaborative approach guarantees the protection of sensitive data during storage and transmission, fostering the responsible integration of digital technologies into Australia's health sector (Australian Government, 2025^[144]).

Box 7. Canada legislation: Interoperability and prohibiting data blocking

In **Canada**, patients and healthcare providers face challenges in accessing, using, and exchanging quality data due to fragmented health information systems, such as electronic health records and medical records. There are no legal bases for vendors to comply to data standards that would improve interoperability, and data blocking, where information is prevented from being accessed or exchanged even when privacy legislation allows for it, remains an issue. One of the way the federal government moved to response to respond to these concerns and improve interoperability by accelerating the implementation of data standards was with the proposed federal legislation.

In June 2024, the Connected Care for Canadians Act (former Bill C-72) was introduced to the Canadian House of Commons. This bill aimed to ensure interoperability by requiring vendors to meet established standards and prohibiting data blocking. Under C-72, vendors would have been prevented from obstructing or interfering with the access, use, or exchange of electronic health information stored within their platforms.

Although the bill did not advance further in the parliamentary process, its tabling remains an influential step toward developing an integrated data infrastructure in Canada.

Source: (Government of Canada, 2024^[100])

Policy Considerations

179. The interviews with the four OECD countries demonstrate varied steps towards the adoption of a federated data architecture which is open by design, scalable, and supports privacy and security measures. These variations stem from the nature of each countries health systems, with differing levels of federal authority over the practices of their jurisdictions. Leading practices have emerged to reach a federated data architecture, including the use of cloud first and cloud smart policies, a focus on the scalability and compliance with privacy and safety during procurement, and an open infrastructure for application programming interfaces. Some countries, such as **Canada** and **Australia**, face challenges with the regional data integration to a common national platform due to the structure of their respective health systems. The **United Kingdom** and **New Zealand** are leading the way with ongoing development of cloud based national data platforms and clear standards for integration with the national technical infrastructure. All countries demonstrate national procurement recommendations which encompass privacy and cyber security criteria, however in federated countries these practices are often left to the jurisdictions to action, and accountability is difficult to enforce.

180. Preparing transparent documentation on standards, privacy and security requirements, APIs and integration approaches set public health systems up the future integration into a federated data architecture. All of the four OECD countries have adopted some level of scalable and open by design practices, though at different states of maturity. **Canada** is leading the way in its recent efforts to legislate vendors to be compliant with standards with the recent legislation prohibiting vendor data blocking and also provides technical assistance for its jurisdiction when procuring new technology solutions. All

countries have national practices to set transparent national data standards, though some are further along with establishing a unified framework for the country. The **United Kingdom** and **New Zealand** are leading the way with extensive national health information standards, application programming interfaces, and privacy and security.

Leading Practices

181. Throughout the interviews, two leading practices were identified to support the technical infrastructure requirements for the digitalisation of public health systems: (1) develop **cost-benefit analysis framework** of existing software solutions to ensure their adaptability and scalability to evolving public health needs (immunisations and surveillance) and (2) foster the adoption of **federated data architecture** across (large) organisations that enable local data collection, regional data integration, and both national and regional data use. The findings from the interviews, as aligned to leading practices are summarised below:

Table 14. Summary of technology practices across four OECD member countries

Country	Establishment of a national federated data architecture	Cost-benefit analysis framework and strategy for public health technical infrastructure
Australia	In development	In development
Canada	No	In development
New Zealand	In development	Yes
United Kingdom	Yes	Yes

Source: Authors

Annex F. Co-creation of digital public health

182. Co-creation with the public, jurisdictions, and stakeholders is an emerging trend in public health strategies, particularly in immunisation and respiratory disease surveillance. Diseases such as influenza, COVID-19, and respiratory syncytial virus (RSV) disproportionately impact communities facing marginalised conditions, highlighting the need to address these disparities to achieve universal healthcare goals. Co-creation of public health strategies understand stakeholders' perspectives on the use and protection of their health data to enable the collection, analysis, and reporting of sociodemographic and health-related data to identify gaps and inform targeted interventions. By implementing culturally sensitive measures and optimising data management processes, these efforts strive to ensure that 'no one is left behind'.

183. This section explores how digitalised health infrastructure supports co-creation of DPH by enhancing the entire data lifecycle. Digital communication channels play a critical role in fostering a shared understanding of how health data is used for public health purposes, while collaborative frameworks emphasise people-centered policies. In addition, initiatives aimed at co-creating health data policies, with a focus on data sovereignty, are helping to address the unique needs of specific national contexts.

184. Comprehensive data collection remains a fundamental enabler for developing health policies (Oderkirk, 2021^[145]). This is particularly important in settings where there is a deep-seated lack of trust in public institutions due to historical instances of systemic data misuse and exclusion. In many cases, these issues are legacies of colonialism that have disproportionality harmed Indigenous populations and other marginalised communities. Increasingly, countries are collecting data not only to better understand the health outcomes of marginalised and Indigenous populations but also to design policies that actively include them in national health programs. Incorporating variables such as Indigenous status, gender, and socioeconomic factors enriches the understanding of diverse healthcare needs. The pandemic underscored the effects of misinformation and mistrust, which often resulted in poorer health outcomes (OECD, 2024^[146]).

185. Building and maintaining public trust is critical when using health data for secondary purposes, such as research, policy development, and public health monitoring. Fostering public acceptance of these uses requires transparency, accountability, and active engagement (Muller et al., 2021^[147]). Clear, transparent, and active communication about data collection, storage, and use, combined with robust privacy and security safeguards, helps reassure the public. Involving local communities in decision-making processes ensures their voices, values and approaches shape data governance policies. In addition, demonstrating the tangible benefits of health data use, such as improved health outcomes, strengthens trust over time.

186. Effectively sharing health information with underserved communities is equally vital. Many groups facing marginalised conditions face barriers to understanding the importance of immunisation and disease

tracking, often leading to worse health outcomes for those communities. To address this, countries are investing in culturally tailored information-sharing campaigns through both digital and traditional channels. Collaborating with local stakeholders further strengthens these efforts, as their established trust and relationships within communities by bridge gaps between local needs and national public health strategies.

187. Reliable connectivity to digital healthcare infrastructure facilitates the use of tools like EHRs systems, which are essential to integrated healthcare systems. Addressing regional disparities in digital infrastructure is crucial to ensuring that all communities benefit from advancements in health technology and are fully integrated into a unified, data-driven public health framework.

Table 15. Co-creation within national public health programs across four OECD members

Country	Strategies to address existing gaps in public health data collection and reporting	Strategies to increase health data literacy	Communication channels to promote and share common understanding of data use for public health purposes	Strategies to engage with hard-to-reach communities and actively include them into the co-creation of health data policies
Australia	In development	Yes	In development	Yes
Canada	In development	Yes	In development	In development
New Zealand	In development	Yes	In development	Yes
United Kingdom	In development	Yes	Yes	Yes

Source: Authors

188. Across the four OECD member states, countries are increasingly integrating fairness objectives into their national healthcare plans, recognising the opportunity to address disparities that were starkly exposed during the COVID-19 pandemic (OECD, 2023^[1]). Individuals living in marginalised conditions faced significantly worse health outcomes, including lower vaccination rates and higher disease prevalence, compounded by gaps in the availability and quality of data, which hindered a nuanced understanding of local conditions (Reitsma, Goldhaber-Fiebert and Salomon, 2021^[148]). In response, countries are advancing health policies aimed at bridging gaps in health coverage, access, and literacy for underserved communities. However, despite countries' efforts in actively co-creating public health programmes, experts highlighted common challenges throughout the interviews:

- Key variables, such as Indigenous status and health information, are frequently omitted, and data on asylum seekers or institutional populations (e.g., prisons) is underrepresented. These issues are exacerbated by the absence of culturally and linguistically sensitive data collection methods, which fail to adequately inform targeted groups about the purpose and benefits of providing their data.
- A historical context of mistrust and systematic discrimination, deeply rooted in the legacies of colonialism in certain communities, complicates efforts to accurately report disease trends and vaccination status. This mistrust often results in reluctance to share health data, hindering informed decision-making based on comprehensive and reliable datasets.
- While digital communication and data-sharing campaigns are evolving, hard-to-reach communities face digital literacy gaps. These gaps underscore the importance of continuing to use traditional channels to ensure that information about the tangible benefits of data collection and its impact in improving public health outcomes is effectively communicated.

189. In response to these shortcomings, countries are developing targeted measures to improve the health data lifecycle, with a focus on actively engaging Indigenous populations and communities living in marginalised conditions. Efforts include standardising data collection processes by incorporating critical

variables, such as Indigenous status, during healthcare encounters to ensure accurate reporting for targeted public health measures. This approach aims to enhance the reliability and quality of health data while ensuring transparency about the secondary use of data for public health purposes. In addition, by raising public awareness of their rights and fostering transparency, these initiatives aim to build social license and trust, ultimately contributing to more effective healthcare systems.

Active inclusion of Indigenous peoples and communities living in marginalised conditions in the co-creation of health data policies to foster social license

190. A key piece to implementing digital solutions in public health is actively engaging and partnering with local communities to foster social license. This can be in the form of targeted information or data sharing campaigns to improve trust and decrease potential misinformation of (historically) marginalised communities to improve individual and population health outcomes. Countries can also reach out to the local communities to understand how best to support their needs and provide public health services in a way which is easily understood. All OECD countries interviewed have made efforts, though with some variation in approach, to reach their marginalised communities.

191. **New Zealand** is actively working to address the needs of its hard-to-reach populations, particularly the Māori, through inclusive policies and initiatives that prioritise co-creation and foster social license. Central to these efforts has been the of Te Mana Raraunga, the Māori Data Sovereignty Network, to protect Māori interests in data governance and promoting the ethical use of health data while respecting Māori values (Te Mana Raraunga, 2024^[149]). The Whakamaua Māori Health Action Plan 2020–2025 further advances this mission by setting a clear framework for achieving equity and focusing on the holistic wellbeing of Māori whānau (families), with plans to update this plan after the Disestablishment of the Māori Health Authority (Ministry of Health, 2020^[150]), (Ministry of Health, 2024^[151]). The disestablishment of the Māori Health Authority in February 2024 highlighted the need for unified governance with the active integration of marginalised communities, to best serve the population's needs (Ministry of Health, 2024^[151]).

192. Health New Zealand is dedicated to advancing health equity by ensuring access to high-quality, fair, and inclusive care for all individuals, underpinned by strong partnerships to address local health needs (Health New Zealand I Te Whatu Ora, 2024^[152]). In alignment with this commitment, Iwi Māori Partnership Boards were established in 2022 to promote equitable health outcomes and address the unique needs of Māori communities (Health New Zealand I Te Whatu Ora, 2024^[153]). A notable initiative in this effort is the Zero Data Policy, which eliminates data charges for accessing vaccine information and test results, thereby reducing income-based inequities in healthcare access (Health New Zealand I Te Whatu Ora, 2024^[154]).

193. In the **United Kingdom**, the Office for Health Improvement and Disparities (OHID) was created in 2021 to lead national efforts to improve public health. With the OHID and the NHS there are a number of ongoing initiatives to foster social license in hard-to reach communities. The Community Champions Programme works with local organisations and community members to engage underserved populations and aim to reduce their barriers to the use of services, such as vaccinations (Office for Health Improvement & Disparities, 2022^[155]). The Immunisation Inequalities Strategy focused on utilising community outreach and local partnership to reduce inequalities in vaccine uptake, specifically in hard-to-reach communities with lower vaccination rates such as Black, Asian, and minority ethnic (BAME) and individuals with lower income (Public Health England, 2021^[156]).

194. In the post-pandemic era, the UK HSA has launched a targeted marketing campaign to improve child vaccination rates, to reverse the concerning decline in childhood vaccination uptake in certain local communities (UK Health Security Agency, 2024^[157]). The UK HSA is also in the process of developing an Accessibility and Translation Policy to ensure that public health communications are accessible to

everyone. For national actions, the NHS developed a framework for action on inclusion of health in 2023 to ensure that vulnerable and hard-to-reach populations have equitable access to health services through targeted vaccination campaigns, immunisation programs, and diseases surveillance (NHS England, 2023^[158]). In addition, statutory guidance for Integrated Care Boards and NHS trusts promotes meaningful community involvement in decision-making processes. These initiatives collectively aim to reduce health disparities, improve trust, and ensure healthcare policies and practices are inclusive and community driven.

195. In **Australia**, partnerships are being developed to support Indigenous data sovereignty and self-determination, including through the National Indigenous Australians Agency (NIAA) to ensure that data is accessible to Indigenous communities for their own use at each stage of the data lifecycle. Through the Framework for Governance of Indigenous Data, Aboriginal and Torres Strait Islander communities are empowered to determine how their health data is collected, stored, and used, with the goal of reducing disparities in health outcomes by ensuring that data management aligns with their aspirations and priorities (Commonwealth of Australia, 2024^[159]). A key organisation in these efforts is the National Association of Aboriginal and Torres Strait Islander Health Workers and Practitioners (NAATSIHWP), which aims to promote Indigenous health equity through data governance and cultural respect to inform tailored public health intervention (NAATSIHWP, 2024^[160]). Also embedded in the way Australia approaches public health, and the responsible use of health data is a social license framework. In this, there is an acknowledgement that community consent is integral, particularly for marginalised groups and to ensure that health data is used for public good in a way that aligns with community expectations and respects cultural norms (Australian Institute of Health and Welfare, 2023^[127]).

196. The Transformational Approach to Indigenous Data Sovereignty is a framework that redefines the control, governance, and use of data concerning Indigenous Peoples in **Canada**. This approach and its implementation align with First Nations, Inuit and Métis Nations (FNIM) cultural values, priorities, and aspirations. It emphasizes reclaiming data governance through the creation of policies, laws, and frameworks that reflect Indigenous governance structures and self-determination. By centering Indigenous worldviews, this approach prioritizes traditional knowledge systems and cultural values, moving away from Western-centric frameworks that have historically marginalised Indigenous voices.

197. A key focus of this approach is capacity building within FNIM communities, ensuring they have the skills, infrastructure, and resources to manage and utilize data effectively. It advocates for using data to serve the collective well-being of Indigenous communities, supporting sustainable development, cultural preservation, and improved social outcomes. Ethical practices and accountability are also essential, emphasizing transparency and compliance with Indigenous laws, protocols, and agreements. Collaborative partnerships are encouraged, where Indigenous nations lead or co-design initiatives with governments, academic institutions, and organisations, ensuring mutual respect and recognition of Indigenous sovereignty. As part of this commitment, the province of British Columbia passed landmark legislation, the Declaration on the Rights of Indigenous Peoples Act (DRIPA), which establishes a legal framework for aligning provincial laws with the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). While DRIPA enshrines UNDRIP principles into provincial law, its implementation requires ongoing collaboration to ensure meaningful action and systemic change of the foundational digital infrastructure (Government of British Columbia, 2024^[161]), (United Nations, 2007^[162]).

198. The Transformational Approach also seeks to address systemic inequities by challenging and transforming existing data systems that perpetuate colonial practices. This involves creating equitable and inclusive data ecosystems that empower Indigenous communities. In alignment with these efforts, national equity-related initiatives such as the Engagement Governance, Access and Protection (EGAP) framework for Black communities and the development of national data standards, such as the inclusion of racialised group classification, are being advanced to measure inclusive, representative data practices across Canada (Black Health Equity Working Group, 2021^[163]). By embracing this approach, Indigenous and

Black data sovereignty becomes a powerful tool for advancing self-determination, promoting cultural revitalisation, and addressing historical injustices, ultimately fostering trust and equitable partnerships.

Box 8. Māori-centred decision-making frameworks with recognition of Indigenous sovereignty

New Zealand is committed to strengthening Indigenous autonomy and partnership by embedding co-governance structures, culturally integrated health models, and Indigenous data sovereignty into its healthcare systems. A few initiatives, like the Iwi-Māori Partnership Boards (IMPBs) and Te Mana Raraunga (the Māori Data Sovereignty Network) highlight New Zealand's efforts to engage with Māori communities, improve wellbeing, and reduce inequalities.

The IMPBs were established under the Pae Ora (Healthy Futures) Act 2022, with a mandate to ensure Māori tino rangatiratanga (self-determination) in healthcare governance. These boards engage directly with Māori communities, assess hauora Māori (Māori health) needs, and influence health sector priorities to ensure culturally relevant and equitable services. This is a leading example of co-creation of health policies to develop social licence for Māori communities, enabling more equitable and culturally respectful health practices.

Te Mana Raraunga asserts Māori data sovereignty, supporting the development of systems that protect the integrity and sovereignty of Māori data while aligning with the needs of Māori individuals and tribes (iwi). In this, Te Mana Raraunga ensures Māori data is safe and protected, is of high quality and appropriately represents the population, and supports Māori data infrastructure of control and govern their data. Together, these initiatives demonstrate a comprehensive commitment to empowering Māori communities while fostering a healthcare system rooted in equity, trust, and cultural respect.

Figure 13. Iwi-Māori partnership boards



Source: (Te Mana Raraunga, 2024^[149]), (Health New Zealand I Te Whatu Ora, 2024^[153])

Awareness and efforts to minimise the perceived risk around the use and collection of public health data

199. Building on initiatives to engage and better support Indigenous and marginalised populations through community engagement, countries are also taking active steps to ensure all groups are appropriately represented in public health data collection. In all data there is a perceived risk of bias based on how it is collected and used, whether misrepresenting or overrepresenting certain populations. A key area of work in health equity is building trust and proper representation of Indigenous peoples and marginalised groups in public health data collection and reporting. Depending on the country, these groups include women, Indigenous peoples, BAME, lower income individuals, 2SLGBTQI+ and Men Who Have Sex with Men.

200. In **Australia**, a first nations dashboard was developed with the key data custodians from the Aboriginal and Torres Strait Islander peoples, along with state and territory representatives (Australian Institute of Health and Welfare, 2024^[164]). The dashboard provides data focused on Indigenous populations to track health trends, disease incidence, and vaccination coverage to support targeted public health interventions and identify any gaps in coverage.

201. In addition, The Australian CDC envisages a role in stewarding use of data for public health benefit to deliver optimal, nationally consistent use of data in a Data Network for public health decision support across prescribed public health entities. It will include dedicated resourcing for First Nations data liaison to support access to data and information at a region level to progress Priority Reform 4 of the National Agreement on Closing the Gap and support the CDC's implementation of the Framework for Governance of Indigenous Data (Australian Governments, 2020^[165]), (Commonwealth of Australia, 2024^[159]).

202. In **New Zealand**, it was noted that in some cases, more work could be done to high the inequalities in the data being collected in public health. A number of groups, including the Māori population, people with disability, people with mental health challenges, and those at the intersection of these are facing inequalities and there is a need to highlight these deficits to tell the whole story. In efforts to reduce the perceived risk in current data practices for data collection and use, the 2021-2024 Data and Information Strategy for Health and Disability (Ministry of Health, 2021^[166]). In this strategy, actions are recommended to stabilise the quality and consistency of data being collected for health purposes, ensure data sovereignty and equity are considered, that citizens are aware of the data which exists about them and provide feedback on how it is being used, and to prioritise community involvement to improve data decision making and governance (Ministry of Health, 2021^[166]).

203. An example dataset collected in New Zealand is the Index of Deprivation (NZDep) which is an geographical mapping of the socioeconomic deprivation of people based on the national census (Environmental Health Intelligence New Zealand, 2023^[167]). There is still room for New Zealand to counter health equities for those in hard-to-reach groups, and work is underway to improve this through quality data and looking at each group for their own inherent attributes and drivers when reporting on the data.

204. In the **United Kingdom**, utilising data to promote health equity is seen as a big opportunity area which is still limited by data availability and data capture. Current data presents potential risks for stigmatisation of certain groups and impacting public trust when while working with incomplete datasets. with inherent bias. In recognition of these challenges, the NHS has developed the Digital Inclusion Strategy to ensuring that all citizens have access to digital health services and with this, improving digital literacy and access to devices so as to not widen the digital divide with new solutions (NHS England, 2024^[168]). This strategy will support access to immunisation programs and inclusion in disease surveillance, which can improve the quality of data collection in the hard-to-reach populations and reduce the risk of data inequalities (NHS England, 2024^[168]).

205. Building on this strategy, the Health and Wellbeing Alliance working in collaboration with the Department of Health and Social Care, NHS England, and the UK HSA to ensure there is equitable access to diseases surveillance and vaccination programs, focusing on hard-to-reach populations. The Alliance works to reduce disease based health disparities and gaps in vaccination uptake by ensuring that public health data is disaggregated by factors like ethnicity, socio-economic status, and geographic location (NHS England, 2024^[169]).

206. In **Canada**, the measuring of inequities among Indigenous Peoples and groups facing marginalised conditions has become increasingly important. There is varied understanding and consistency of race-based data collection, and its links to the social determinants of health across the country, with some growing focus on linking these datasets to gain a better understanding of potential inequities existing in the population. Across Canada, there are over 500 First Nations communities and work is underway to understand Indigenous data sovereignty to better report on data about these communities, along with those of racial minorities. There is an opportunity to better collect and report data the more accurately measures the inequalities in the public health system.

207. To support this need, the Canadian Institute for Health Information has recently developed the pan-Canadian minimum standard for the collection of race-based and Indigenous data in Canada to support higher quality data collection and address racial inequalities (CIHI, 2022^[170]). In addition, CIHI is incorporating Cultural Safety Indicators into data collection frameworks, which are designed to assess and ensure that healthcare services are respectful of and responsive to the cultural needs of diverse populations (CIHI, 2021^[171]). Adding gender, sex and sexual orientation (GSSO) standards is also being considered by CIHI to improve the collection of demographic data related to these factors, which are crucial of addressing health disparities across different populations (Health Data Research Network Canada, 2025^[172]).

208. The Government of Canada is actively working on distributing surveys to communities facing marginalised conditions, such as recent immigrants, to assess their attitude towards child vaccinations. However, there is room to grow regarding approaches to health equity and reducing inherent risks in the public health data in Canada (Advanis Inc., 2024^[173]), (Ekos Research Associates Inc., 2023^[174]), (Advanis Inc., 2024^[175]). Another stream of work is to address mis and disinformation around public health, such as vaccine hesitancy, and more broadly, health literacy in the population for hard-to-reach groups (Dubé, Gagnon and Vivion, 2020^[176]).

209. Health equity and social determinants of health data are key focuses for the PCHDCF and the CACDI. Both initiatives aim to bridge data gaps and integrate health equity considerations into public health policy, promoting inclusive policies that reflect the diverse experiences of Indigenous peoples and marginalised populations (CIHI, 2024^[73]).

Box 9. Australian First Nations Dashboards

Australia has prioritised First Nations data sovereignty and is working to better understand the underlying health inequalities affecting Aboriginal and Torres Strait Islander communities. A key initiative supporting this is the Regional Insights for Indigenous Communities (RIFIC) platform. In Australia, there are several remote First Nations communities and work is ongoing to better understand to what extent health inequalities exist for these groups. RIFIC provides locally relevant data on health, social determinants, and service access to support decision-making in and with First Nations communities.

In addition, a Digital Gap dashboard has been developed as part of the Mapping the Digital Gap project (2022–2024), which contributes to the broader Australian Digital Inclusion Index. This project monitors digital inclusion across 10 remote First Nations communities and highlights persistent inequalities in access, affordability and digital ability. The findings show that First Nations people living in remote areas experience greater digital exclusion than other Australians living in similarly remote settings.

Figure 14. Australian digital inclusion index: First Nations



Source: (Australian Digital Inclusion Index, 2022^[177])

Policy Considerations

210. The interviews with the four OECD countries reveal diverse approaches to engaging hard-to-reach populations and fostering social license for the equitable use of health data. Common practices include the co-creation of health data policies with marginalised communities, targeted information-sharing campaigns to improve trust and counter misinformation, and efforts to ensure data collection processes respect cultural norms and address inequities.

211. Countries like **Canada** and **Australia** face challenges due to the decentralised nature of their health systems, requiring regional engagement to ensure the inclusion of Indigenous peoples and communities facing marginalised conditions. However, this approach also yields positive outcomes, as the collection of data requires localised efforts to address specific needs and build trust within communities. Canada, for instance, emphasises Indigenous data sovereignty through national standards

for race-based and Indigenous data collection, complemented by initiatives like the Immunisation Partnership Fund to address vaccine disparities. Similarly, Australia supports its Aboriginal and Torres Strait Islander communities through partnerships that embed Indigenous values into data governance and tools like the First Nations Disease Dashboard to track disparities.

212. In contrast, **New Zealand** and the **United Kingdom** are leading efforts to integrate marginalised communities through national frameworks. New Zealand's Te Mana Raraunga and Iwi-Māori Partnership Boards ensure Māori self-determination in data governance, while the Whakamaui Māori Health Action Plan embeds equity in health policies. The United Kingdom combines statutory guidance for community engagement with initiatives like the Community Champions Programme and the Immunisation Inequalities Strategy to reduce barriers for underserved populations. Both countries are also advancing accessibility through strategies that prioritise community involvement and culturally sensitive approaches to data use.

Leading practices

213. Through the interviews with the four OECD countries, two leading practices emerged regarding co-creation: (1) the adoption of **co-creation principles** within health data policies to foster **social license** and (2) investing in information-sharing campaigns to establish common understanding of data collection and use for public health purposes to **minimise perceived risks vs. actual risks**. The findings from the interviews, as aligned to leading practices are summarised below:

Table 16. Summary of co-creation practices across four OECD member countries

Country	Adoption of co-creation principles within health data policies to foster social license	Information sharing campaigns to establish common understanding of data collection and use for public health purposes
Australia	Yes	No
Canada	Yes	In development
New Zealand	Yes	No
United Kingdom	Yes	Yes

Source: Authors