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Implementing Cancer Genomics in State Health Agencies: Mapping Activities to an Implementation Science Outcome Framework

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Abstract

Objective: To show how state health agencies can plan and evaluate activities to strengthen the evidence base for public health genomics, we mapped state cancer genomics activities to the Doyle et al. implementation science outcome framework.

Methods: We identified state health agency activities addressing hereditary breast and ovarian cancer (HBOC) and Lynch syndrome (LS) by reviewing project narratives from Centers for Disease Control and Prevention (CDC) Cancer Genomics Program funding recipients, leading discussions with state health agencies, and conducting an environmental scan.

Results: State health agencies' cancer genomics activities included developing or adding to state surveillance systems, developing educational materials, bidirectional reporting, promoting health plan policy change, training providers, and promoting recommendations and standards. To address

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Author Contributions

RFG was the primary author of the manuscript, led discussions with states, reviewed project narratives, conducted the environmental scan, and analyzed the data collected. MTK and JLR reviewed project narratives, identified state activities, assisted with data analysis, and assisted with manuscript preparation. SA and SHB scheduled and participated in discussions with states, obtained project narratives from states, and reviewed the manuscript. LS participated in discussions with states, identified state activities, assisted with data analysis, and assisted with manuscript preparation.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Statement of Ethics

Ethical review was not required as this project was determined to be public health practice, not research by the CDC Division of Public Health Information Dissemination Associate Director for Science.

Disclosure Statement

The authors have no conflicts of interest to declare.

health disparities, programs have tracked group differences, developed culturally-appropriate educational materials, and promoted access to services for underserved populations.

Conclusion: State health agencies can use the Doyle et al. performance objectives and outcome measures to evaluate proposed and ongoing activities. By demonstrating whether activities result in improved outcomes, state health agencies can build the evidence for the implementation of cancer genomics activities.

Keywords

state health agency; hereditary breast and ovarian cancer; Lynch syndrome; implementation; evaluation

Introduction

State health agencies have played a pivotal role in implementing the United States Preventive Services Task Force (USPSTF) (1) and Evaluation of Genomics Activities in Practice and Prevention (EGAPP) (2) recommendations on Hereditary Breast and Ovarian Cancer (HBOC) and Lynch syndrome (LS) (3, 4). These recommendations address identification of individuals with HBOC and LS, who may be appropriate for risk-reducing interventions due to their increased cancer risk. Changes in criteria regarding who should be offered HBOC testing, as well as calls for population-based HBOC screening (5), could mean a widening pool of those eligible for HBOC testing. This will increase the need for a population-level approach that addresses health disparities. State health agencies are well positioned to help meet this need due to their experience in collecting population-level cancer surveillance data, working to improve cancer screening in low-income populations (6), establishing partnerships, and program planning and evaluation. By serving as an "honest broker," state health agencies can bring stakeholders together and provide an unbiased assessment of the benefits and limitations of genomics applications (7).

Approximately 70% of state cancer plans include objectives, strategies, or goals related to cancer family history, hereditary cancers, LS, or HBOC, indicating that cancer genomics is a priority for most states (3). Seven state health agencies have received or currently receive CDC Cancer Genomics Program funding to develop innovative programs that will advance implementation of public health genomics. Broadening cancer genomics approaches beyond the CDC Cancer Genomics Program funding recipients requires both evaluating cancer genomics activities to strengthen the evidence base supporting their use and disseminating information about these activities. While state health agencies without CDC Cancer Genomics Program funding might find implementation of cancer genomics activities challenging, they might be able to adapt some programs developed by CDC funding recipients. Furthermore, some state health agencies might already include cancer genomics approaches in health promotion activities, even if state health agencies do not label them as such, and could contribute to the evidence base by evaluating these activities.

This publication is a product of a subgroup of the Genomics and Population Health Action Collaborative (GPHAC) (8), an *ad hoc* activity of the National Academies of Sciences, Engineering, and Medicine's Roundtable on Genomics and Precision Health convened to

identify challenges and best practices for the widespread integration of evidence-based genomics applications in population health programs, with a focus on state health agencies. As part of GPHAC, Doyle et al. (9) developed performance objectives and outcome measures that state health agencies can use to evaluate activities addressing HBOC and LS. They categorized performance objectives and outcome measures as: a) top priority outcomes all states are encouraged to pursue, b) outcomes states can readily perform, c) outcomes states can readily perform if data sources are available, and d) aspirational outcomes (9).

In this paper, we present examples of state health agencies' cancer genomics activities and show how they can be mapped to Doyle et al.'s performance objectives and outcome measures. Our goal is to encourage state health agencies to use the Doyle et al. framework to evaluate activities they are already doing or have proposed to do and to help state health agencies make connections between potential cancer genomics activities and outcomes that are priorities for their state.

Materials and Methods

We identified state health agency activities that address HBOC and LS using three methods: review of project narratives from CDC Cancer Genomics Program 2014–2019 funding recipients, discussions with state health agency officials, and an environmental scan to identify published literature and other publicly available resources.

Project narratives

CDC funded five state health agencies through a 2014–2019 cooperative agreement to enhance cancer genomics best practices through education, surveillance and policy (10). We reviewed the project narratives from the initial funding applications, which provided brief descriptions of the proposed approaches for the first year of funding.

Discussions with State Health Agency Officials

We consulted GPHAC participants to identify state health agencies with different levels of experience in implementing genomics and contacted a convenience sample of 20 state health agencies to ask whether they would be willing to discuss HBOC and LS activities in their states. Contacted states varied by whether they had current or previous CDC funding for cancer genomics activities; state cancer plan goals, objectives, or strategies addressing HBOC or LS (3); and experience implementing cancer genomics activities. We were able to talk with staff from 12 state health agencies, with two or more states from each U.S. census region (West, Midwest, Northeast, and South) included. Discussions focused on current, past, and potential projects addressing HBOC or LS, including facilitators, barriers, interest level, and lessons learned. When possible, discussions included multiple participants, such as state genetics coordinators, cancer division directors, chronic disease directors, and cancer registry directors, to stimulate conversations within health agencies about HBOC and LS. We recorded discussions and produced short summaries and verbatim transcripts.

Environmental scan

To gather publicly available materials for specific activities that were described in discussions with state health agencies or program documents, we performed a series of brief web and literature searches using key words identified from those sources, for example, searching for the name that a state health agency used to refer to a program. For these searches, we used PubMed to identify peer-reviewed literature. To identify materials that had not been published in the scientific literature, we reviewed websites of state health agencies with which we had discussions or which were current or previous CDC Cancer Genomics Program funding recipients. Other resources included the CDC website and websites identified through Google and other search engines, such as those of organizations that partnered with state health agencies.

Data Analysis

We categorized activities according to the core public health functions of assessment, policy development, and assurance (11); the CDC Cancer Genomics Program activity type categories of education, policy, and surveillance (10); and the Doyle et al. performance objectives and outcome measures they addressed. Assessment relates to identification of health problems in a population, policy development involves allocation of resources to meet public health challenges, and assurance deals with providing services to meet health objectives. We excluded activities that did not address any Doyle et al. performance objectives or outcome measures and Doyle et al. performance objectives and outcome measures not addressed by activities we identified.

Results

Table 1 lists the Doyle et al. performance objectives and outcomes and the corresponding education, surveillance, and policy activities proposed or conducted by state health agencies, grouped by the core public health functions of assessment, policy development, and assurance (12). Here we highlight select approaches and provide published or publicly available examples of state activities.

Top-Priority Objectives

The Doyle et al. framework includes three top-priority performance objectives: increase use of genetic counseling in women with a family history of HBOC or LS, increase LS genetic testing in those with newly diagnosed colorectal cancer, and increase the number of family members tested for HBOC or LS through cascade screening (9).

Assessment

Some state cancer plans include goals, objectives, or strategies similar to the performance objectives to increase use of genetic counseling in women with a family history of HBOC or LS and increase LS genetic testing in those with newly diagnosed colorectal cancer (3). To collect baseline data and monitor progress toward achieving these objectives, some state health agencies have added questions to the Behavioral Risk Factor Surveillance System

(BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS), and other surveillance systems. The Michigan Department of Health and Human Services (Michigan) used BRFSS data to track changes in the proportion of women with a family history consistent with HBOC who received genetic counseling to measure progress towards Healthy People 2020 objectives (13). The PRAMS Phase 8 standard questions include questions about family history of breast and ovarian cancer and genetic counseling, which could be used to look at genetic counseling in women with a family history consistent with HBOC (14). CDC provided a competitive funding opportunity to state health agencies to include these questions on their state PRAMS. Colorado Department of Public Health and Environment (Colorado), Utah Department of Health (Utah), Washington Department of Health (Washington), and Michigan included these questions in their Phase 8 (2016–2020) PRAMS survey (14, 15). Michigan included (without funding support) breast and ovarian cancer family history questions in their 2012–2015 surveys (14, 15).

Assurance

While the role of state health agencies in moving cascade screening forward is still being explored, some state health agencies have laid the groundwork. The Oregon Health Authority (Oregon) reviewed opportunities and challenges to HBOC and LS cascade screening, including lack of awareness of increased risk and need for genetic testing among family members; inadequate insurance coverage; providers not identifying and referring at-risk patients; shortage of genetics specialists, especially outside metropolitan areas; and lack of family communication support (16). Washington and Oregon surveyed gastroenterologists about current practices and needs related to LS cascade screening (17), and Washington developed a fact sheet on cascade screening for LS based on the survey findings (18). Several state health agencies have promoted tools to help the public collect and share family history information, such as the Surgeon General's My Family Health Portrait (19) and Kintalk (20).

Ready for Action and Aspirational Objectives

Doyle et al. identified 19 objectives they considered ready for action and which state health agencies could implement immediately, two that can be readily performed if data sources are available, and 14 classified as aspirational.

Assessment

Ready for action: States have access to reliable information/data to inform program planning and policy—State health agencies have used secondary data analysis, existing state-level surveillance systems, and primary data collection for surveillance. Utah and partners linked cancer registry data to genealogic records in the Utah Population Database to develop a population-based estimate of the percentage of Utahns with and without a personal history of *BRCA*-related cancer who met criteria for HBOC genetic testing (21). Some state health agencies have tracked genetic services use through hospital chart review by partnering with genetics clinics in the state and analysis of claims data (22). Including state-added questions on BRFSS can provide population-level data to measure outcomes related to personal and family cancer history, information sharing with

providers and family members, and genetic services use. Pilot testing new fields for family history, LS screening, and genetic testing in the state cancer registry has enabled state health agencies to determine the feasibility of extracting and systematically collecting these data from hospital registries. Since 2006, the Michigan Cancer Report Form (23) has included questions asking whether the patient has a family history of cancer, whether it affected an immediate relative, and whether it was in the same anatomical site.

Aspirational: Bidirectional cancer registry reporting—Some state health agencies have used state cancer registry data to identify individuals at increased risk for HBOC or LS, based on their cancer diagnosis and age at diagnosis, and have developed reports that are shared with the reporting provider or institution and include aggregate data on numbers of individuals who are candidates for risk assessment. While the delay in the registry receiving patient information meant that these data did not influence patient care (24), state health agencies have used this these reports to raise awareness of the number of at-risk patients within the institution, encourage quality assessment to determine whether patients are being referred appropriately, and provide educational materials useful for providers, patients, and hospital administrators involved in quality improvement (4). One state health agency recommended working with graphics and health communications specialists to make the reports given to each institution personalized, easy to understand, and visually appealing (D.L. Doyle, *personal communication).* To assist state health agencies, CDC developed customizable written materials (25) on HBOC and LS, including fact sheets for providers and patients, guideline summaries, sample reporting forms, and letters for relatives.

Policy development

Ready for action: Mechanisms exist for adequate billing and reimbursement of services—State health agencies have worked with health plans to align cancer genetic services coverage with recommendations from the USPSTF (1) EGAPP (2) and National Comprehensive Cancer Network (NCCN) (26, 27). Michigan found that lack of insurance or concern about out-of-pocket cost was one of the most common reasons for not pursuing *BRCA* genetic testing following genetic counseling (22). In response to this, Michigan promoted the development of written policies aligned with the USPSTF recommendation (28) to their health plan partners with the goal of increasing the proportion of insured Michigan residents who had coverage aligned with the recommendation. This approach included identifying and working with a key health plan policymaker who championed coverage according to the recommendation, educating health plan administrators, assessing current health plan policies, and partnering with a statewide health plan organization to honor health plans that aligned their policies with the recommendation. For those health plans that did not provide coverage in alignment with national recommendations at the time of the award, Michigan offered technical assistance, such as an explanation of evidence-based recommendations and model language that insurers could include in policies (29). Their efforts increased the number of health plans in their state with written policies consistent with the USPSTF *BRCA* Recommendation, from 4 to 16 between 2008 and 2014 (4, 29). The implementation of the Patient Protection and Affordable Care Act of 2010 likely contributed to the success of this strategy (29, 30). To evaluate the impact of this work, Michigan tracked *BRCA* genetic counseling and testing at cancer genetics clinics in patients

with and without coverage consistent with the USPSTF recommendation (29). Most patients receiving *BRCA* genetic services had coverage aligned with the USPSTF recommendation, and fewer patients cited inadequate insurance as the reason for not having testing as the number of plans providing coverage aligned with the USPSTF recommendation increased (29).

Ready for action: Increase the number of providers who are comfortable and willing to provide HBOC/LS screening services and appropriately refer HBOC/LS families—State health agencies have surveyed providers to determine knowledge, interest, barriers, and current practices related to HBOC and LS and offered provider training to address existing gaps. For example, Oregon surveyed providers and identified multiple barriers, such as providers' lack of confidence in their medical genetics knowledge and lack of familiarity with recommended genetic tests (31). State health agencies have offered in-person training, including presentations at Grand Rounds and other meetings that clinicians regularly attend and one-day educational workshops. For providers in rural and frontier areas, state health agencies reported more participation in trainings when health agency staff traveled to regional sites across the state compared with giving providers travel awards to attend trainings at a central location. State health agencies recommended making training sessions case-based and interactive and identifying a presenter with subject matter expertise. To assist with these presentations, CDC developed a customizable presentation on HBOC and LS (25). To evaluate trainings, some state health agencies have used surveys to assess knowledge before and after trainings, as suggested by Doyle et al. (9).

Although some state health agencies reported limited participation for in-person trainings, some have tried to encourage participation by providing incentives to those completing training, such as continuing medical education (CME) credits and working with insurers to offer a discount on annual medical liability insurance premiums. Some state health agencies offered opportunities for technical assistance through a toll-free number or email (32). Some state health agencies offered online training or recorded live sessions, allowing clinicians to access the information on demand (32–34). Michigan, Oregon, and the Georgia Department of Public Health (DPH) developed an online CME course on HBOC (35) in collaboration with the Jackson Laboratory Clinical and Continuing Education Program (formerly the National Coalition for Health Profession Education in Genetics).

Assurance

Ready for action: Increase appropriate genetic counseling linked with HBOC/LS testing and reduce misinterpreted genetic test results—State health agencies have taken steps to help ensure quality in genetic counseling. Some state health agencies have educated stakeholders about the impact of state licensure for genetic counselors, which requires that those providing genetic counseling meet minimum competency standards. The American College of Surgeons' Commission on Cancer accreditation includes standard 2.3 "Genetic Counseling and Risk Assessment," which addresses access to genetics services and defines the training required for clinicians providing genetic counseling (36). Some state health agencies reported that accreditation

may serve as an incentive for institutions to implement approaches to identify patients at increased risk for hereditary cancers and provided technical assistance in meeting this standard to health systems and clinics lacking on-site genetics professionals. To identify areas for improvement, state health agencies have surveyed patients about barriers and facilitators for genetic counseling and testing (22).

Taking Action to Mitigate Health Disparities

Ready for action if data available: Decrease health inequalities regarding access to genetic testing/counseling

States have tracked health disparities in genetic counseling, testing, and health outcomes to identify populations needing targeted efforts. Michigan staff collaborated on a survey of black young cancer survivors enrolled in a research study to explore drivers of the lower rates of genetic counseling and testing in blacks compared with whites and found that “no one ever suggested it” was the main reason reported for not seeking cancer genetic services (37). Using PRAMS data, Michigan estimated the prevalence of family history of breast and ovarian cancer in Michigan mothers who gave birth between 2012–2015 and found that black non-Hispanic mothers reported higher rates of family history of breast cancer at a young age compared with white non-Hispanic mothers (15).

Some state health agencies have sought to mitigate disparities by ensuring that educational materials are culturally sensitive and translated into languages other than English, targeting educational outreach to high-risk or underserved populations, and disseminating materials through community health workers or peer navigators (38). For example, the Connecticut Department of Health partnered with community-based health organizations to reach underserved populations with family history educational messages through radio public service announcements, dissemination of materials at community events, incorporation of family history questions or discussion into health consultations, and training outreach educators on family history collection (39).

State health agencies have introduced policy innovations that could help reduce disparities in access to care. Some state health agencies have integrated family history questionnaires or risk assessment tools into the workflow of clinical programs like breast and cervical cancer screening, women’s health, and family planning programs (40). Georgia DPH, through the Georgia Breast Cancer Genomic Health Consortium, worked with public health centers staff to screen minority and underserved women for HBOC using the Breast Cancer Genetics Referral Screening Tool (B-RST) during visits to family planning clinics and to public health centers for routine exams or breast complaints (41). Those identified at risk received assistance for further family history risk assessment and genetic testing funded through the state Breast Cancer License Plate Program (42).

Ready for action: Increase the availability of telegenetic services

To support underserved communities with limited access to reliable transportation and those living in areas without nearby genetic services, some state health agencies have provided telegenetics training for genetic services providers, educated rural providers and residents

about the availability of telegenetics and regional outreach clinics, and convened telegenetics stakeholders.

Discussion

Figure 1 illustrates guiding questions and steps that we propose for state health agencies interested in expanding their cancer genomics activities. State health agencies may consider priorities, local context, available data sources, partners, and state-specific policies and resources to determine which approaches are feasible for their state (Figure 1). State health agencies might prioritize activities not requiring significant resources, such as promoting existing online CME courses, integrating cancer genomics messaging into existing materials, and developing partnerships to integrate cancer genomics into existing programs. After identifying the inability to pay for genetic counseling and testing as a barrier to integrating risk assessment into existing programs, some CDC Cancer Genomics funding recipients were able to leverage partnerships with other state health agency units to allocate fees from the Breast Cancer License Plate Program to pay for genetic services for under- and uninsured women (42), while others sought funding from foundations or other sources. To establish cancer genomics as a state priority, state health agencies can add objectives, strategies, or goals related to HBOC and LS if they are not already included in their state cancer plan (3).

Although CDC Cancer Genomics funding is limited to a few state health agencies, some state health agencies without dedicated funding have been able to take action on cancer genomics. While most state health agencies that have added questions to BRFSS have been CDC Cancer Genomics Program funding recipients, a few state health agencies without this funding have added questions related to family history of cancer and genetic testing. Likewise, most states with bidirectional reporting programs have been CDC Cancer Genomics Program funding recipients. However, a few states without this funding used cancer registry data to inform institutions in their state about the number of patients in their care potentially at high risk for HBOC and LS, and one reported that two large clinics in their state changed their policies to automatically refer patients meeting the risk criteria (D.L. Doyle, *personal communication).* Some state health agencies that have not received CDC Cancer Genomics Program funding have obtained funding for specific projects, for example, adding HBOC-related questions to PRAMS or pilot testing the addition of new or emerging cancer prognostic factors (such as *BRCA)* to the state cancer registry.

Some states have mobilized state-specific resources that may make it challenging to replicate a program in other settings. For example, Michigan partnered with a state-level professional organization for payers to recognize health plans with coverage aligned with national recommendations, but some states lack an equivalent professional organization for payers. Utah worked with their partners to link data from the cancer registry to the Utah Population Database, a research database housed at the University of Utah. Bidirectional reporting requires a strong relationship with the state cancer registry and partnerships with the reporting institutions to encourage action.

Our study has several limitations. CDC Cancer Genomics Program funding recipients' project narratives submitted to the CDC were proposals for the first year of funding and these activities might not have been subsequently initiated, completed, or evaluated rigorously by the state health agency. The activities described here have varying levels of evidence to support their implementation and assessing the effectiveness of the activities is beyond the scope of this paper. Since most activities identified here have limited evidence to support widespread implementation, it is important for state health agencies to pilot activities in multiple settings with diverse populations and to rigorously evaluate these activities to build the evidence base for implementation of cancer genomics activities. Project narratives and most discussions with state health agencies were completed prior to the publication of the Doyle et al. framework. Thus, state health agencies did not consider the framework when describing activities. Mapping of activities to the framework was done by the authors. Although we did not identify activities that addressed some objectives and outcomes, we cannot assume that state health agencies did not have activities that addressed them. The fact that we did not identify related activities does not mean that these objectives and outcomes are less important than the others for which activities were identified. Furthermore, how state health agencies themselves identified activities varied. For example, some state health agencies described activities that we might have labeled as bidirectional reporting but did not themselves consider these activities to be bidirectional reporting and when asked about their bidirectional reporting activities would state that they did not have any. Most state health agency activities aligned with the Doyle et al. performance objectives and outcome measures, with one notable exception. Many state health agencies have public education activities focused on family history and hereditary cancers, but the Doyle et al. framework did not include a performance objective or outcome measure related to increasing the public's awareness of hereditary cancers, as this was considered a process rather than outcome measure. Our study focused only on cancer genomics activities related to HBOC and LS, but similar approaches may be relevant for other conditions such as familial hypercholesterolemia.

Conclusion

The Doyle et al. performance objectives are structurally similar to activities state health agencies are already conducting as part of the core public health functions. By linking current and planned activities to healthcare service utilization and health outcomes, such as those in the Doyle et al. paper, state health agencies can identify feasible activities to prioritize and contribute to the evidence base for public health action in cancer genomics through evaluation of activities. State health agencies play an important role in monitoring and addressing health disparities, and their involvement will be essential to ensure that genomics advances do not widen health disparities.

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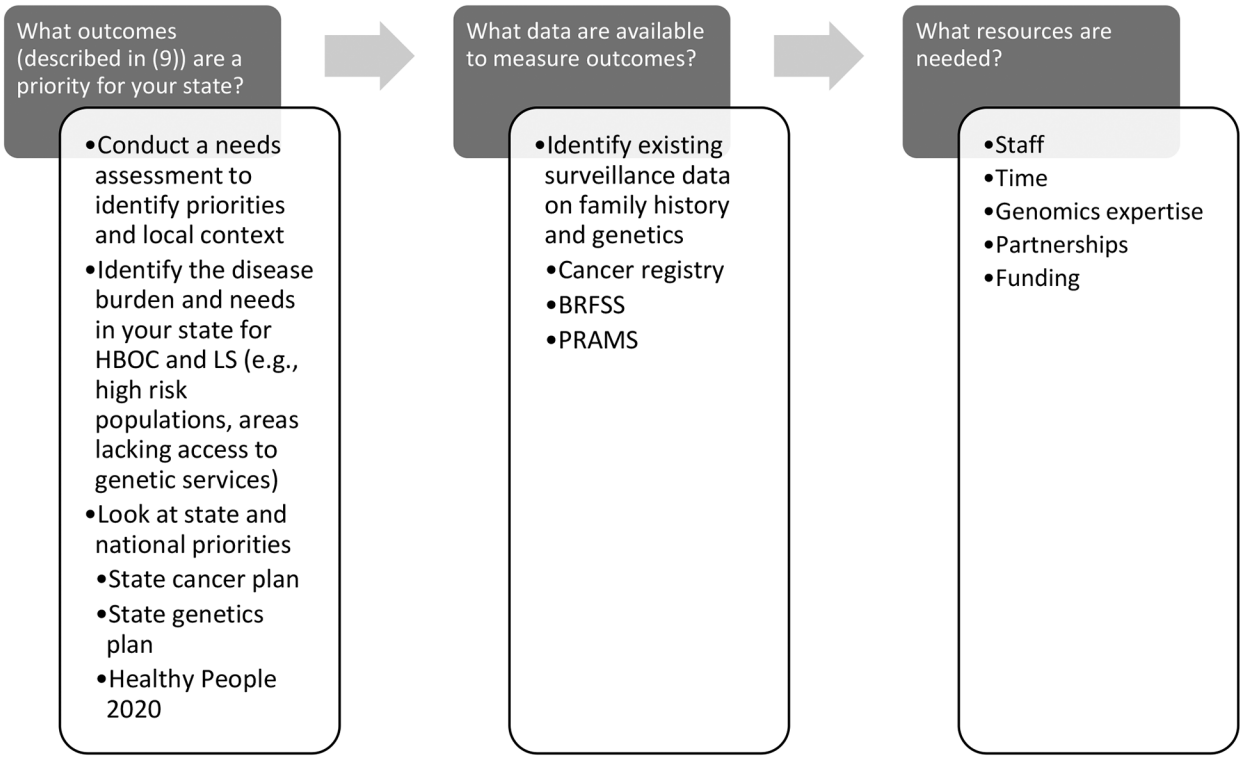
Surveillance



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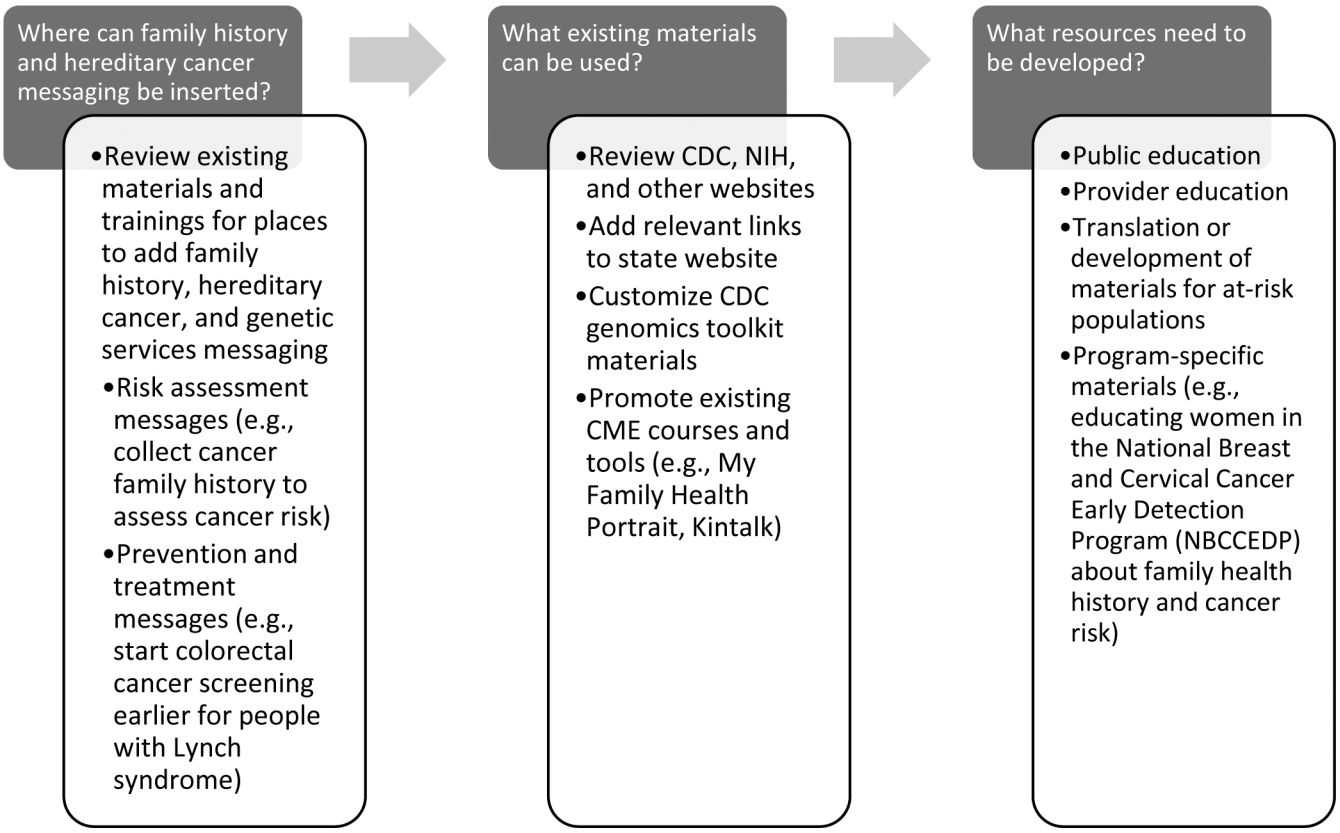

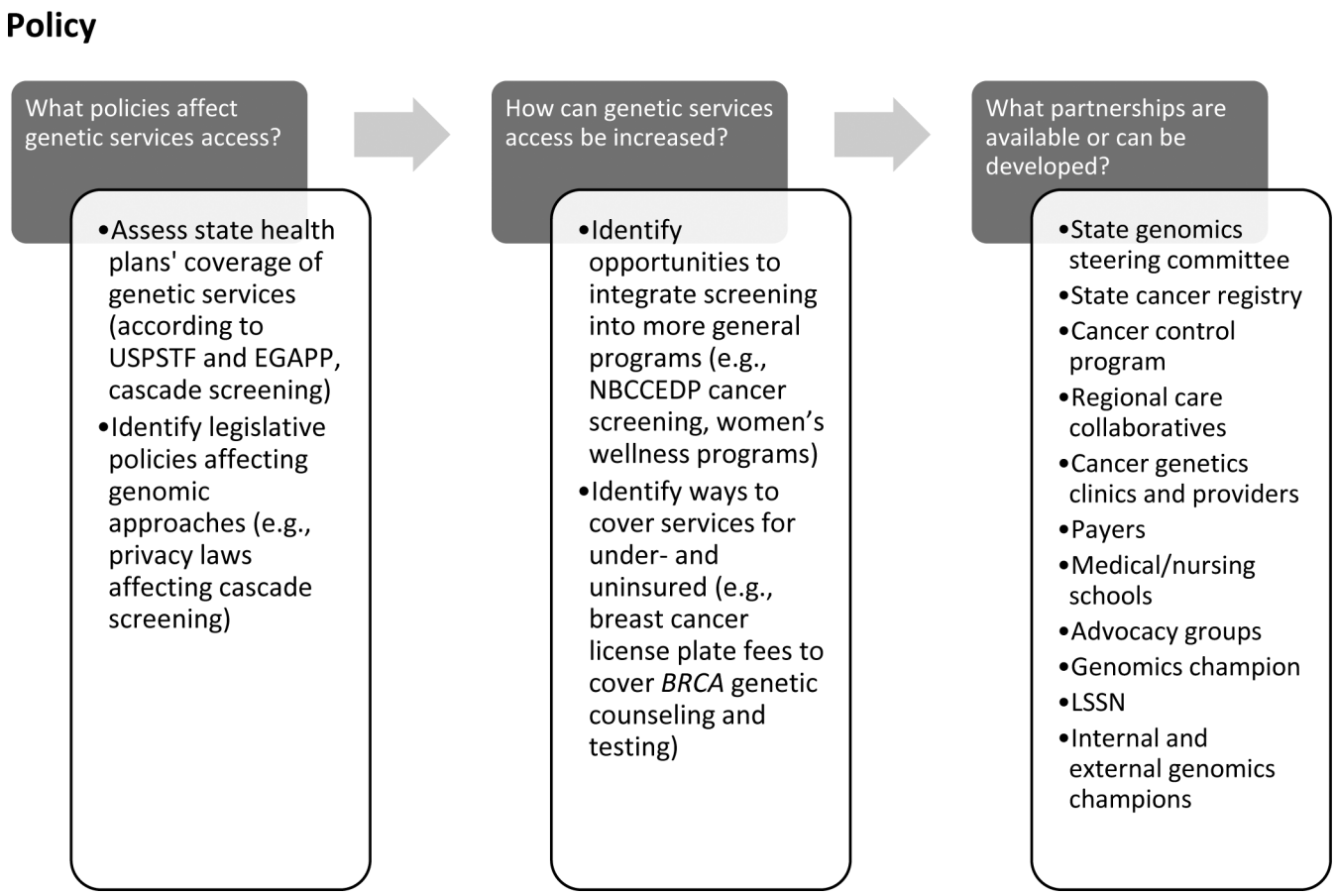

Fig. 1.

First steps for state health agencies to consider when implementing genomics activities Acronyms used: HBOC=hereditary breast and ovarian cancer, LS=Lynch syndrome, BRFSS=Behavioral Risk Factor Surveillance System, PRAMS=Pregnancy Risk Assessment Monitoring System, CDC=Centers for Disease Control and Prevention, NIH=National Institutes of Health, CME=continuing medical education, NBCCEDP=National Breast and Cervical Cancer Early Detection Program, USPSTF=United States Preventive Services Task Force, EGAPP=Evaluation of Genomics Activities in Practice and Prevention, *BRCA=breast cancer gene,* LSSN=Lynch syndrome screening network

Table 1.

Types of state activities that address performance objectives and outcomes described by Doyle et al. (9)

Doyle et al. (9) Performance Objectives	Doyle et al. (9) Outcome Measures	State-level activities that have addressed objective or outcome
Top Priority		
Assessment		
Increase the proportion of women with a family history of hereditary breast and ovarian cancer (HBOC)/Lynch syndrome (LS) who receive genetic counseling (reworded version of Healthy People (HP) 2020 objective) Increase the proportion of persons with newly diagnosed colorectal cancer (CRC) who receive genetic testing to identify LS or other familial CRC syndromes (HP2020 objective)	Number of women with a family history of HBOC/LS who receive genetic counseling Number of persons with newly diagnosed CRC who receive genetic testing to identify LS (or familial CRC syndromes)	*Policy*: SHA have developed state cancer plans that include these priorities in their goals, objectives or strategies SHA have provided public comments on United States Preventive Services Task Force (USPSTF) and other recommendations *Surveillance*: SHA have added questions to BRFSS, PRAMS, and other surveys to monitor progress toward achieving these outcomes
Assurance		
Increase the number of family members (per family) tested for HBOC/LS through cascade screening	Number of family members screened following identification of HBOC/LS pathogenic variants	*Education*: State health agencies (SHA) have educated providers and the public about cascade screening to help identify at-risk relatives of individuals diagnosed with HBOC and LS SHA have promoted My Family Health Portrait (19) and Kintalk (20) to collect and share family health history information *Policy*: SHA have reviewed state health plan policies to see in what way cascade screening is covered to determine impact *Surveillance*: SHA have used survey methods to identify barriers and facilitators for cascade testing SHA have surveyed providers about current practices regarding cascade screening SHA have monitored trends in single site genetic testing, a type of genetic test used in cascade screening SHA have partnered with Kintalk (20) to monitor use in state
Ready for Action, Ready for Action if Data Available, and Aspirational		
Assessment		
States have access to reliable information/ data to inform program planning and policy[a]	Numbers and types of population-level data inclusive of genomics	*Surveillance*: SHA have abstracted medical records of individuals from the cancer registry to determine if family history, referrals for genetic services, genetic counseling, and genetic testing are documented in the medical record in order to determine feasibility of including this information as required data fields in the cancer registry SHA have added data fields to cancer registry, including cancer family history, genetic testing results, and microsatellite instability (MSI) screening results SHA have promoted inclusion of genetic data in state-based claims databases SHA have developed surveillance systems by partnering with genetics clinics to collect HIPAA-limited data on patients receiving genetic counseling and testing SHA have piloted data linkages between claims, cancer registry, and available clinical data SHA have added questions to existing surveillance systems such as BRFSS and PRAMS to assess breast, ovarian, and colorectal cancer family history, and whether respondents had undergone risk assessment, genetic counseling and testing
Increase the number of hospitals/ institutions that have implemented tumor	Number of hospitals/institutions offering tumor screening Number of CRC patients screened	*Policy*: SHA have promoted membership in the Lynch Syndrome Screening Network to hospitals in the state that treat colorectal cancer patients

Doyle et al. (9) Performance Objectives	Doyle et al. (9) Outcome Measures	State-level activities that have addressed objective or outcome
screening to identify LS[a] All newly diagnosed patients with CRC are screened for LS[c] Increase the number of tumors screened for LS at each institution[c] Increase the number of hospitals performing tumor screening that have a tracking system in place[a]	for LS Number of tumors screened for LS by Institution Number of hospitals with a tracking system for tumor screening	*Surveillance*: SHA have reviewed hospital charts of patients with colorectal cancer to track rates of LS tumor screening
Initiate bidirectional reporting by identifying individuals at increased risk for hereditary cancer through personal history in cancer registry[c]	Number of state cancer registries that offer bidirectional reporting Number of state cancer registries that offer bidirectional reporting; number of investigations conducted/ year; number of hospital cancer registries that have the capacity for bidirectional reporting	*Education/Policy:* SHA have reached out to reporting hospitals that have added patients to the cancer registry who were appropriate for evaluation for referral to cancer genetic services due to their personal cancer history. Materials developed for outreach to the reporting hospital, the reporting provider, and directly to the patient include: • Individualized hospital reports for each reporting institution in the state with aggregate numbers of patients that meet National Comprehensive Cancer Network (NCCN) guidelines (26,27) • Follow up surveys for institutions to identify any changes to institutional policies in response to reports received • Patient and provider educational materials • Letters sent by cancer registry to providers alerting them of at-risk individuals who should be assessed for referral to genetic counseling • Follow up surveys for providers seeking feedback on how they plan to use data and educational materials • Letters sent by the cancer registry to patients alerting them of their cancer risk • Follow up surveys for patients to see which services they have obtained
Policy development		
Mechanisms exist for adequate billing and reimbursement of services[a] Mechanisms for adequate billing and reimbursement services are maintained over time[a]	Number of health plans with existing reimbursement for services Description of existing mechanism for billing and reimbursement	*Education*: SHA have educated payers about coverage for cancer genomics services according to guidelines by: • Working with regional organizations that coordinate the care of Medicaid patients in the state as a means to educate major health plans • Meeting health plan administrators and medical directors to review the guidelines • Developing individualized educational packets for health plans • Providing model written policies • Offering technical assistance to health plans *Surveillance*: SHA have analyzed claims data to determine the number and percent of individuals covered by insurance or Medicaid who have received genetic counseling and testing for HBOC SHA have worked with clinical genetics providers to track the number of patients seen for genetic counseling and testing for HBOC and reasons for not pursuing *BRCA* testing, including inadequate insurance coverage *Policy*: SHA have reviewed written policies of health plans operating in the state and developed individual health plan reports SHA have recognized state health plans for having written policies aligned with cancer genomics best practices

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Doyle et al. (9) Performance Objectives	Doyle et al. (9) Outcome Measures	State-level activities that have addressed objective or outcome
		for HBOC and LS SHA have conducted key informant interviews and focus groups with health plan administrators to assess barriers and facilitators to having evidence-based coverage policies SHA have created and disseminated forms for clinicians to use when ordering genetic tests for Medicaid clients to aid in coverage decisions by managed care directors
Increase the number of providers who are comfortable providing HBOC/LS screening services[a] Increase the number of providers who are willing to provide HBOC/LS screening services[a] Increase the number of providers who appropriately refer HBOC/LS at-risk families[a] Health care providers receive initial training and periodic refresher training to diagnose, treat and counsel families for HBOC/LS in accordance with most current NCCN recommendations (26,27)[c]	Number of providers for each item Number or percentage of facilities offering initial training on NCCN guidelines for HBOC/LS (26,27); number or percentage of providers receiving initial training on NCCN guidelines for HBOC/LS (26,27); number of facilities offering periodic refresher training on NCCN guidelines (26,27)	*Surveillance*: SHA have assessed needs, knowledge, and current practices of providers using quantitative and qualitative methods. Provider types that have been surveyed have included primary care, OBGYN, gastroenterologists, pathologists, medical residents, and providers associated with the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) *Education*: SHA have developed and disseminated web and print materials targeting providers using: • State health department web pages • Fact sheets • Provider education booklets • Letters addressed to providers • Newsletters • Articles written for partner newsletters • Resources disseminated through provider network listserv • Materials distributed at professional meetings • Journal publications SHA have developed and disseminated distance training for providers using webinars, online courses with or without CME opportunities, and by uploading recordings of in-person training events SHA have conducted in-person training to educate providers on relevant topics using: • One-day professional education opportunities • Grand Rounds presentations • Case-based educational programs with audience response systems • In-depth retreat • In-person consultation for providers • Mentorship program with genetic counselors • Presentations at professional meetings SHA have assessed knowledge and behavior change as a part of training using pre- and post-assessment design *Policy*: SHA have provided technical assistance to providers through a variety of mechanisms: • Standard templates (for example, for written informed consent for genetic testing) • Opportunities for case consultation • Contact information for nearby cancer genetic clinics • Monthly cancer genetics consortium • Toll free phone line for state genomics program

Doyle et al. (9) Performance Objectives	Doyle et al. (9) Outcome Measures	State-level activities that have addressed objective or outcome
		• Email contact for state genomics program
Increase partnerships with regional clinics, academic institutions, CDC-funded programs, state programs, nonprofits, insurance groups, and industry to ensure efforts are sustainable[a]	Number of partnerships	*Policy*: SHA have convened geographically diverse and multidisciplinary steering committee to assist with program planning, evaluation, and reviewing materials
Assurance		
Increase appropriate genetic counseling linked with HBOC/LS testing[a] Reduce misinterpreted genetic test results[a] People can access genetic services in a timely manner[a] Increase the proportion of patients who report timely appointments for genetic counseling/testing[c]	Frequency of genetic counseling; frequency of HBOC/LS testing Quality control of interpreted tests Time from referral Number or percentage of patients who report good or very good levels of satisfaction	*Education*: SHA have educated providers and the public about appropriate use of genetic counseling and testing and how to access genetic counselors in the state *Policy*: SHA have educated stakeholders about state licensure for genetic counselors SHA have promoted adherence to the USPSTF(1) and Evaluation of Genomics Activities in Practice and Prevention (EGAPP)(2) guidelines as part of compliance with the 2016 Commission on Cancer standard 2.3 Genetic Counseling and Risk Assessment SHA have provided support and promoted the development of referral networks for health systems without on-site cancer genetics professionals *Surveillance*: SHA have abstracted data from medical records to track use of appropriate cancer genetic services and shared the findings with the participating health system SHA have surveyed patients to identify barriers and facilitators for genetic counseling and testing
Training programs continue to recruit, train, and graduate genetic service providers[a]	Number of training programs and numbers of applicants/graduates for each type of provider; number of slots being filled; types of applicants (i.e., diversity)	*Education*: SHA have worked with state universities to establish or increase training programs for genetic counselors and other genetic service providers
Increase state's readiness to implement public health genetics programs[a]	Level of readiness, including willingness and capacity to implement public health genetics	SHA have built cancer genomics program infrastructure by hiring staff and developing partnerships within the state health department and have identified an internal or external influential genomics "champion" *Surveillance:* SHA have conducted a state genetics needs assessment *Policy:* SHA have developed a state genetics plan and included genetics subject matter experts in the state cancer plan development process
Increase the proportion of individuals diagnosed with potentially heritable cancers who undergo genetic testing[b]	Number of individuals diagnosed with potentially heritable cancers who undergo genetic testing	*Surveillance:* SHA have developed data collection methods to assess the use of genetic testing using the cancer registry and have performed analyses using claims data
Increase number or percentage of women diagnosed at or below age 50 with breast cancer who undergo genetic risk assessment (per NCCN guidelines (26))[c]	Number or percentage of women diagnosed at or below age 50 with breast cancer who undergo genetic risk assessment (per NCCN guidelines (26))	*Surveillance:* SHA have tracked genetic risk assessment in women with a personal history of breast cancer at or before age 50 by adding state-added questions to the BRFSS
Families receive written visit summary information, including risk assessment that can be shared with other family members[c]	Number of facilities that have policies in place for written visit summaries; number of families who reported receiving materials; number or percentage of families who receive a visit summary and information they can share with families	*Policy:* SHA have created family history questions designed to identify patients at risk for HBOC and LS and messaging encouraging updating of family history information, for inclusion in survivorship care plans

Doyle et al. (9) Performance Objectives	Doyle et al. (9) Outcome Measures	State-level activities that have addressed objective or outcome
Addressing Health Disparities		
Providers are available to perform genetic services including in rural and frontier areas[a] Increase the proportion of providers in rural and frontier areas that screen and refer patients for HBOC/LS[c]	Number of providers across geographical areas Number or percentage of providers delivering HBOC/LS screening; number of patients screened for HBOC/LS in rural and frontier counties; number who screen positive; percentage of population in rural and frontier areas screened	*Education*: SHA have offered provider education through in-person regional events or distance learning opportunities to make trainings more accessible to providers in rural and frontier communities
Increase the availability of telegenetic services (telemedicine)[a]	Number of originating sites connected to a distant site	*Surveillance*: SHA have identified regions lacking genetic services providers that could benefit from telegenetics
Decrease health inequalities (population subgroups who are more vulnerable than others due to social forces) regarding access to genetic testing/counseling[b]	Number of genetic testing/ counseling sessions by subgroup	*Education*: SHA have developed or translated public education materials for at-risk or underserved populations SHA have targeted outreach to at-risk or underserved populations, including community-based approaches such as peer navigators SHA have educated clinicians and the public about the availability of telegenetics and trained genetic services providers in telegenetics *Policy*: SHA have partnered with their National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to integrate hereditary cancer risk assessment into their intake forms SHA have screened women for HBOC during visits to family planning clinics and to public health centers for routine exams or breast complaints SHA have used available funds raised through sale of Breast Cancer Awareness License Plates to provide HBOC genetic counseling and testing for low income, un- and underinsured at-risk women SHA have used survey methods to identify barriers to seeking cancer genetic services SHA have convened stakeholders in telegenetics to help move forward implementation in the state *Surveillance*: SHA have tracked and reported annually the frequency at which HBOC family health history is recorded for NBCCEDP participants by site SHA have developed surveillance systems by partnering with genetics clinics to collect HIPAA-limited data on patients receiving genetic counseling and testing, including demographic data which has been used to run analyses to identify disparities SHA have surveyed cancer survivors to assess awareness, knowledge, facilitators, and barriers to use of family history and genetic services

Abbreviations: SHA=state health agencies

[a]Outcomes states can readily perform

[b]Outcomes states can readily perform if data sources are available

[c]Aspirational outcomes