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REVIEW

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A review of data systems for assessing the impact of HPV vaccination in selected high-income countries

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ABSTRACT

Introduction: The introduction of effective human papillomavirus (HPV) vaccination, screening, and treatment programs has led the World Health Organization to call for the global elimination of cervical cancer. Assessing progress toward this goal is supported through monitoring vaccination coverage and its impact.

Areas covered: We performed a targeted review to assess the characteristics of HPV-related data systems from seven high-income countries (HICs) that represented varied approaches, including Australia, Canada, France, Italy, Scotland, Sweden, and the United States (US). Included data systems focused on preventive and early detection measures: HPV vaccination and cervical screening programs, as well as HPV-related disease outcomes. Differences were observed in approach to development of data systems, along with variation in geographical scope and methods of data collection.

Expert opinion: A challenge exists in how to best follow-up the ongoing global-scale elimination efforts in a comprehensive manner. These sources provide a wealth of information regarding the strengths and limitations of, and notable variation among, current data systems used in HICs. This review can inform improvements to existing prevention programs and the implementation of new programs in other countries, and thus support optimization of cervical cancer prevention policy.

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1. Introduction

Human papillomavirus (HPV) infection is well established as a necessary cause of cervical cancer, and an important cause in a proportion of other anogenital (anus 91%, vagina 75%, vulva 69%, and penis 63%), and head and neck cancers (oropharynx 70%) [1–3]. Globally, approximately 4.5% of newly diagnosed cancers are attributable to HPV, with cervical cancer being the fourth most common female cancer [4,5]; an estimated 604,127 cases are diagnosed annually [2,5,6].

Given that cervical cancer is highly preventable through prophylactic HPV vaccines and detection and appropriate treatment of HPV-associated pre-cancerous lesions, the World Health Organization (WHO) made a global call to action for its elimination as a public health issue, by reducing its incidence to the level of a rare disease (less than 4 per 100,000 woman-years) [7–9]. As high rates of vaccination, cervical screening, and treatment are fundamental to achieving this aim, the WHO has established interim targets, to be achieved by 2030, to facilitate elimination ('90–70-90 strategy') [9]. These include full vaccination among 90% of girls by age 15, high-performance screening among 70% of women at least by age 35 and 45 years, and appropriate treatment initiated for 90% of women diagnosed with cervical malignancy [9]. Currently approved HPV vaccines are available in various formats including: bivalent (*Cervarix, Cecolin*) [10,11], quadrivalent (*Gardasil, Cervavac*) [12,13], and nonavalent (*Gardasil 9*) [14]. Related to this, it has been predicted that achieving the 90–70-90 targets by 2030 could result in a 42% reduction in cervical cancer incidence by 2045, and 97% by 2120, averting more than 62 million deaths by 2120 [9].

Since 2006, at least 115 countries have implemented HPV vaccination programs to help reduce the burden of cervical cancer [15,16]. While the scope of these programs is varied, at the time of writing, approximately 40 countries had begun gender-neutral vaccination initiatives; this includes the United States and Australia (who were early adopters of this approach and began vaccinating males in 2011 and 2013, respectively) [17–20]. Several efforts have been made to evaluate the impact of these programs [21–24]. However, whilst surveillance of the prevalence of HPV and its related outcomes is

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Article highlights

- This review presents an overview of existing data systems of HPV-related outcomes across seven high-income countries, which can be used as a measure of progress against the World Health Organization target for elimination of cervical cancer
- Data systems capturing HPV-related outcomes such as vaccination coverage, cervical screening, HPV infection rates, and HPV-related cancers were included in the review
- There were substantial differences observed across collated data systems, including in data collection methods and geographical scope
- This review presents an overview of current data system practices in selected countries, and can provide a basis for establishing new programs of surveillance in other countries

not recommended by the WHO as a prerequisite to implementing vaccination programs, it can play an important role in documenting both the benefits and progress of vaccination, as well as informing future policy [15,25–28].

Because of the range of possible tools and processes in preventing HPV-related diseases, there are several interventions and biological endpoints which are relevant for monitoring and analyzing the impact of HPV vaccination programs [29]. Disease prevention through vaccination programs targeting HPV aims to reduce rates of cervical cancer as well as other HPV-related cancers: therefore, precancer and cancer incidence are important outcome variables [25]. However, due to the long latency in disease onset, more immediate outcomes, such as the incidence of HPV infection (especially persistent, high-risk HPV infection), or short-incubation diseases such as genital warts (GW), can be used as surrogate impact measures [25].

Vaccination programs are increasingly demonstrating success through impact and effectiveness studies, which show decreasing prevalence rates of both infection and subsequent HPV-related disease (including cervical precancer and cancer) [30]. However, whilst details are available for individual data systems, an overview detailing the characteristics of data systems that enable such analyses is not currently available.

This review focused on selected high income countries (HIC), to help identify, understand, and summarize the characteristics of existing data systems within countries that have established HPV vaccination programs and associated monitoring systems [31]. These findings offer insight into factors that are common across successful programs established in HICs. This, in turn, can be used to inform the design and development of future monitoring and evaluation systems, which is of relevance for low- and lower-middle income countries (LMICs) where program implementation is ongoing.

2. Methods

To identify data systems that have been used in HICs, we performed an initial targeted literature review and gray literature search. Using the World Bank classification of HICs as having a gross national income of >12,235 per capita, several HICs were identified with potentially relevant HPV-related data systems [31]. Of these, seven countries with established vaccination programs were selected based on the expertise of the contributing authors, to provide illustrative findings on different approaches to HPV outcome monitoring and in program approach (even among countries where vaccination programs were initiated in the same year). The selected countries (and years when national HPV vaccination programs were launched) were the United States (2006), Australia (2007), Canada (2007), France (2007), Italy (2008), Scotland (2008), and Sweden (2012) [32]. Of note, Scottish data are based on public domain descriptions only; however, for the other countries, contributing authors have provided their expert insight to augment the publicly available information.

Publications reporting on the above countries of interest were sourced from PubMed, Google, Google Scholar, and other sources (including websites of public health bodies, and the bibliographies of key references). These searches focused on identifying data systems containing relevant information on the prevalence of HPV infection, related diseases, and vaccine coverage (primarily those detailing prevention and early detection). Systems describing treatments for HPV-related diseases, such as cervical cancer, are also key to the elimination of this public health issue but were not the focus of this review.

Included publications report on records and data systems for surveillance of at least one of the following: cervical screening, abnormalities, and cancer; anal, vulvar, vaginal, or penile lesions and cancer; genital warts; recurrent respiratory papillomatosis (RRP); HPV-related disease, infection, or vaccine coverage.

Data presented in this review include the objectives of key data systems in each country of interest, along with information on data collection (including regularity and timings), data linkage, and scope of included outcomes (e.g. monitoring of HPV infection status or genotype).

Characteristics of data systems captured included: mechanisms of vaccine distribution and assessment of coverage, populations targeted, healthcare system structures, types of surveillance mechanisms, and range of conditions. Qualitative assessment of the characteristics of HPV vaccination data surveillance amongst these high-income countries could thereby allow a comparison of approaches and guide development of less established programs going forward.

3. Results

Data systems containing data relevant to HPV vaccination were reviewed in 2021 (see Table 1 for an overview of the number of data systems for each outcome; see Supplementary material Table S6 for a full breakdown by country).

Identified data systems were classified according to the following reporting categories: vaccination coverage, cervical screening, early-onset HPV-related disease outcomes, and HPV-related cancer outcomes, with several data systems being included in more than one category.

The data sources were categorized as claims databases, databases of electronic health records (EHRs), registries, or surveys. Claims databases are defined as those detailing diagnosis and procedure codes associated with medical, pharmacy

Table 1. Summary of the number of identified HPV-related data systems for each outcome of interest from seven HICs.

Country	Vaccination	Screening	GW	RRP	HPV infection	Cancer	Precancer
Australia	3	7	3	2	2	20	5
Canada	5	14	4	1	x	33	1
France	3	4	1	1	1	4	4
Italy	1	2	1	x	x	2	2
Scotland	3	2	x	x	1	2	x
Sweden	2	1	2	x	x	2	1
US	3	4	1	1	2	12	1

GW: genital warts; HIC: high-income country; HPV: human papillomavirus; RRP: recurrent respiratory papillomatosis; US: United States.
A full summary of each data system is provided in Supplementary material Table S6, organized by country for geographical comparison.

and dental claims documented by private and/or public payers. EHR databases systematically collect patient health information in a digitalized format. Registries refer to disease- or intervention-specific databases that collect information indirectly (such as cancer or cervical screening registries, or vaccine registries). Lastly, surveys obtain information directly from respondents by asking them to provide information or insight into a topic of interest such as sexual behaviors or vaccination status.

The characteristics of key data systems are detailed in Tables 2, 3, 4, and 5, to provide an illustration of their varied objectives and outcomes.

3.1. Data systems on vaccination coverage

All of the HICs included within the review had a system to allow vaccination coverage to be determined (Table 2). Australia, Scotland, and Sweden have a national immunization registry or equivalent system, whereas the US, Canada, and Italy have relied on survey-based approaches or regional registries to collect these data. In France, such data are collected by monitoring reimbursement claims, with databases such as the Permanent Sample of Beneficiaries (PSB) supporting determination of uptake [33,34].

3.2. Data systems on cervical screening

Key identified data systems from the different HICs reporting on cervical screening programs are summarized in Table 3. Screening systems were present within all of the identified HICs; however, some fundamental differences were identified. National-level, organized monitoring or surveillance systems were present in Australia, Scotland, and Sweden, with national survey reports also being available in Italy. Other HICs (Canada, France, and the US) do not maintain national-level organized screening programs but have jurisdictional coverage via organized or opportunistic screening programs.

Australia and Sweden have established organized screening programs, which invited women from a prespecified population to attend at regular time intervals [35–38]. Meanwhile, only some provinces in Canada maintain organized screening; most other jurisdictions rely on opportunistic screening for the detection of cervical precancer and cancer, i.e. screening based on professional guidelines done by a primary healthcare provider when the opportunity arose, rather than as part of a predetermined program [39,40]. In France, an organized screening program has been implemented since 2018 [41], which coexists with preexisting systems that involve opportunistic screening.

Interestingly, all of the identified HICs currently use cytology-based screening, except for Australia, which switched to national HPV testing in December 2017 [28,42,43]. Data relating to screening were collected through a combination of administrative mechanisms, registry reports, and surveys. Amongst all of the identified surveillance systems, few had reported provisions to enable data linkage i.e. the ability to bring together information from different sources to permit enhanced multi-source surveillance.

HIC: high-income country; HPV: human papillomavirus; NR: not reported.

3.3. Data systems on HPV infection and early outcomes

Data systems relating to early HPV infection and related outcomes (for example, genital warts) were more limited (Table 4). In addition, methods of data collection varied between countries and not all data were routinely collected.

Routine collection was particularly lacking in relation to HPV infection status and genotyping; however, sentinel site-based data were identified in several countries, which set a baseline for infection. For instance, in France, the Center National de Référence des HPV (CNR-HPV) biospecimen database for the screening of cervical cancer also recorded data on the prevalence of high- and low-risk HPV types [44]. In Australia, a research project (WHINURS; Women HPV Indigenous Nonindigenous, Urban Rural Study) estimated the genoprevalence of HPV in women presenting for Pap cytology screening before vaccination [45]; thereby contributing to subsequent vaccine impact research. Subsequently, a national surveillance system has been funded by the Commonwealth Department of Health, including monitoring of genoprevalence among males as well as females [46].

Only one routine surveillance system was identified for the identification and monitoring of genital warts: the Kirby Institute Genital Warts Surveillance Network in Australia [47]; genital warts are typically not a reportable condition under regulations on notifiable/reportable health care events. However, several administrative claims databases and drug registries were identified, alongside surveillance activities within sexual health clinics and general practice, which could be used to help determine incidence. For instance, in Sweden, as the therapies used to treat genital warts are only dispensed via prescription, information on the quantity of pharmaceuticals within the Swedish Prescribed Drug Register (PDR) can be used to inform incidence [34]. Surveillance systems for RRP

Table 2. Key data systems reporting on vaccination coverage in seven HICs.

Country	Data system	Source	Comments
Australia	National HPV Vaccination Program Register (NHVPR)	Victorian Cytology Service (VCS) Foundation	Collected information about HPV vaccine doses given across Australia from 2008 to 2018. All HPV vaccination records held in the HPV Register have subsequently been transferred into the whole-of-life Australian Immunization Register (AIR).
	Australian Immunization Register (AIR)	Australian Government Department of Human Services	From 30 September 2016, the AIR became a whole of life register with the ability to record all vaccinations for people of all ages given by a registered vaccination provider. As of November 2018, HPV vaccinations are recorded on the AIR. The AIR also houses HPV vaccination data transferred from the NHVPR.
	Tasmanian Immunization Strategy 2019–2024	Tasmanian Government	Tasmania's guiding document for the administration of publicly funded vaccines. Contains data on HPV vaccine coverage. (Developed within the context of the Australian National Immunization Strategy 2019–2024.)
Canada	Childhood National Immunization Coverage Survey (cNICS)	Public Health Agency of Canada (PHAC)	Survey conducted approximately every 2 years.
	HPV reimbursement database (HPVRD)	Ontario Ministry of Health and Long-Term Care	Used by health units to receive financial remuneration for HPV vaccine doses administered by health unit staff. Although not specifically designed for this purpose, the HPVRD may also be used to assess HPV vaccine coverage. Centralized database (Ontario Ministry of Health and Long-Term Care can extract data)
	Immunization Records Information System (IRIS)	Ontario Ministry of Health and Long-Term Care and individual health units	Ontario legislation requires that all public health departments (health units) maintain a record of immunization for all school pupils in their jurisdiction. IRIS is used to assess coverage locally and to contribute to provincial coverage assessment for vaccines administered in infancy, childhood, and Ontario's three school-based programs (including HPV vaccination). Decentralized database (requires data extraction by health unit with transfer to Ontario Ministry of Health and Long-Term Care)
	Panorama	NR	
	Primary Access Regional Information System	NR	
France	Permanent Sample of Beneficiaries *(Echantillon généraliste de bénéficiaires; EGB)*	National Health Insurance Information System	Sample of beneficiaries from the General health insurance scheme (1/97th of the full Système national des données de santé [SNDS]). Pharmacy reimbursement claims database for the number of vaccine doses claimed.
	MesVaccins.net	GEP (preventive medicine study group)	Survey of previous vaccination for teenagers aged 16–18 years old during mandatory participation at the National Defense Preparation Day (NDPD). Electronic medical records created and validated by healthcare providers.
	Système national des données de santé (SNDS)- Datamart de Consommation Inter Régimes (DCIR)	French National Health Insurance Fund for Employees *(Caisse nationale de l'assurance maladie des travailleurs salariés; CNAMTS)*	Reimbursement claims database (number of vaccine doses) for patients covered by the main healthcare insurance plans in France.
Italy	Vaccination coverage data (report based on survey)	Ministry of Health	Pre-2014, data was collected by the National Institute of Health (ISS) with a dedicated surveillance. Afterward, the Ministry of Health started collecting coverage data with the survey of coverage routinely used for other vaccinations, on an annual basis. Data are collected at the regional level and collated to give a national average coverage for different birth cohorts
Scotland	Scottish Immunization & Recall System (SIRS)	National Data Catalog	Used in conjunction with the CHSP-S to monitor the uptake of teenage immunizations delivered in schools
	Scottish HPV Immunization Programme	Public Health Scotland	
	HPV Immunization Statistics Scotland	National Services Scotland	
	Child Health Schools Programme-System (CHSP-S)	NR	The CHSP-S facilitates the call/recall of both primary and secondary school pupils for immunization, review and screening

(*Continued*)

Table 2. (Continued).

Country	Data system	Source	Comments
Sweden	National Vaccination Register (*Nationella vaccinationsregistret*) and SVEVAC (Swedish Vaccination Register)	Swedish Public Health Agency (*Folkhälsomyndigheten*)	Reports vaccination data for children aged ≤18 years who received vaccinations as part of the general vaccination program (NVR) and adults who opt to vaccinate at their own cost (SVEVAC)
	Swedish Prescribed Drug Register (*Läkemedelsregistret*)	Swedish National Board of Health and Welfare	HPV vaccines that are subsidized have to be prescribed and picked up at a pharmacy. They are then automatically registered in the Prescribed Drug Register.
United States	Immunization Information Sentinel System (IIS)	Centers for Disease Control and Prevention (CDC)	A confidential, computerized, population-based information system that collects and consolidates vaccination data from vaccination providers.
	National Immunization Survey–Teen (NIS-Teen)	Sponsored by the National Center for Immunizations and Respiratory Diseases (NCIRD) and conducted by the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC)	Monitors vaccination coverage among persons aged 13–17 years. Survey respondents are parents/guardians of teens in the target age group.
	National Immunization Survey–Adult (NIS-Adult)	NR	Assessed HPV vaccination coverage in women aged 18–49 years.

specifically were identified in Australia, Canada, France, and the US [48–52].

GW: genital warts; HIC: high-income country; HPV: human papillomavirus; NR: not reported; RRP: recurrent respiratory papillomatosis.

*While disease registries in Sweden do not specifically capture RRP diagnoses, studies have demonstrated that the ICD-10 code D14.1 (benign neoplasm of larynx) may be used to monitor incidence using Swedish registries [53].

3.4. *Data systems on HPV-related cancers*

With regards to HPV-related cancers, population-based cancer registries were identified for all of the included HICs. Many countries had multiple databases to help determine both HPV-related cancer incidence and mortality rates (Table 5). Australia had a particularly comprehensive approach, with information available both nationally through databases such as the Australian Cancer Database (ACD), and regionally through databases covering regions such as New South Wales, Victoria, and Queensland [35,54]. Similar to Australia, Sweden had nationally-based data systems, with registries such as the Swedish Cancer Register (*Cancerregistret*), which provided information not only on incidence and mortality, but also (sometimes to a varying extent) on factors such as stage and grade [55,56].

4. Discussion

High rates of vaccination are fundamental to achieving the aim of eliminating cervical cancer, as determined by the WHO. At the time of writing, at least 115 countries have begun vaccination programs for HPV, and at least 40 countries are pursuing gender-neutral vaccination strategies. It is to be noted, however, that for young girls of vaccine eligible age only 13% are fully vaccinated [57]. Therefore, the availability of data systems to monitor vaccination rates and related outcomes is key.

This review summarizes data systems relating to HPV vaccination impact monitoring and evaluation, across a set of high-income countries (HICs). We provide pertinent characteristics for individual data systems, examining the degree of coverage across different process and outcome variables (and population segments of interest). Further, we highlight differences in approach between countries, including associated strengths and limitations. Some of the issues are related to specific features of the prevailing healthcare systems, e.g. national in Australia and Sweden versus regional in a federated system, such as Canada and Italy.

Planning and deliberately setting up a holistic data system that captures linked data on interventions and outcomes is ideal, as has been observed in Australia, especially for assessment of vaccine effectiveness [29]. In addition, the availability of national-level databases for key several outcomes, such as has been observed in Sweden, is likely beneficial. Where impractical or unfeasible, other sources such as administrative data provide opportunities to assess the impact of preventive interventions [25]. Further, while national systems ensure data consolidation, appropriate access and analysis could negate any limitations of a more-fragmented approach. As such, the timely collection and compilation of health data at both the national and sub-national levels can enable progress to be measured toward specified targets, which is of increasing importance given the introduction of performance-based disbursement by several organizations [26].

We identified several data system characteristics that exposed probable limitations in their effectiveness. For example, reliance on voluntary participant inclusion and surveys (such as in Italy), which may affect the breadth and accuracy of available data; in comparison to data recorded in registries by healthcare professionals and/or through structured mechanisms of systematically available administrative systems. Conversely, administrative data systems or data systems using medical records (as seen in the US) may also be inherently limited in terms of coverage (e.g. through collecting information for insured individuals only).

Table 3. Key data systems reporting on cervical screening in seven HICs.

Country	Data system	Source	Comments
Australia	National Cervical Screening Program monitoring data	Australian Government Department of Health	Data from cervical screening registries from all eight jurisdictions in Australia (six states and two territories). Established 1991, updated 2015 to five-yearly screening of individuals aged 25–74. As of 2017, screening for primary HPV with partial genotyping and reflex LBC-based triage.
	New South Wales Pap Test Register (PTR)	Cancer Institute NSW	The PTR collected cervical test data for residents of NSW from July 1996 to November 2017. Inclusion on the PTR was voluntary, with people having an option to have their identifying information removed from the register. For record linkage by the Center for Health Information, data are currently available from July 1996 to December 2016.
	NSW Health Interview Surveys	NSW Health	Self-reporting survey of cervical screening participation. Data are collected on conditions, sub-populations or in areas that are not routinely monitored by existing health data systems on a population basis.
	Queensland Pap Smear Register (now part of the National Screening Register – NCSR)	Queensland Health	Cervical cancer screening histories of South Australian women.
	Victorian Cervical Cytology Registry	Victorian Department of Health	The Victorian Cervical Cytology Registry was established in 1989 by an amendment to the Cancer (Central Registers) Act to prevent women developing cervical cancer through early detection and encouraging women with reminders to participate regularly in the screening program. Replaced by the NCSR.
	Western Australia Cervical Screening Registry	WA Cervical Cancer Prevention Program (WACCPP)	This confidential state-based register holds a copy of all cervical test results from individuals living in WA at the time of their test. The registry was operational from 1994 until 2018 when its registry services transitioned to the Australian Government Department of Health's National Cancer Screening Register (NCSR). Locally, the WA Cervical Cancer Prevention Program (WACCPP) continues manage the WA Cervical Screening Register, receiving a copy of cervical test information from the NCSR.
	Australian Capital Territory (ACT) Cancer Registry	Australian Capital Territory Government Department of Health	The ACT Cancer Registry was established in 1994, when cancer reporting became mandatory in the ACT. Data was collected from 1985 but it is not considered complete prior to mandatory reporting. The purpose of the ACT Cancer Registry is to monitor the incidence and trends of cancer in the ACT. Data are collected from hospital records, pathology laboratories, day surgeries, hospices and nursing homes. About 1,000 to 2,000 new cases are reported each year. Currently, there are approximately 33,000 records in the registry.
Canada	Canadian Community Health Survey	Statistics Canada	Collects data about health at the community level using computer-assisted telephone and personal interviews
	Cervical cancer Screening in Canada – Monitoring & Evaluation of Quality indicators 2011–2013	Canadian Partnership Against Cancer's Monitoring and Evaluation Working Group	Data available by province. Ontario not hysterectomy corrected (only British Columbia and Manitoba corrected for hysterectomies). Data from 2011–2013. No recent data following change to guidelines.
	Alberta Cervical Cancer Screening Program	Alberta Health Services	The Alberta Cervical Cancer Screening Program is a provincial screening program that works to educate and increase the number of women, aged 25 to 69, who have regular cervical cancer screening using Pap tests (a screening test that checks the cells of the cervix for abnormal changes).
	BC Cancer Cervix Screening	BC Provincial Health Services Authority	BC Cancer Cervix Screening has oversight responsibility for cervix screening in BC. The program reminds healthcare providers when their patients are due for screening, tracks adherence to screening recommendations, and monitors system performance and outcomes of cervix screening activities.
	Cervical Cancer Screening in Canada	Canadian Partnership Against Cancer	The Canadian Partnership Against Cancer collects information on national, provincial and territorial cervical screening guidelines, strategies and activities.
	CervixCheck	CancerCare Manitoba	CervixCheck partners with over 100 clinics across Manitoba to provide increased access to cervical cancer screening services.
	CytoBase	INCYTE Corporation	Centralized interactive database of cervical cytology (Pap) reports
	Manitoba Immunization Monitoring System (MIMS)	Government of Manitoba	
	New Brunswick Cervical Cancer Prevention & Screening Program	Government of New Brunswick	The provincial Cervical Cancer Prevention and Screening Program (CCPSP) offers screening for cervical cancer using Pap tests to NB sexually active women aged 21–69.
	NL Cancer Care Registry (NLCCR)	Eastern Health's Provincial Cancer Care Program	Managed and operated by Eastern Health's Provincial Cancer Care Program, the NLCCR is a population-based registry that collects, uses and shares health information related to cancer screening and the delivery of cancer care in Newfoundland and Labrador.
	Nova Scotia Cancer Registry	Nova Scotia Department of Health and Wellness (DHW)	Nova Scotia's population-based cancer registry is operated as part of the provincial cancer programme funded by the government. Nova Scotia has organized population-based screening programmes for several cancers. Provincial data (e.g. incidence, mortality, and survival data) are reported annually to local stakeholders and used for programme evaluation and planning purposes.
	Our Health Counts	Keenan Research Center: The Center for Research on Inner City Health (CRICH)	Population health database for urban aboriginal people in Ontario
	PEI Childhood Immunization registry	NR	
	Physicians' Claims Database	Government of Ontario	

(*Continued*)

Table 3. (Continued).

Country	Data system	Source	Comments
France	SNIIRAM-PMSI databases: National Information System for Health Care Insurance (*Système national d'information inter-régimes de l'assurance maladie*; SNIIRAM)	National Health Insurance (*Caisse Nationale de l'Assurance Maladie; CNAM*)	French national health insurance covers the entire population living in France and is divided into several specific schemes according to beneficiary profiles. The SNIIRAM data warehouse comprises the characteristics and medical information of the beneficiaries of the various national health insurance schemes, containing outpatient reimbursed healthcare expenditures. The data included in this database is part of the Système national des données de santé (SNDS) which merges data from PMSI, SNIIRAM and CépiDC.
	Program for the medicalization of information systems *(Programme de médicalisation des systèmes d'information; PMSI)*	Agency for Information on Hospital Care *(L'Agence technique de l'information sur l'hospitalization; ATIH)*	French Hospital Discharge database, which contains medical information on all patients, admitted to hospitals in France. Administrative and claims database. The data included in this database is part of the Système national des données de santé (SNDS) which merges data from PMSI, SNIIRAM and CépiDC.
	Data housed by the: Center de Regroupement Informatique et Statistique en Anatomie et cytologie Pathologiques (CRISAP), Rhône-Alpes	Center de Regroupement Informatique et Statistique en Anatomie et cytologie Pathologiques (CRISAP), Rhône-Alpes	Cytological and histological results provided by Pap smears of women undergoing screening in the Rhône-Alpes region.
	Population-based organized cervical cancer screening pilot program *(Le programme national de dépistage du cancer du col de l'utérus)*	National Health Insurance Fund	Initiated 2018. Population-based registry from an organized screening program in different departments in France for women aged 25–65 years who had not undergone a cytological screening in the past 3 years.
Italy	Data monitoring system PASSI (*Progressi delle Aziende Sanitarie per la Salute in Italia: la sorveglianza Passi [PASSI]*)	Department of Infectious Diseases, National Institute of Health (Istituto Superiore di Sanità – ISS)	National survey report
	Cancer screening reports (region-specific)	Region-specific screening programs with corresponding data reports, including but not limited to: Toscana (*Istituto per lo studio, la prevenzione e la rete oncologica (ISPRO)*) Lombardia (*Struttura Promozione della Salute e Screening*) Veneto (*Osservatorio Nazionale Screening*) Piemonte (*Prevenzione Serena*) Emilia-Romagna (*Servizio Prevenzione Collettiva e Sanità Pubblica/Servicio Sanitario Regionale Emilia-Romagna (SSREM)*)	
Scotland	Scottish Cervical Screening Programme	Public Health Scotland	Includes data on uptake by deprivation and Human papilloma virus (HPV) immunization status, laboratory turnaround times, number of cervical screening tests processed and results.
	Scottish Cervical Call Recall System (SCCRS)	NR	Nationwide, population register with demographic data, immunization status, cytology, histology and HPV results.
Sweden	Swedish National Cervical Screening Registry (*Nationella Kvalitetsregistret för cervixcancerprevention; NKCx*)	Karolinska University Hospital, Stockholm Region	National registry, collects data on all cervical smears, cervical histopathologies, invitations to cervical screening, and HPV tests in Sweden
United States	National Breast and Cervical Cancer Early Detection Program (NBCCEDP)	Centers for Disease Control and Prevention (CDC)	High-quality and timely breast and cervical cancer screening and diagnostic services to low-income, uninsured women
	Behavioral Risk Factor Surveillance System (BRFSS)	Centers for Disease Control and Prevention (CDC)	Cervical cancer and precancerous lesions by Papanicolau (Pap) smear testing every 3 years
	National Health Interview Survey (NHIS)	National Center for Health Statistics (NCHS)	The National Health Interview Survey (NHIS) is the principal source of information on the health of the civilian noninstitutionalized population of the United States.
	New Mexico HPV Pap Registry	University of New Mexico	Includes information on cytology tests and results, HPV tests, and cervical pathology

There were also limitations in the time duration of reporting and/or accessibility of the data, such as data available from a one-time event with no follow up i.e. a standalone survey, or data collected within a specific timeframe that has since been discontinued. Continuous consolidated reporting into national registers is preferable for effective monitoring and evaluation [25]. However, country restrictions on patient data use may lead to use of targeted or sentinel-site-based studies.

In addition, the emergence of the COVID-19 pandemic in early 2020 has affected subsequent HPV vaccination or monitoring activities in a way that is difficult to predict. The continuity of data collection activities in areas such as HPV has been disrupted due to the pandemic. However, increased awareness of population health outcomes, and new systems put in place to improve such outcomes in the context of COVID-19, may prove beneficial for control of other conditions such as HPV and associated cancers.

In general, procedures for comprehensive data linkage constitute a significant gap in many countries. This hinders effective data consolidation and comparison, and should be an important consideration moving forward, particularly in light of the elimination goals established by the WHO. There is, however, strong potential amongst several national cancer registries for data linkage, due to the use of unique identifiers. An additional area of note is that most countries did not have systems in place for routine recording and monitoring of HPV prevalent infection, genital warts, RRP and precancer incidence. Due to the long latency associated with HPV infection, collecting data on early endpoints (particularly prevalent infection rates and incidence of genital warts) has been essential to

Table 4. Key data systems reporting on HPV infection and early-onset HPV-related diseases in seven HICs.

Country	Outcome	Data system	Source	Comments
Australia	HPV infection	National HPV Surveillance Program	Australian Government Department of Health and the HPV Surveillance Working Group of the Communicable Diseases Network Australia (CDNA)	HPV surveillance is conducted as a component of the National HPV Vaccination Program and aims to monitor the effectiveness of the HPV vaccination on circulating HPV genotypes in the Australian population. HPV is not a nationally notifiable disease in Australia and therefore the surveillance of HPV infection operates outside of the National Notifiable Diseases Surveillance System. The Australian Government has funded a number of HPV surveillance projects, including the current National HPV Surveillance Program. The Program is a national genotype-specific surveillance system that includes demographic and behavioral data relevant to HPV infection. Also participates in HPV surveillance in women living with chlamydia. Note that this page has not been updated since 2016, and the HPV Surveillance Working Group of the CDNA is currently on hold.
		National Cervical Screening Program	Australian Government Department of Health	From May 2017, screening is done by HPV testing, and is now a passive surveillance system for HPV prevalence monitoring in women attending screening (restricted to women aged ≥25 years)
	GW	National Hospital Morbidity Database (NHMD)	Australian Institute of Health and Welfare (AIHW)	Comprehensive population-based national dataset of routinely collected admissions data from all public and private hospitals in Australia. Hospitalizations with one or more codes associated with genital wart treatments
		Bettering the Evaluation of Care and Health (BEACH) database	Family Medicine Research Center, University of Sydney, and the Australian Institute of Health and Welfare (AIHW)	National study of general practitioner clinical activity. Rolling GP sample, with ~20 GPs participating in any one week, 50 wks/yr. Final BEACH database includes records for almost 1.8 million GP–patient encounters from 17,707 GP participants, representing 10,798 individual GPs.
		Genital Warts Surveillance Network	The Kirby Institute	Sentinel surveillance system comprising 54 sexual health clinics in all states and territories of Australia. The network brings together routinely collected information, includes data on demographics, sexual behavior, and wart diagnosis. HPV vaccination status is collected in a subset of clinics.
	RRP	Australian Pediatric Surveillance Unit (APSU) surveillance of rare pediatric diseases	Australian Pediatric Surveillance Unit (APSU)	Established to monitor incidence and demographics of juvenile-onset recurrent respiratory papillomatosis (JoRRP) cases nationally. Practitioners contacted monthly; offered HPV testing.
		Pediatric Active Enhanced Disease Surveillance (PAEDS) system	National Center for Immunization Research and Research and Surveillance of Vaccine Preventable Diseases	Five tertiary hospitals in the capital cities of five states. JoRRP.
Canada	GW	Ontario Health Insurance Plan (OHIP) database	Institute for Clinical Evaluative Sciences (ICES)	The OHIP database captures fee-for-service claims from inpatient, outpatient and long-term care settings made by Ontario physicians, and represents claims from approximately 98% of physicians in the province. Physician visits for anogenital warts can be identified using a combination of diagnostic and procedural codes.
		Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD)	Canadian Institute for Health Information (CIHI)	Hospitalizations for anogenital warts can be identified in CIHI-DAD.
		National Ambulatory Care Reporting System (NACRS)	Canadian Institute for Health Information (CIHI)	National database covering hospital and community-based ambulatory care services. Can be used to identify emergency department visits for anogenital warts.
		Same-day-surgery (SDS) database	Canadian Institute for Health Information (CIHI)	The SDS summarizes same day surgery information about individuals. Each record contains the procedures undergone as well as clinical information about the individual. Surgeries and procedures for anogenital warts can be identified in the SDS.
	RRP	JoRRP national database	Canadian Juvenile Onset Recurrent Respiratory Papillomatosis Working Group	Retrospective database. Data from 1994 to 2007.
France	HPV infection	National Reference Center for Human Papillomavirus *(Center national de référence des HPV; CNR-HPV)*	NR	Biospecimen database from women residing in Ile-de-France or in the provinces for the individual screening of cervical cancer. Biospecimens analyzed by PCR and Papillocheck to identify high risk and low risk HPV types.
	GW	EFFicacité de la vaccination HPVsur l'Incidence des Condylomes Acuminés Externes (EFFICAE)	NR	Data collected for women 15–26 years-old and men 20–30 years-old from an observational cross-sectional study from dermatologists and gynecologists.
	RRP	RRP registry	Hôpital Edouard Herriot, Lyon	Facility-based registry based on a larger database (not identified) for children and adults with RRP who received treatment at the department over a 30 month period
Italy	GW	Data monitoring system PASSI (*Progressi delle Aziende Sanitarie per la Salute in Italia: la sorveglianza Passi [PASSI]*)	Department of Infectious Diseases, National Institute of Health (Istituto Superiore di Sanità – ISS)	National survey report

(*Continued*)

Table 4. (Continued).

Country	Outcome	Data system	Source	Comments
Scotland	HPV infection	National Surveillance System for Human Papillomavirus Infection and Related Disease in Scotland	Health Protection Scotland	The dataset is created through collaboration with the Scottish Human Papillomavirus Reference Laboratory (SHPVRL)
Sweden*	GW	Swedish Prescribed Drug Register (*Läkemedelsregistret*)	National Board of Health and Welfare *(Socialstyrelsen)*	Drugs to treat genital warts are only dispensed by prescription in Sweden. They are then automatically registered in the Prescribed Drug Register
		Swedish Patient Register (*Patientregistret*)	National Board of Health and Welfare (*Socialstyrelsen*)	All diagnoses and treatment of GW in inpatient and outpatient hospital care are registered in the Swedish Patient register (ICD-10 code A63)
United States	HPV infection	STD Surveillance Network (SSuN)	Centers for Disease Control and Prevention (CDC)	Provides information on patients presenting for care in STD and family planning clinical settings
		National Health and Nutrition Examination Survey (NHANES)	CDC National Center for Health Statistics	The National Health and Nutrition Examination Survey (NHANES) assess the health and nutritional status of adults and children in the United States.
	GW	Optum's Clinformatics	NR	Includes claims for medical services
	RRP	JORRP Registry	Centers for Disease Control and Prevention (CDC)	The registry collects demographic data, information about the disease progress, anatomical sites affected, medication, surgical and other information.

understand the impact of interventions in the short-term, and remains a priority [30]. However, owing to both the scope of information already recorded and the prevalence of existing screening programs, there is potential for a number of the identified cancer programs to be expanded to include precancers. In addition, as organized cervical screening efforts become more common, surveillance of HPV prevalence will also become more feasible.

Despite accumulating experience in many countries worldwide, the practice of recording information about national HPV vaccination programs and outcomes is still developing in many places. As such, relevant data systems may not have been captured by the available literature, and limited information was available regarding many characteristics of identified systems. Further, this review does not describe data systems from all HICs, rather with focus on seven countries that were selected as priority and then characterized through targeted searches. However, whilst limitations exist, this review provides an important information resource to support the strengthening and development of HPV data monitoring initiatives.

4.1. Conclusion

Data systems play an important role in assessing the impact of preventative interventions on HPV-related disease outcomes, particularly in light of the ongoing global cervical cancer elimination effort. This work highlights the need for data collection for all HPV-related disease endpoints, ranging from HPV prevalent infection and genital warts to invasive cervical cancer and beyond, due to the long lag time seen for oropharyngeal and other HPV related cancers to occur. Effective systems will therefore require sustainability and longevity. The characteristics of the established systems identified here thereby provide learnings for countries planning to create or expand data systems based on their local needs. This is of particular pertinence for low- and low-middle income countries where vaccination programs are limited, and where more than 85% of all cervical cancer cases and deaths occur [26,58].

5. Expert opinion

Sustained population-based epidemiologic surveillance is essential for evaluating the short-term impact and monitoring the long-term benefits of public health interventions. In light of the cervical cancer elimination goals enacted by the WHO, understanding effective approaches to real-world data collection on coverage of HPV vaccination, adherence to screening, and treatment recommendations is key to monitoring effectiveness of public health interventions against HPV and associated cancers. This overview of high-income countries' surveillance of HPV-associated diseases serves as a knowledge base for considering best practices on implementing HPV-related data systems, their similarities and differences, and considering contextual factors in their establishment.

Improving completeness and accuracy of data collection is a priority toward WHO's elimination goals and country-specific policies to control HPV-associated diseases. However, simply maintaining individual data collection mechanisms specific to individual objectives, such as measuring coverage of HPV vaccination or tracking HPV screening, is not enough. It is imperative that mechanisms be put in place to enable integration of data systems for higher level surveillance of all fronts in prevention, thus allowing linkage at the individual level of HPV vaccination registries with monitoring of HPV prevalence via surveys and with screening and treatment outcomes. Integration and linkage of data systems will also enable robust epidemiologic research on possible bottlenecks and mishaps along the chain from primary prevention to incidence of and mortality from HPV-associated cancers, e.g. by allowing to countries to identify disparities in access, monitor for possible shifts in HPV type distribution in cancer causation, and take policy corrections in screening algorithms. Although most countries in this overview maintain

Table 5. Key data systems reporting on HPV-related precancers and cancers in seven HICs.

Country	Outcome	Data system	Source	Comments
Australia	Cervical precancer	National Cervical Screening Program monitoring data	Australian Government Department of Health	Data from cervical screening registries from all eight jurisdictions in Australia
		New South Wales Pap Test Register (PTR)	Cancer Institute NSW	The PTR collected cervical test data for residents of NSW from July 1996 to November 2017. Inclusion on the PTR was voluntary, with people having an option to have their identifying information removed from the register. For record linkage by the Center for Health Information, data are currently available from July 1996 to December 2016.
		Queensland Pap Smear Register (now part of the National Screening Register – NCSR)	Queensland Health	Cervical cancer screening histories of Queensland women
		Victorian Cervical Cytology Registry	Victorian Department of Health	The Victorian Cervical Cytology Registry was established in 1989 by an amendment to the Cancer (Central Registers) Act to prevent women developing cervical cancer through early detection and encouraging women with reminders to participate regularly in the screening program. Replaced by the NCSR.
		Western Australia Cervical Screening Registry	WA Cervical Cancer Prevention Program (WACCPP)	This confidential state-based register holds a copy of all cervical test results from individuals living in WA at the time of their test. In July 2018, the WA Cervical Screening Registry transferred its services to the new National Cancer Screening Register (NCSR). The WACCPP receives a copy of cervical test information from the NCSR.
	Cancer incidence	Australian Cancer Database (ACD)	Australian Institute of Health and Welfare (AIHW)	National, population-based database. Cancer is a notifiable disease; the ACD contains data about all new cases of primary, malignant cancer diagnosed in Australia since 1 January 1982, excluding basal and squamous cell carcinomas of the skin.
		Sydney Head and Neck Cancer Institute Database (SHNCI)	Chris O'Brien Lifehouse	Clinicopathological database, including hospital records; over 14,000 records included.
		Queensland Cancer Statistics Online (QCSOL)	Cancer Council Queensland	Online interactive platform that provides statistics on cancer diagnoses, deaths, survival and prevalence for the most common cancers among Queensland residents.
		Queensland Cancer Register	Cancer Alliance Queensland	The QCR maintains a register of all cases of cancer diagnosed in Queensland since 1982 (excluding basal and squamous cell carcinomas). Contains demographic information, information on cancer diagnosis, information on patient's hospital stay, and mortality information.
		South Australia Health Cancer Incidence and Mortality Statistics	Government of South Australia – South Australia Health	Yearly reports on cancer incidence and mortality statistics.
		Tasmanian Cancer Registry	University of Tasmania and Menzies Institute for Medical Research	Reports on incidence, mortality, survival and prevalence of cancers in Tasmania.
		Victorian Cancer Registry	Cancer Council Victoria	A record of people with cancer in Victoria; mandatory reporting of all cancer diagnoses by health services, including pathology laboratories. Up-to-date and complete data are collected from 254 hospitals, 11 radiotherapy centers, 7 interstate registries, screening registries, 26 pathology laboratories and death registries, and are collated by person and tumor streams.
		Western Australia Cancer Registry	Government of Western Australia Department of Health	Collects information about cancer diagnoses across the State. Reporting is mandatory from pathology reports and radiation oncology treatment records. The registry can supply incidence and mortality case counts.
		Queensland Cancer Statistics Online (QCSOL)	Cancer Council Queensland	Online interactive platform that provides statistics on cancer diagnoses, deaths, survival and prevalence for the most common cancers among Queensland residents.

(*Continued*)

Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
	Cancer mortality	Cause of Death Unit Record Files (CODURF)	Australian Bureau of Statistics (ABS)	Compiled and coded (ICD-10) by the Australian Bureau of Statistics
		Australian Cancer Database (ACD)	Australian Institute of Health and Welfare (AIHW) and Australian Association of Cancer Registries (AACR)	
		The National Mortality Database (NMD)	Australian Institute of Health and Welfare (AIHW)	Holds records for deaths in Australia from 1964; include cause of death information and other characteristics of the person (including sex, age at death, area of usual residence and Indigenous status).
		National Death Index (NDI)	Australian Institute of Health and Welfare (AIHW)	Data comes from Registrars of Births, Deaths and Marriages in each jurisdiction, the National Coronial Information System and the Australian Bureau of Statistics. Linkage variables are used to link datasets to the NDI.
		Queensland Cancer Statistics Online (QCSOL)	Cancer Council Queensland	Online interactive platform that provides statistics on cancer diagnoses, deaths, survival and prevalence for the most common cancers among Queensland residents
		Queensland Cancer Register	Cancer Alliance Queensland	The QCR maintains a register of all cases of cancer diagnosed in Queensland since 1982 (excluding basal and squamous cell carcinomas). Contains demographic information, information on cancer diagnosis, information on patients' hospital stays, and mortality information.
		South Australia Health Cancer Incidence and Mortality Statistics	Government of South Australia – South Australia Health	Yearly reports on cancer incidence and mortality statistics.
		Tasmanian Cancer Registry	University of Tasmania and Menzies Institute for Medical Research	Reports on incidence, mortality, survival and prevalence of cancers in Tasmania.
		Victorian Cancer Registry	Cancer Council Victoria	A record of people with cancer in Victoria; mandatory reporting of all cancer diagnoses by health services, including pathology laboratories. Up-to-date and complete data are collected from 254 hospitals, 11 radiotherapy centers, 7 interstate registries, screening registries, 26 pathology laboratories and death registries, and are collated by person and tumor streams.
		Western Australia Cancer Registry	Government of Western Australia Department of Health	Collects information about cancer diagnoses across the State. Reporting is mandatory from pathology reports and radiation oncology treatment records. The registry can supply incidence and mortality case counts.
		ACT Registrar of Births, Deaths and Marriages	Australian Capital Territory (ACT) Government	The Center for Health Record (CHeReL) at NSW Health provides data linkage infrastructure and services for the linkage of ACT administrative data collections, such as the ACT Cancer Registry, Maternal Perinatal Data Collection, Admitted Patient Care (APC) and Emergency Department (ED) records from public hospitals, and the ACT Notifiable Diseases Management System, and births and deaths from the ACT Registrar of Births, Deaths and Marriages.
Canada	Cervical precancer	Cytobase	Inscyte	Centralized interactive database of cervical cytology (Pap) reports
	Cancer incidence	Administrative Health Datasets	Alberta Health	This dataset consists of processed claims for eligible Albertans and medical reciprocal patients to pay medical doctors and other allied practitioners.
		Alberta Cancer Registry	Not reported	
		BC Cancer Registry	BC Provincial Health Services	The BC Cancer Registry is a database of all new cancers diagnosed in BC residents. It contains personal and demographic as well as diagnosis and death information.
		Canadian Cancer Registry (CCR)	Statistics Canada	Person-oriented dynamic database. Replaced OCRIS; contains cases from 2010 onwards.

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Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
		Canadian Cancer Society	Canadian Cancer Society, Public Health Agency of Canada, Statistics Canada	Canadian Cancer Society provides comprehensive, up-to-date estimates of the cancer burden in Canada.
		Canadian Community Health Survey – Annual component (CCHS)	Canadian Institute for Health Information (CIHI), Statistics Canada and Health Canada	Collects data about health at the community level using computer-assisted telephone and personal interviews
		Cancer Registry	Saskatchewan Cancer Agency	The Saskatchewan cancer registry is a population-based registry and information system designed for the collection, management and analysis of data for residents diagnosed with cancer in the province. The registry links with Saskatchewan Vital Statistics to receive notification on deaths for case ascertainment.
		Cancer System Performance 2018 Report	Canadian Partnership Against Cancer	Measuring and reporting on standardized, high-quality data of the performance of cancer systems across Canada
		Data Holdings	Health Data Nova Scotia	Contains records from provincial administrative health databases, clinical databases and survey datasets provide valuable information related to: insured health services, determinants of health and health outcomes, geographical mapping, national and provincial census and surveys. These datasets are linkable to each other, and to external datasets.
		Health and Community Services	Government of Newfoundland and Labrador	In-province claims history information contains: the date of service the name and specialty of the physician who rendered the service the type of service rendered
		JoRRP national database	Canadian Juvenile Onset Recurrent Respiratory Papillomatosis Working Group	Retrospective database. Data from 1994 to 2007.
		London Health Sciences Center (LHSC) pathology database	NR	
		Manitoba Cancer Registry	CancerCare Manitoba	The Manitoba Cancer Registry is a data system designed for the collection, management and analysis of data on all persons in Manitoba with the diagnosis of a malignant neoplasm (cancer).
		Manitoba Population Research Data Repository	University of Manitoba	Health data maintained by Manitoba Health consisting of claims for physician visits in offices, hospitals and outpatient departments
		Medical Services Plan data set	BC Ministry of Health	Data on medically necessary services provided by fee-for-service practitioners to individuals covered by the Medical Services Plan (MSP), BC's universal insurance program.
		National Cancer Incidence Reporting System	NR	
		National Cancer Reporting System	Statistics Canada	The Canadian Cancer Registry evolved in 1992 from the National Cancer Incidence Reporting System established in 1969.
		New Brunswick Provincial Cancer Registry	New Brunswick Cancer Network	The NBPCR is a population-based central cancer registry.
		NL Cancer Care Registry (NLCCR)	Eastern Health's Provincial Cancer Care Program	The registry is part of the provincial Cancer Care Program of Eastern Health.
		Nova Scotia Cancer Registry	Nova Scotia Department of Health and Wellness (DHW)	Nova Scotia's population-based cancer registry is operated as part of the provincial cancer programme funded by the government.
		Ontario Cancer Registry	Ontario Ministry of Health	Provincial database of information about all Ontario residents diagnosed with cancer. Data sourced from: hospital admission and discharge information from CIHI, pathology reports from public hospitals and community laboratories, consultation and treatment records of patients referred to one of 14 regional cancer centers/ associated hospitals, death certificates from the Ontario Registrar General.

(*Continued*)

Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
		Ontario Cancer Incidence Survey	Not identified	Information only on the 1966 survey identified, and only regarding collection of data on cervical cancer; other types of cancer may also be included.
		PEI Cancer Registry	Government of Prince Edward Island	The information collected includes demographics, cancer-specific diagnostic information, stage at diagnosis, and some treatment information. The registry's main data source is pathology reports with a diagnosis of cancer.
		Quebec Cancer Registry (RQC)	Quebec Ministry of Health and Social Services	The Quebec Cancer Registry (RQC) is a system for recording nominative and clinical data on people with cancer in Quebec.
	Cancer mortality	Administrative Health Datasets	Alberta Health	This dataset consists of processed claims for eligible Albertans and medical reciprocal patients to pay medical doctors and other allied practitioners.
		Annual Statistics Canada Publications	Statistics Canada	
		BC Cancer Registry	BC Provincial Health Services	The BC Cancer Registry is a database of all new cancers diagnosed in BC residents. It contains personal and demographic as well as diagnosis and death information.
		Canadian Cancer Registry (CCR)	Statistics Canada	Person-oriented dynamic database. Replaced OCRIS; contains cases from 2010 onwards.
		Canadian Vital Statistics – Death database (CVSD)	Statistics Canada	Cervical cancer mortality, other types of cancer mortality were not specified in publication
		Cervical cancer screening programs	Statistics Canada	
		Data Holdings	Health Data Nova Scotia	Contains records from provincial administrative health databases, clinical databases and survey datasets provide valuable information related to: insured health services, determinants of health and health outcomes, geographical mapping, national and provincial census and surveys. These datasets are linkable to each other, and to external datasets.
		Manitoba Population Research Data Repository	University of Manitoba	Health data maintained by Manitoba Health consisting of claims for physician visits in offices, hospitals and outpatient departments
		Medical Services Plan data set	BC Ministry of Health	Data on medically necessary services provided by fee-for-service practitioners to individuals covered by the Medical Services Plan (MSP), BC's universal insurance program.

(Continued)

Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
France	Cervical precancer	French Network of Cancer Registries *(Réseau français des registres des cancers observant l'incidence et la mortalité; FRANCIM)*	Le service de biostatistique des Hospices Civils de Lyon	Registry database of different cancer registries in France reporting on cancer incidence and mortality. FRANCIM is linked with the Institute for Public Health Surveillance (*Institut de veille sanitaire; InVS*), the French National Cancer Institute (*Institut national du cancer; INCa*) and the French Epidemiological Center for the Medical Causes of Death (*Center d'épidémiologie sur les causes médicales de Décès; CépiDc*). The different cancer registries include Bas-Rhin, Haut-Rhin, Martinique, Isère, Lille, Calvados, Loire-Atlantique, Manche, Somme, Vendée, New Caledonia, Limousin, French Guiana, Hérault, Maine-et-Loire, Doubs, Territoire de Belfort, Tam, La réunion and Côte-d'Or. This registry comprises data for 20% of the French population.
		EVE organized screening program	National Educational and Health Information Funds *(Fonds national de prévention et éducation sanitaire; FNPEIS)*	Registry of cytological (ASCUS, LSIL, HSIL) and histological (CIN 2/3) results. SCC, cervical adenocarcinoma and invasive endometrial cancers) results from Pap smears.
		Population-based organized cervical cancer screening pilot program	National Health Insurance Fund	Population-based registry from an organized screening program in different departments in France for women aged 25–65 years who had not undergone a cytological screening in the past 3 years.
	Other precancer	Cohort of High-Grade AIN3 Anal Dysplasia	Société Nationale Française de Colo-Proctologie (SNFCP)	Cohort database from a hospital and private practice centers where the treatment of AIN3 is available.
	Cancer incidence	French Network of Cancer Registries *(Réseau français des registres des cancers observant l'incidence et la mortalité; FRANCIM)*	Le service de biostatistique des Hospices civils de Lyon	Registry database of different cancer registries in France reporting on cancer incidence and mortality. FRANCIM is linked with the Institute for Public Health Surveillance (*Institut de veille sanitaire; InVS*), the French National Cancer Institute (*Institut national du cancer; INCa*) and the French Epidemiological Center for the Medical Causes of Death (*Center d'épidémiologie sur les causes médicales de Décès; CépiDc*) registry. The different cancer registries include Bas-Rhin, Haut-Rhin, Martinique, Isère, Lille, Calvados, Loire-Atlantique, Manche, Somme, Vendée, New Caledonia, Limousin, French Guiana, Hérault, Maine-et-Loire, Doubs, Territoire de Belfort, Tam, La Réunion and Côte-d'Or. This registry comprises data for 20% of the French population.
		French HospitalDatabase on HIV (FHDH-ANRS CO4)	Agence Nationale de Recherches sur le SIDA et les Hepatites Virales (ANRS)	French hospital database registry for HIV-infected patients. This database is linked with FRANCIM and INSEE.
		Program for the medicalization of information systems *(Programme de médicalisation des systèmes d'information; PMSI)*	NR	French Hospital Discharge database, which contains medical information on all patients, admitted to hospitals in France. Administrative and claims database. The data included in this database is part of the Système national des données de santé (SNDS) which merges data from PMSI, SNIIRAM and CépiDC.
	Cancer mortality	French Epidemiological Center for the Medical Causes of Death *(Center d'épidémiologie sur les causes médicales de Décès; CépiDc)*	National Institute for Health and Medical Research *(Institut national de la santé et de la recherche médicale; INSERM)*	Registry of mortality and cause of death data first established in 1975. The data included in this database is part of the Système national des données de santé (SNDS) which merges data from PMSI, SNIIRAM and CépiDC.
Italy	Cervical precancer	Data monitoring system PASSI (*Progressi delle Aziende Sanitarie per la Salute in Italia: la sorveglianza Passi [PASSI]*)	Department of Infectious Diseases, National Institute of Health (Istituto Superiore di Sanità – ISS)	National survey report

(*Continued*)

Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
		Cancer screening reports (region-specific)	Region-specific screening programs with corresponding data report, including but not limited tos: Toscana (*Istituto per lo studio, la prevenzione e la rete oncologica; ISPRO*) Lombardia (*Struttura Promozione della Salute e Screening*) Veneto (*Osservatorio Nazionale Screening*) Piemonte (*Prevenzione Serena*) Emilia-Romagna (*Servizio Prevenzione Collettiva e Sanità Pubblica/Servicio Sanitario Regionale Emilia-Romagna; SSREM*)	
	Cancer incidence	Italian Association of Tumor Registries (*Associazione Italiana Rigistri Tumori [AIRTUM]*)	Italian Association of Medical Oncology (*Associazione Italiana di Oncologia Medica*)	AIRTUM is a network of 50 population-based registries and seven accredited specialized registries covering 70% of the Italian population.
		Region-specific cancer registries	Region-specific cancer registries with corresponding data reports: Piedmont Cancer Registry, Umbrian Population-Based Cancer Registry, Parma Cancer Registry, Reggio-Emilia Cancer Registry, Veneto Cancer Registry, Modena Cancer Registry, Ferrara Cancer Registry, Romagna Cancer Registry, Varese Cancer Registry, Sondrio Cancer Registry, Brescia Cancer Registry, Milan Cancer Registry, Mantova Cancer Registry, Como Cancer Registry	
	Cancer mortality	Causes of Death Registry	Italian National Institute of Statistics *(Istituto Nazionale di Statistica; Istat)*	Vaginal, vulvar, and penile cancer are not specifically listed in our sources, however ICD-10 codes are used to access this data.
Scotland	Cancer incidence	Cancer Registry in Scotland	Public Health Scotland	Collects and gives access to cancer-related information from across NHS Scotland
	Cancer mortality	Vital Events – Deaths	National Records of Scotland	Provides statistics about causes of deaths.
Sweden	Cervical precancer	Swedish Cancer Register (*Cancerregistret*)	National Board of Health and Welfare (*Socialstyrelsen*)	Centralized, nationwide register
	Cancer incidence	Swedish Cancer Register (*Cancerregistret*)	National Board of Health and Welfare (*Socialstyrelsen*)	Centralized, nationwide register
	Cancer mortality	Cause of Death Register (*Dödsorsaksregistret*)	National Board of Health and Welfare (*Socialstyrelsen*)	Centralized, nationwide register

(*Continued*)

Table 5. (Continued).

Country	Outcome	Data system	Source	Comments
United States	Cervical precancer	Human Papillomavirus Vaccine Impact Monitoring Project (HPV-IMPACT)	Centers for Disease Control and Prevention (CDC)	Monitors the rates of high-grade cervical lesions in women in the United States to determine the impact of the U.S. HPV vaccination program on cervical precancers caused by HPV.
	Cancer incidence	National Program of Cancer Registries (NPCR)	Centers for Disease Control and Prevention (CDC)	The National Program of Cancer Registries (NPCR) collects data on cancer occurrence (including the type, extent, and location of the cancer), the type of initial treatment, and outcomes.
		SEER Registries	National Institutes of Health – National Cancer Institute	SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 35% of the U.S. population.
		United States Cancer Statistics (USCS)	*[Combined data from the NPCR and SEER registries]*	*[Combined data from NPCR and the SEER Program include cancer incidence and population data for all 50 states, the District of Columbia, and Puerto Rico; reporting all incident cases coded as in situ (nonmalignant) and invasive (malignant; primary site only).]*
		National Cancer Database (NCDB)	The Commission on Cancer (CoC) of the American College of Surgeons and the American Cancer Society	A nationwide oncology outcomes database for more than 1,500 Commission-accredited cancer programs in the United States and Puerto Rico. Some 70% of all newly diagnosed cases of cancer in the United States are captured at the institutional level and reported to the NCDB.
		MarketScan® Commercial Claims and Encounters (Commercial) Database	IBM	Includes claims for medical services
		Optum's Clinformatics	NR	Includes claims for medical services
		Truven's MarketScan Medicaid database	NR	Includes claims for medical services
		Automated Central Tumor Registry (ACTUR)	Department of Defense (DOD)	Registry used for cancer research and surveillance in DOD beneficiaries.
		Military Health System Data Repository (MHS)	Department of Defense (DOD)	Centralized data warehouse about healthcare provided to beneficiaries of the MHS
	Cancer mortality	National Vital Statistics System (NVSS) – Mortality Medical Data System	CDC National Center for Health Statistics	Includes cause-of-death information reported on death certificates.
		National Program of Cancer Registries (NPCR)	Centers for Disease Control and Prevention (CDC)	The National Program of Cancer Registries (NPCR) collects data on cancer occurrence (including the type, extent, and location of the cancer), the type of initial treatment, and outcomes.
		SEER Registries	National Institutes of Health – National Cancer Institute	SEER currently collects and publishes cancer incidence and survival data from population-based cancer registries covering approximately 35% of the U.S. population.

HIC: high-income country; HPV: human papillomavirus; NR: not reported.

effective surveillance of multiple interventions, processes, and clinical outcomes, at present fully integrated systems are rare because of privacy protection legislation that prevail in most jurisdictions. Data collection relating to interventions (e.g. vaccination), processes (e.g. cervical cancer screening), and outcomes (prevalence of infection, early detection of precancer, and cancer incidence) are currently collected as independent non-linked activities. Comprehensive data systems with valid data sources and reliable linkage among segmented platforms will allow researchers to develop actionable conclusions from the collected data.

Strengths and limitations of existing data systems in high income countries should be closely considered by those who are designing or implementing new systems in LMICs. Such limitations may include fragmented collection of data by subnational entities (without organized national pooling of data), collection of incomplete or non-validated data that is not 'research-grade,' or lack of coverage of surrogate endpoints. In all, these limitations hinder a proper understanding of the burden of disease, or the effectiveness of interventions. The groundswell of support in recent years for universal health care is a positive development, by placing political will in support of the aforementioned tenets for effective, centralized data collection and rational integration of resources and information.

Serendipitously, since the onset of the SARS-CoV-2 pandemic in 2020, countries have had to rapidly adopt disease monitoring, deploy COVID-19 vaccination, and track vaccination coverage using real-time digital platforms. It would be a wasted opportunity not to apply the hard lessons learned with pandemic control and surveillance, as well as the key learnings from research into COVID-19 vaccination, to data collection activities in other preventable infectious diseases, such as those caused by HPV. Improvements in this area may contribute to a greater understanding of the effectiveness of newer intervention paradigms, such as gender-neutral HPV vaccination.

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Authors contributions

All authors have contributed to the conception and design of the review and interpretation of results. All authors were also involved in the writing and review of the presented manuscript.

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