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Review of Public Health Ethics in State Comprehensive Cancer Control Plans, 2005-2020

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Review of Public Health Ethics in State Comprehensive Cancer Control Plans, 2005-2020

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Abstract

Delivery of appropriate cancer care for communities is reliant on the awareness of pertinent ethical concerns. Created by the Public Health Leadership Society with support from the Centers for Disease Control and Prevention and adopted by the American Public Health Association, the Principles of Ethical Practice of Public Health is the most widely utilized code of ethics for the field of public health. The Comprehensive Cancer Control (CCC) Plans are guiding documents that describe states' goals for addressing their population's cancer burden. This qualitative observational research study intends to evaluate the degree that public health ethics concepts are included in the CCC plans. We reviewed the 50 state plans covering 2005-2020 for terms corresponding to these ethical principles in addition to different variations of the terms "ethics," "morality," and "institutional review board." While none of the plans reviewed mentioned the Principles of Ethical Practice of Public Health explicitly, twelve of the fifty plans (24%) mentioned 'ethics' or 'morality' and six (12%) mentioned 'institutional review boards' or 'IRBs.' The mean number of principles discussed per plan was approximately nine, ranging between four and twelve. Principles 2, 4, and 10 were discussed in less than 50% of the plans. While most of the CCC plans discussed a majority of the principles, a minority of the plans included more than nine, and only five included all twelve (AL, AR, CO, NJ, OR). When updating the CCC plans, cancer coalitions should consider reviewing the Principles of Ethical Practice of Public Health, particularly focusing on principles 2, 4, and 10, pertaining to patients' rights, empowering disenfranchised community members, and confidentiality, respectively.

The Principles of Ethical Practice of Public Health are as follows: 1. Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes. 2. Public health should achieve community health in a way that respects the rights of individuals in the community. 3. Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members. Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary 5. Public health should seek the information needed to implement effective policies and programs that protect and promote health. 6. Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation. 7. Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public. 8. Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community. 9. Public health programs and policies should be implemented in a manner that most enhances the physical and social environment. 10. Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others. 11. Public health institutions should ensure the professional competence of their employees. 12. Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness. Principles of the Ethical Practice of Public Health, Version 2.2. (2002) (2nd ed.). Retrieved from http://phls.org/CMSuploads/Principles-of-the-Ethical-Practice-of-PH-Version-2.2-68496.pdf

Results

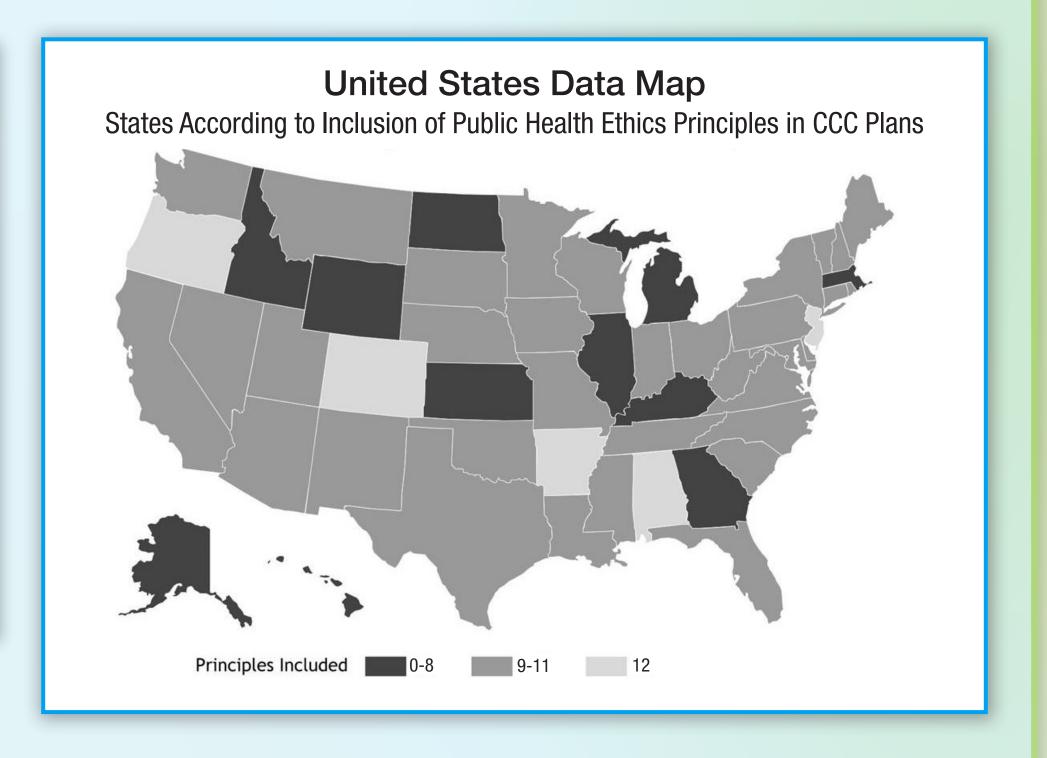
Principle	Principle Text	Summary	Search Terms
Number	Principle Text	Concept	
1	Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.	fundamental cause	"risk factor" "genetic*" (used as example of fundamental cause) "tobacco" (used as example of fundamental cause)
2	Public health should achieve community health in a way that respects the rights of individuals in the community.	respecting rights	"right*" (excluding instances where referring to correctness)
3	Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.	community member input	"community" (as in community coalition, member, partner, or community-based participatory research and excluding references the document, itself, being created community input)
4	Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.	empowering disenfranchised	"empower*"
5	Public health should seek the information needed to implement effective policies and programs that protect and promote health.	seeking appropriate information	"gather information" "evidence base*" "evidence-base*" "data driven"
6	Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.	obtaining consent	"consent" "informed decision" "advantages and disadvantages"
7	Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.	timeliness	"time*" "early" (as in detection)
8	Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.	respecting diverse values	"values" "cultur* competen*" "culturally"
9	Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.	enhancing physical & social environment	"environment" "transportation" (used as example of physical barrie
10	Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified on the basis of the high likelihood of significant harm to the individual or others.	confidentiality	"confidential*" "privacy"
11	Public health institutions should ensure the professional competence of their employees.	professional competence	"competen*" (particularly of workforce, and excludin cultural competence) "skill*" "expertise" (importance of proficien*" "qualified"
12	Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.	collaboration	"collaborat*"
OTHER	N/A	Ethics or Morality	"ethic*" "moral*"
OTHER	N/A	Institutional Review Board	"IRB" "Institutional Review Boar
OTHER	N/A	Principles of Ethical Practice	"Principles of Ethical Pract of Public Health"

Principle Number	Summary Concept	Example	
1	fundamental cause	"Like most complex diseases, cancer has major genetic and environmental components. Some cancers have simple genetic causes, but most cancers are cause by complex interactions between lifestyle factors and multiple genes." - Oregon CCC Plan	
2	respecting rights	"Patient rights include: 1. The right to facilitate their own health care decisions. 2. The right to accept or refuse medical treatment. 3. The right to make an advance health care directive." – Alabama CCC Plan	
3	community member input	"Strategy 8.2.6: Engage in community coalition building and development in prior communities to ensure a comprehensive community-based solution to increasing the early detection of CRC." – Ohio CCC Plan	
4	empowering disenfranchised	"Implement a social marketing campaign targeting at-risk Marylanders to empowe them to take advantage of the policies and programs being implemented throughout Maryland and in local communities that make it easier to make healthier choices." Maryland CCC Plan	
5	seeking appropriate information	"The ACCCC agreed that all of the objectives should be data driven, utilizing valid, reliable state data in the public domain with assurance of data points throughout plan period." – Alabama CCC Plan	
6	obtaining consent	"Federal rules help ensure that clinical trials are run in an ethical manner. All potential participants go through an informed consent process. In this process potential participants learn the purpose, risks, alternative treatments and benefits a clinical trial before deciding whether to join. It is a critical part of ensuring patient safety in research." – New Mexico CCC Plan	
7	timeliness	"Ensure that all Commonwealth residents have equal and timely access to cancer information, treatment, and clinical trials that are based on nationally recognized best-practice standards." – Massachusetts CCC Plan	
8	respecting diverse values	"This includes providing support for the psychological, spiritual, and social aspects of coping with cancer and incorporating care according to the patients need, value beliefs, and culture." – Arizona CCC Plan	
9	enhancing physical & social environment	"The social environment in which people live, work, play and go to school has a significant influence on diet and activity habits. The guidelines include an explicit Recommendation for Community Action to promote the availability of healthy food choices and opportunities for physical activity in schools, workplaces and communities." – Wyoming CCC Plan	
10	confidentiality	"Data Confidentiality All individuals working with NHSCR data are governed by the confidentiality police implemented under the specific New Hampshire rules and regulations. Release of confidential cancer data for research or other purposes is governed by RSA 141B. The law permits disclosure of certain confidential data to other cancer registries and federal cancer control agencies. However, strict requirements, including prior approval of the researcher's proposal with the Institutional Review Board for the Protection of Human Subjects, must be met. Public data releases, such as publish statistical reports, are designed to provide data to the fullest extent possible while still realizing the mandate to protect patient confidentiality." – New Hampshire Copplan	
11	professional competence	"Another major factor in quality treatment is the need for competent nurses who are knowledgeable about how to treat cancer patients. Advances in cancer care require nurses to know and do more than ever before, and the aging population a increasing prevalence of cancer mean that fewer nurses are caring for more patie with cancer. Certification provides validation of the specialized knowledge and experience required for competent performance." – Connecticut CCC Plan	
12	collaboration	"If the coalition focuses efforts on shared priorities, we can more efficiently and effectively collaborate to reduce the cancer burden." – North Dakota CCC Plan "Increase the proportion of health care professionals who collaborate to enhance knowledge, opportunities and resources that can assist with improving cancer patients' quality of life." – Oregon CCC Plan	

Table 2: Percentage of Plans that Included Eac Ethical Principle, in Order of Principle.				
Principle Number	Summary Concept	Search Terms		
1	Fundamental cause	100%		
2	2 Respecting rights			
3	3 Community member input			
4 Empower disenfranchised		48%		
5	5 Seek appropriate information			
6 Obtaining consent		84%		
7	Timeliness	100%		
8	Respecting diverse values	88%		
9	Enhancing physical & social environment	98%		
10	Confidentiality	28%		
11	Professional competence	54%		
12	Collaboration	98%		
OTHER	Ethics or Morality	24%		
OTHER	OTHER Institutional Review Board			
OTHER	Principles of Ethical Practice of Public Health	0%		

Average of 9 Principles in Their CCC Plans		
State	Number of Principles	
Idaho	4	
Alaska	6	
Hawaii	7	
Illinois	7	
Rhode Island	7	
Georgia	8	
Kansas	8	
Kentucky	8	
Massachusetts	8	
Missouri	8	
North Dakota	8	
Wyoming	8	

Table 3: States Addressing Less Than the



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