

Role of regional civil society organizations in cancer control in the Eastern Mediterranean Region

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Civil society organizations (CSOs) play a key part within the cancer control continuum, ranging from service delivery, raising awareness, advocacy with policy-makers, patient empowerment, monitoring progress and accountability, and engaging in research. A thriving, independent and empowered civil society in cancer control can hold policy-makers accountable and shape health services to better respond to people's needs, particularly in underserved areas and for hard-to-reach populations, ultimately contributing to improving cancer control services.

Here we attempt to shed light on the role and contributions of CSOs to the cancer control agenda, highlighting a few examples of CSOs engagement and contributions to cancer control programmes throughout the cancer control continuum from prevention to rehabilitation.

Cancer is one of the leading causes of disability and death worldwide. GLOBOCAN estimated that 19.3 million new cancer cases (18.1 million excluding nonmelanoma skin cancer) and almost 10.0 million cancer deaths (9.9 million excluding nonmelanoma skin cancer) occurred in 2020 (1). There is a disparity in its distribution around the world as it is decreasing in some developed countries but is increasing in low-income countries where the access to care is lower. Cancer incidence in Eastern Mediterranean Region (EMR) is lower than in high-income countries where it is still the fourth cause of death, however, the accelerated trends will change the situation in near future (2). Unfortunately, it is anticipated that the largest increment in cancer incidence among World Health Organization (WHO) regions will happen in EMR countries, where projection modelling has shown that cancer incidence will have doubled by 2040 (3, 4).

The region consists of diverse countries which are extremely different in economic aspects. This fact could mainly explain the discrepancies in access to cancer care and implementation of cancer prevention programmes (2). However, most countries are in the middle- or low-income group based on World Bank

which results in lower resources to allocate to health (2). Inadequate resources for cancer control along with a dramatic increase in cancer incidence in the EMR countries, emphasizes the value of a comprehensive and effective cancer control programme.

Another substantial problem in EMR countries which is also common in most parts of the world is not involving all stakeholders in cancer policy-making (5). Comprehensive cancer control plans are scarce in this region and existing plans have been devised without an effective partnership with stakeholders (5).

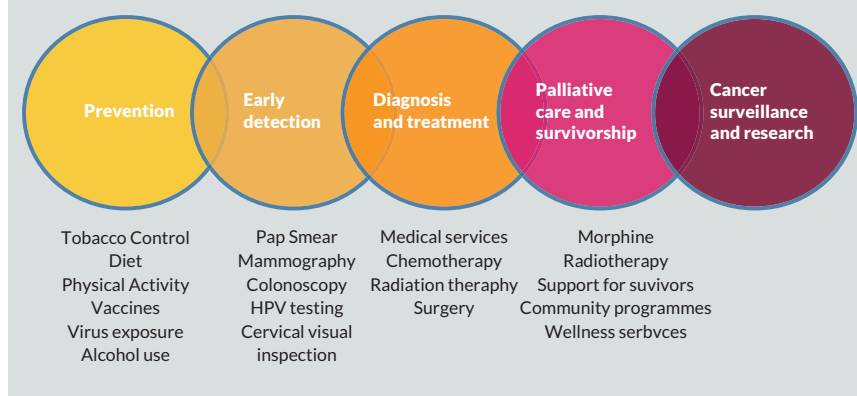
A comprehensive cancer control plan should cover every aspect in the cancer control continuum (Figure 1). However, in low- and middle-income countries usually most resources are allocated to diagnosis and treatment with the least, and often no resources, directed to prevention (2). Following this, there is therefore an urgent necessity to raise budgets and, more importantly, set more sensible priorities.

In moving forward to build a solid and effective cancer response for better health, resilient health systems, WHO has recognized the need to partner with all stakeholders

Figure 1: CSOs has a great role in cancer prevention and control



Figure 2: Illustration of the cancer control continuum and some of the interventions available at each stage



at different levels. Their five main roles (Figure 1) consist of advocacy, capacity building, knowledge exchange, providing evidence-based information, coalition building, monitoring and service provision (7, 8). Although their main efforts are focused on advocacy and communication to address cancer control, mobilizing resources in partnership with the private sector, delivery of cancer services (9), raising awareness among communities and healthcare professionals, monitoring

including CSOs to guide and coordinate effective responses through addressing national policies, including the integration of cancer care into Universal Health Care benefit packages. Regional CSOs are well positioned to play a critical role in cancer control

Furthermore in 2017, the 70th World Health Assembly endorsed a cancer resolution: “Cancer prevention and control in the context of an integrated approach”, which highlighted the need for strong partnerships between government and civil society, building on the role and contribution of the health-related nongovernmental organizations and patient organizations to support, as appropriate, the provision of services for the prevention, control, treatment and care of cancer, including palliative care.

The role of CSOs in cancer control

Civil society organizations are entities outside governmental organizations and distinct from any commercial institutions. They comprised a variety of entities such as research institutions and think tanks, nongovernmental organizations (NGOs), community groups, charities, faith-based organizations, professional associations, trade unions and voluntary organizations (6). Governments’ priorities change when the political environment shifts through democratic or undemocratic measures. However, CSOs have a more robust position, which can help achieve consistency in cancer control programmes. They are recognized as identifiers of innovative ideas and implementers of creative models in health systems worldwide (6).

These organizations are already involved in all parts of the continuum of cancer control all over the world and

progress and developing shadow reports, building the capacity of CSOs and health professionals, research (including operational research), and advocacy for voices and engagement of people living with cancer, including vulnerable groups such as refugees and patients in low- and middle-income countries.

Globally, CSOs have been very active in advocacy, raising awareness, collations, resource mobilization and patient empowerment in high-income countries (10, 11). However, a review of cancer control plans in different countries revealed that a CSO’s role is limited and that they are rarely engaged in the policy-making process (12).

The engagement of CSOs is well reflected throughout the cancer control continuum from prevention to palliative care and rehabilitation (Figure 2).

Cancer prevention

Cancer prevention is defined as minimizing or eliminating exposure to potential environmental causes of cancer. It is estimated that 50% or more of cancers’ incidence is attributed to three factors: tobacco, infection and unhealthy nutrition, and lack of physical activity (13). Eastern Mediterranean countries have the highest rate of modifiable lifestyle risk factors worldwide. Tobacco use, unhealthy diet and physical inactivity are major regional health affecting factors. EMR populations consume sugar, salt and trans-fatty acids well above WHO recommended levels (14).

Tobacco control

The World Health Organization Framework Convention on Tobacco Control (WHO FCTC) which introduces measures to decrease the demand for tobacco along with limiting its

production, distribution and availability and supply, came into force in 2005 (15). In line with this framework, WHO developed a set of six measures to diminish tobacco demand, known as MPOWER (16). Most EMR countries (19 out of 22) are parties to WHO FCTC (17). Tobacco advertising, promotion and sponsorship have been banned in 10 countries, national legislation banning smoking in indoor public places has been established in most countries and 15 countries put warnings on cigarette packets (18, 19). Unfortunately, the EMR has a lowest price of tobacco products and no countries in this region have implemented the six measures of the WHO FCTC and only six countries implemented at least three measures from MPOWER (17). In the last WHO report on the prevalence of tobacco smoking, this region was the only WHO region that predicted showing an increase in prevalence of tobacco use among men (20). Moreover, there is a concern about increasing smoking prevalence in women (17). Tobacco smoking is prevalent in this region as dual waterpipe and cigarette use and it is a crucial issue in cancer control in this countries (21).

Civil society organizations have been taking part in the FCTC since the beginning as 200 CSOs from 90 countries are members of the convention and have been supporting the development, ratification and implementation of the treaty. The Framework Convention Alliance (FCA) is a heterogeneous alliance of CSOs from all over the world which was initiated through the FCTC process and it continued its actions to ensure FCTC implementation in all countries (22). The FCA developed several innovative measures including two awards to compel countries to accept the FCTC. Their awards, named the "Orchid Award" and the "Dirty Ashtray Award", described different countries and industries operation in tobacco control and revealed the latent reason of disagreements. It was effective in weakening the big four – China, Japan, Germany and the United States – position against FCTC (22). The FCA became a good example of CSOs effectiveness and power to inform public and politicians about health issues and to force national and international governments to ratify and implement advantageous policies (22).

Although CSOs are in their infancy in most EMR countries, they have built advocacy campaigns and push their governments to act more proactively on tobacco control programmes. Some governments are not impartial to tobacco control as there is a conflict of interest.

Some of the best practices in the region, include the King Hussein Cancer Foundation's lead on the development of an effective strategy to limit exposure to tobacco smoke in public areas. The Foundation's smoke free zone certification programme, which is undertaken in collaboration with local government encourages companies or other local institutions to prevent smoking inside their premises. Another successful

Box 1: Cervical cancer CSO initiatives

➔ The European Cervical Cancer Association initiated a network of politicians called "Politicians Against Cervical Cancer", which supports integration of HPV vaccination into cancer prevention programmes. They provided an impressive white paper to support national HPV vaccinations in their region. They made a strong alliance with other associations like European Public Health Alliance (EPHA) to support European Union efforts to prevent cervical cancer (33). Women Against Cervical Cancer (WACC) is another network of about 50 CSOs in 20 countries which are guided by medical experts. It is a creative approach to share medical knowledge with the public through CSOs. The network provides standard and accurate information through websites, meetings, flyers and videos in multiple languages. Medical experts can refresh their information for the public about the acceptance of vaccinations and other valuable data through researches done by CSOs as well (33).

example is the NGOs coalition to ratify and implement tobacco control policies in Egypt.

Several CSOs are engaged in tobacco control and play a crucial role in compelling governments to ratify and implement the FCTC in their countries (6). This involves lobbying with community leaders and other influential people, i.e. religious leaders, health professionals or teachers (2).

Another example of the engagement of CSOs is the collaboration with communities of schools and universities to boost tobacco control and create a tobacco-free environment. The Qatar Cancer Society (QCS) has been running a "World No Tobacco Day" art and video competition in collaboration with the Ministry of Education and Higher Education among the schools and university students to mobilize their communities to encourage healthy habits and tobacco abstinence in future generations, as well as creating advocates for tobacco control in every household. In addition, there is recognition of corporates that have tobacco free facilities. The QCS has also been working on spreading awareness about smoking cessation at clinics and health centres.

Vaccination

Some chronic infections are clearly distinguished as carcinogenic agents. Among them, hepatitis B (HBV) and human papillomaviruses (HPVs) are preventable through vaccination (2). In 2009, WHO estimated the incidence of HBV in the EMR at over four million people annually (23). The high prevalence of HBV infection in this region convinced Member States to adapt a target for reducing HBV infection to less than 1% among children aged <5 through childhood vaccination by 2015 (24). The EMR countries have reached a remarkable achievement in the HBV vaccination of infants with coverage rising from only 6% in 1992 to 83% in 2014 (24).

Contrary to this, the introduction of HPV vaccination programmes is very slow in the EMR. While most countries in

the EMR have endorsed the WHO global strategy for cervical cancer elimination (25), implementation of the strategy has been affected by several factors including HPV vaccination hesitancy and vaccine unavailability (26). There are huge disparities in HPV vaccinations worldwide and only 2.7% of vaccinated women live in low- and middle-income countries (27). Among the 91 countries who introduced HPV vaccination only two, the United Arab Emirates and Morocco, are from the EMR (28). Other Gulf Cooperation Council (GCC) countries such as Qatar and Saudi Arabia in the process of introducing HPV vaccination.

Incidence rates of cervical cancer vary between EMR countries, with highest rate registered in Somalia (24/100,000 population) and the lowest in Iraq (1.9/100,000 population). It should be mentioned that several EMR countries lack robust cancer data to assess the real burden of cervical cancer and HPV infection (29, 30).

HPV vaccines are expensive and some EMR countries cannot afford them and, unfortunately, most of them do not qualify for GAVI support. Many countries in this region did not consider HPV vaccinations mainly due to lack of data on the disease burden, moreover, most countries presumed other health problems were more important (31). However, the availability of HPV vaccine in many countries did not remarkably increase the vaccine coverage due to vaccine hesitancy (26). This refusal to take the vaccine could be due to concerns about safety and cultural or religious sensitivities. Based on these reasons, CSOs could be for or against vaccinations. Some CSOs are worried about side effects of the vaccine and some believe HPV vaccination will increase sexual relationships outside of marriage (31).

Civil society organizations such as First Ladies Initiatives and Cervical Cancer Prevention Initiatives who are pro-vaccination can play a substantial role in increasing access and acceptance of HPV vaccination. They could enhance cervical cancer registries, advocate to establish HPV vaccination and increase public awareness to mobilize the public (31, 32). They could initiate joint vaccine procurement programmes for EMR countries to improve their purchasing power (31). The CSOs who work on cervical cancer prevention should also embrace other CSOs working on women's empowerment, sexual and reproductive rights, maternal and HIV/AIDS to insure more successful activities (27).

Friends of Cancer Patients (FOCP) in Sharjah, United Arab Emirates, led the regional work on HPV and cervical cancer elimination in partnership with the Ministry of Health and Prevention in the United Arab Emirates, United Nations Population Fund (UNFPA) and WHO. Two regional forums were organized under the leadership of CSOs resulting in key recommendations to scale up the fight against HPV (Sharjah

Declaration Document).

In Morocco, local CSOs have been very active in raising community awareness and they displayed a positive role in high-level advocacy that led to the introduction of the HPV vaccination programme in Morocco, implemented in November 2021 (31).

The Qatar Cancer Society has been doing annual community cervical cancer awareness campaigns in Qatar that have included workshops in collaboration with the public and private sectors in addition to media campaigns in local newspapers, TV, radio, websites, and social media platforms. The annual campaign spread knowledge about the signs and symptoms of the disease, its risk factors, as well as methods of prevention and early detection including HPV vaccination and Pap smears with HPV testing. Also, private healthcare clinics participated in the campaigns by providing free Pap smear tests.

Lifestyle modifications

The WHO recommended a set of cost-effective evidence-based interventions ("best buys") to reduce the exposure to NCD risk factors as an important step in cancer prevention in the EMR (2). There is a great deal of research which highlights the importance of effective policies to decrease cancer risk by making healthy choices as easy choices (34).

Civil society organizations have not acted strongly in advocacy for food reformulation or taxing less healthy foods national or internationally. For example, 81% of participants in the Codex Committees between 1989 and 1991 were from industry, and only 1% were from public interest groups. This resulted in food standards that favour the food industries' interest (35). Consumer-representing CSOs are not active in most countries and occupy just an informal role in governance (35).

Reducing sodium intake is one of the "best buys" advised by WHO to prevent and control NCDs around the world. This followed by a voluntary global target of a 30% reduction in salt intake among population by 2025 (36, 37). Sodium intake in EMR countries ranged from 5.22–13.5 g/person/day, where the recommendation of WHO is less than 5g/person/day (38, 39). A number of salt reduction initiatives have been undertaken in this region, but there is a lack of comprehensive data on salt intake in many countries and greater public activity is needed to reduce salt intake (40).

Regional civil society's activity is predominantly focused on raising awareness among the public and health professionals. They have endorsed the idea that public education on NCD risk factors is CSOs most important priority followed by advocacy (41).

As part of these regional CSO initiatives, the Qatar Cancer Society has been including the lifestyle modification as a

methodology for cancer prevention, including healthy eating habits and being physically active, in all of its cancer awareness campaigns with a major emphasis during the Gulf Federation for Cancer Control's GCC Cancer Awareness Week and the Union International for Cancer Control's World Cancer Day. In addition to working with the Ministry of Education and Higher Education as part of the school health awareness programme "Your Success is in Your Health" that focuses mainly on healthy lifestyle among school students.

Cancer early detection

Early detection is a crucial step in cancer control which could increase survival rates (5). While the majority of EMR countries do not have well organized cancer screening programmes, most screening activities remain mostly opportunistic (43), and associated with late stage presentation for most cancers.

Civil society organizations have the capacity and are in the best position to support early diagnosis programmes through regular campaigns to improve public awareness, training of health professional and the public on the early signs and symptoms of common cancers. In order to improve screening uptake, CSOs could help in raising awareness, fighting cultural barriers and stigmas (2).

In Jordan, the King Hussein Cancer Foundation brought about a successful example of how an NGO's activity to enhance the early diagnosis of cancer and other NCDs impacted positively on the early diagnosis of breast cancer. The proportion of late stage diagnosis declined from 56% to 23% between 2005 and 2009, thus the survival rate showed a substantial increase (44). A similar approach in Morocco in addition to a health professionals training programme increased early stage diagnosis of breast cancer (45).

Several charities in Iran shown a great interest in cancer screening campaigns. The Society for Helping Cancer Patients, located in Mazandaran Province of Iran, established few clinics for the early detection of cancer. This society performed a campaign to screen women over 40 for breast cancer. A total of 5,994 women were screened in 2018, which was followed by 2,278 mammography scans and 1,586 ultrasound evaluations (42). Other charities, such as Shams, Daheshpour, Nastarn and Pejvaktaher hold campaigns on the early signs of cancer and there are even some screening programmes in Iran (46).

The Friends of Cancer Patients in the United Arab Emirates has performed several awareness and educational campaigns about prevention and screening of cancers including the Pink Caravan (for breast cancer and cervical cancer awareness and screening), Shanab (for prostate and testicle cancer awareness and screening), skin cancer awareness, and ANA for childhood cancer awareness. In Lebanon, the Children's Cancer Center of Lebanon (CCCL) organized several educational sessions for

paediatricians with a focus on the early detection of tumours in children.

The Qatar Cancer Society has conducted monthly comprehensive multi-media collaborative community cancer awareness campaign with each month focusing on different cancer according to the top 10 most common cancers in Qatar. The monthly campaign will focus on the signs and symptoms, risk factors, prevention and early detection for a specific cancer. This monthly cancer awareness calendar has had significant momentum since 2018 and the establishment of the Qatar Cancer Awareness Calendar under the leadership of Ministry of Public Health – National Cancer Programme and the involvement of all the main stakeholders of the cancer control community in Qatar including Qatar Cancer Society. People living with cancer and others were involved in those campaigns as cancer awareness advocates and champions. Also public and private sector primary healthcare professionals were given continuing medical education activities co-organized by the Qatar Cancer Society and the academic and health entities that focus on cancer early detection and screening.

Service delivery

Civil societies' role in service delivery is well documented in the region. Many CSOs have a long existing experience in delivering cancer care, for instance MAHAK a non-profit charity-based organization in Iran, funded entirely by donations, has supported 35,000 children affected with cancer up to 1999. MAHAK mainly focus on treatment of childhood cancer.

MAHAK's activities are not limited to the hospital, it supports children with cancer who are treated in other hospitals. Moreover, it has supported 2,438 refugee children as it is officially recognized by UN High Commissioner for Refugees (UNHCR) as the organization which helps refugee children (Afghan and Iraqi) in and out of refugee camps. In 2007, this NGO was presented with the Swiss SGS NGO Benchmarking Award for the best and most transparent NGO in the Middle East.

In Jordan, King Hussein Cancer Centre (KHCC) provides another example of a non-profit NGO providing cancer treatment for over 7,000 adult and children cancer patients every year from Jordan and the region. KHCC's bone marrow transplantation (BMT) is one of the largest and most successful BMT programmes in the Middle East which performs approximately 250 bone marrow transplants each year with cure rates compatible with international standards. It has several other activities in early detection of cancer and research.

Other successful regional examples is the Friends of Cancer Patients in United Arab of Emirate, Qatar Cancer Society in Qatar, and the Children's Cancer Center of Lebanon (CCCL) in Lebanon. The first two associations provide access to treatment for cancer patients through financial aid and also

offering support group for moral and psychological support for cancer patients and their families. The CCCL administers and covers treatment, free of charge, for almost 40% of kids with cancer in Lebanon and refugees from neighbouring countries.

Palliative care

Despite the long existing needs for palliative care in EMR, only few countries have established palliative care programmes within their public health system (5).

Gaps in regional palliative care is related to a multiplicity of factors including, but not limited to, poor commitments, scarcity of resources, lack of technical capacity, limited funding, emphasizing the need to actively engage CSOs in enhancing palliative care in this region.

Home care and psychological support of patients and their families are two important parts of palliative care which could be effectively improved by CSOs (2). Volunteers who are trained and supported by CSOs could play important roles in this field. Moreover, there are some preconception about pain, death and some concern about abuse of narcotic substances (2) which could all be rectified by CSOs' public campaigns and education initiatives. Regional CSOs have played a critical role in enhancing palliative care services through advocacy, training, psychological and financial support to patients; supply of equipment and medications and service delivery in many countries (48).

Some examples from the region:

- ➔ In Pakistan, 17 out of 20 palliative care centres are private, whereas charitable services are provided mainly by volunteers (48).
- ➔ The Al-Malath foundation for humanistic care has a hospice with a team of volunteer nurses who provide medical and psychological support in Jordan.
- ➔ The Jordan Palliative Care Society enhances the culture of palliative care through advocacy, networking, education and training (49, 50).
- ➔ The Lebanese Centre for Palliative Care performed capacity building activities beside providing comprehensive support to patients (51).
- ➔ The Children's Cancer Centre of Lebanon (CCCL) provides palliative care in hospital and at home.
- ➔ The Oman Cancer Association has provided between 2017 and 2019 comprehensive training in palliative care for the region in collaboration with the Oncology Nursing Society and the Omani Ministry of Health.
- ➔ SANAD is an independent nongovernmental, non-profit organization that provides home hospice care to advanced chronically and terminally ill patients and their families in Lebanon. Also SANAD undertakes extensive awareness-raising activities at the the community and

the medical and nursing professions level to facilitate a better understanding of the issues and the concepts behind hospice and palliative care in Lebanon.

Advocacy for cancer control

Civil society organizations play a key role in health advocacy, especially in high-income countries. They convene different organizations from extremely different background behind common goals and build strong alliances and collaborations to powerfully advocate through public opinion polling and preparing white papers. They prepare effective fact sheets which translate complicated science topics into more understandable papers for the public and politicians (7). The most successful CSO alliance is the FCA, which is a powerful coalition of more than 200 organizations from 90 countries. It exemplified an effective coalition which brought about a powerful advocacy (22). Several examples of national coalitions against tobacco has been made in EMR countries such as Egypt, Jordan, Lebanon and Pakistan (41). For example, the NCD Alliance Pakistan (NCDA-PAK) was set up in 2014, this is a partnership between leading cardiologists, the Pakistan Medical Association, media and health professionals, CSOs and lawyers. It focuses on tobacco control and is a member of FCA and it works on cancer control as well (41).

Opportunities and challenges

Civil societies in the EMR have great powers to mobilize volunteers and enjoy strong support from the population. However, they are facing multiple challenges including a lack of sustainable funding, limited technical and administrative capacity, weak coordination at local and regional levels, weak leadership and a poor connection with government (59).

Lack of trust and a suspicion of the role CSOs play is the most important barrier to CSO activities in this region and elsewhere. It largely stems from authoritarian political governance and xenophobia. Some governments consider CSOs to be advantageous, however, most view them as threatening and illegitimate organizations that should be limited (60). However, the growth in CSOs is an ineluctable part of transitional period which is happening in the EMR.

Limited funding resources is an enormous obstacle towards CSO performance in the EMR countries. Unfortunately, lack of resource could place CSOs in direct competition with each other which is a considerable barrier to building coalitions (58). On other note, receiving funding from industry or even governmental organizations will increase the chance of conflict of interest and halt appropriate assessment of governmental activities or weaken a CSO's position to voice their concerns and limit the harmful activities of industry.

While most local CSOs rely on volunteers, often lack skills

and knowledge. Advocates should receive specialized training and should not treat their roles as a hobby. A coalition with specialist scientific institutions could enhance their ability and promote their credibility to make more sensible and trustworthy advocacy.

While there is a huge potential in the EMR to develop a coalition and united actions based on a cultural and religion background, there are some strong conflicts in the region which disturb this and ignite conflicts which not only weaken CSOs' positions but also brings serious problems to cancer control programmes. Geopolitical conflicts and economic crises among countries in this region limit CSOs' capacities (14).

Civil societies need a responsible and free media that help them encourage public debates and challenge all stakeholders including governments to be fair and transparent and to force them to make evidence-based policy (61). There are several examples of the alliance of the media with CSOs to force

governments to make more appropriate decisions. The case promoting exclusively breast feeding, access to HIV medication and restrictions on tobacco marketing are good examples of such alliance (61).

By acknowledging the pivotal role of CSOs, governments need to support the CSOs functions and provide the right platform and legislation to empower CSOs through professional education and training. It is important to perceive them as a communities' voice and ratify legal protections for them. They should be strengthened and encouraged to provide the power and direction for effective health change in this region (61).

However, CSOs success stories and strong civil societies are a symbol of a healthy democracy and could empower society to improve quality of life. Unfortunately, most CSOs in the EMR are still far from meeting their potential in all health-related issues including cancer control. ■

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