Global oncology 1

Cancer surveillance in northern Africa, and central and western Asia: challenges and strategies in support of developing cancer registries

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The Global Initiative for Cancer Registry Development partnership, led by the International Agency for Research on Cancer (IARC), was established in response to an overwhelming need for high-quality cancer incidence data from low-income and middle-income countries. The IARC Regional Hub for cancer registration in North Africa, Central and West Asia was founded in 2013 to support capacity building for cancer registration in each of the countries in this region. In this Series paper, we advocate the necessity for tailored approaches to cancer registration given the rapidly changing cancer landscape for this region, and the challenges faced at a national level in developing data systems to help support this process given present disparities in resources and health infrastructure. In addition, we provide an overview of the status of cancer surveillance and activities country-by-country, documenting tailored approaches that are informing local cancer-control policy, and potentially curbing the growing cancer burden across the region.

Introduction

The shift of the global cancer burden towards low-income and middle-income countries (LMICs), with more than half of the 14.1 million new cancer cases alongside a projected 60% increase in the cancer burden by 2030, has been increasingly recognised as a global health challenge. The present targets of the WHO Global Monitoring Framework (ie, 25% reduction of premature mortality from cancer and other non-communicable diseases [NCDs] by 2025), alongside the UN Sustainable Development Goals (ie, a one-third mortality reduction by 2035), highlight the importance of prioritising support for NCD surveillance infrastructure through the development and enhancement of population-based cancer registries (PBCR), in parallel with complementary risk factor and mortality data systems.

The International Agency for Research on Cancer (IARC) has provided sustained support for cancer surveillance activities throughout its 50-year history, with a particular focus on the development of PBCR for local and global cancer-control planning and research. Although technological developments have led to increases in data quality over the past few decades in high-income countries, increasing inequities in health infrastructure, resources, and competing priorities have resulted in inadequate availability of high-quality cancer data in LMICs. An overwhelming need remains for registry implementation as a core component of disease surveillance and national health planning. To facilitate this goal, the Global Initiative for Cancer Registry Development partnership, led by IARC, has developed six regional hubs that directly support country-led capacity building for cancer registration (figure 1). The main roles of the hubs include the delivery of structured programmes in technical training, consultancies through site visits, mentorship arrangements, analysis to produce scientific and policy reports, formation of regional networks, and advocacy to increase cancer awareness and political commitments to cancer surveillance. In October, 2013, the IARC Regional Hub for cancer registration in North Africa, Central and West Asia was launched. The Hub, hosted by the Izmir Cancer Registry, Turkey, spans a geographically and culturally diverse set of 30 countries and territories, each at different stages of cancer registry and national cancer-control plans development (figure 2). The Hub Advisory Committee, with representatives of main regional partners, has been established to provide leadership and strategic directions for the planning, implementation, and review of the Hub’s activities. The agreements with key partners, such as WHO Eastern Mediterranean Regional Office (WHO EMRO), WHO Regional Office for Europe (WHO EURO), and the US National Cancer Institute Center for Global Health, helped initiate a new set of actions in cancer surveillance development across the region. This Series paper provides an overview of the socioeconomic and health-care system context in northern Africa, and central and western Asia, and outlines the cancer burden and surveillance strategies for this region. To describe the scale and profile of cancer for this region, we used the estimates from GLOBOCAN, which are based on best data available. These estimates should nevertheless be interpreted with a degree of caution given the modest coverage by PBCR in this region. We identified the tailored approaches being adopted to ensure national progress in cancer-control planning through the availability of robust cancer data in three subregions of this area.

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Northern Africa

Northern Africa has had major emigration over the past half century, with 1.3–1.5 million migrants from former French colonies emigrating to France annually from the mid-1970s to the mid-1980s, and further emigration to other European countries, North America, and Gulf countries. After the Arab Spring in 2011, parts of northern Africa were left in political unrest—ie, the separation of South Sudan and continuous armed conflicts in Libya—taking a toll on health-care systems already in need of greater government accountability. According to the UN Development Programme, most northern African countries have a medium or high Human Development Index (HDI), except for Sudan and South Sudan, which both have a low HDI (table).4

The first PBCR of high quality was in Setif, Algeria, which published incidence data from 1988–92 in Cancer Incidence in Five Continents (CI5) volume VI.1 Several registries were established in north Africa;2 registries from Tunisia (north), Libya (Benghazi), and Egypt (Gharbiah) comprising data from 2003–07 were considered of sufficient quality to be included (in addition to Setif) in CI5 volume X, but not in the subsequent volume XI.3 Registry developments and collaborative studies involving registries in high-resource settings (eg, the Benghazi registry, Libya, with the Modena registry, Italy) have been facilitated by technical support from IARC and WHO EMRO.2 Other initiatives have contributed financial support for cancer registration, both regionally and nationally; the Gharbiah registry was initially supported by the Middle East Cancer Consortium via funding from the US National Cancer Institute, and the Lalla Salma Association in Morocco supported the establishment of Grand Casablanca regional registry during the mid-2000s.20

Given the scarce resources and limited technical capacity in countries in northern Africa, exacerbated in some cases by state failure, conflict recurrence, and ongoing migration, the challenges for cancer registration in this subregion apply equally to the processes of acquiring information on patients with cancer and to obtaining accurate population data.13 An additional problem noted across the EMRO region is the low quality and accessibility of mortality data, which is now being addressed by the Regional Strategy for the Improvement of Civil Registration and Vital Statistics Systems. Mortality is a crucial indicator of progress in cancer control alongside incidence and survival, as well as being an essential data source for cancer registration both in terms of estimating cancer incidence and survival, and evaluating registry data quality.14–16

According to GLOBOCAN 2012 estimates, over 220000 new cancer cases and over 143000 cancer deaths occur in northern Africa annually.1 The liver, lung, bladder, and colorectum represent the most common cancer sites in men, whereas the breast, liver, colorectum, and cervix are the most frequent sites in women. The increased incidence of liver cancer in the region is largely driven by its incidence in Egypt, which is linked to a high historical prevalence of hepatitis C virus infection.17,18 Although the overall incidence of cancer in northern Africa is between a third and a half of that observed in Europe,19 reports from the established registries in Algeria and Tunisia indicate that incidence of most common cancers is increasing, except the incidence of cervical cancer, which is decreasing in both countries.20–22

Morocco was the first northern African country with an operational cancer plan that incorporates cancer surveillance (National Cancer Control Plan 2010–19). The progress achieved in cancer control in the country since the plan’s introduction, which was facilitated by the Lalla Salma Foundation, provides further evidence of the need...
to include non-governmental bodies in the creation of a framework for cancer surveillance. Algeria and Tunisia introduced cancer plans for 2015–19 that include action items to improve the quality of both cancer registration and death certification. The National Cancer Strategy for Sudan 2012–16 mentions the role of the cancer registry and its status, but does not include a development plan involving its integration into cancer-control planning.22

| Human Development Index | History of cancer registration | Cancer incidence\(^a\) (age-standardised rate [world standard]\(^b\) per 100,000) (men:women) | National cancer-control plan\(^c\) | Main challenges | Global Initiative for Cancer Registry Development actions (2012–16) |
|-------------------------|--------------------------------|-------------------------------------------------|---------------------------------|-----------------|-------------------------------------------------|
| **Northern Africa**     |                                |                                                 |                                 |                 |                                                 |
| Medium to high          | From 1980s, starting in hospitals | 92:158 91:148                                  | –                               | Inadequate follow-up systems and scarcity of survival data due to inaccessibility of mortality data or methods in place to ascertain vital status via other means, inadequate referral systems, inadequate funding or sustainability, insufficient technical capacity | Advocacy; technical support; training |
| Morocco                 | Medium                         | 123:134                                       | Yes, 2010–19                    | Low quality of mortality data; inadequate funding; problems with software | Site visit and recommendations, 2014 |
| Algeria                 | High                           | 116:133                                       | Yes, 2015–19                    | Lack of mortality data; inadequate funding; problems with software | No country-specific activities |
| Tunisia                 | High                           | 127:96                                        | Yes, 2015–19                    | Lack of mortality data; inadequate funding; problems with software | Site visit and recommendations, 2014 |
| Libya                   | High                           | 136:113                                       | No                             | Armed conflicts | WHO EMRO cancer registry assessment workshop, 2016 |
| Egypt                   | Medium                         | 158:148                                       | No                             | Scarcity of mortality data | Site visit and recommendations, 2014; WHO EMRO basic cancer registration course, Cairo, Egypt, 2014 |
| South Sudan             | Low                            | 123:143                                       | No                             | No information | No activities |
| Sudan                   | Low                            | 92:91                                         | No                             | Mostly hospital-based cancer registries | Cancer registration workshop, IAEA, 2014 |
| Central Asia and former Soviet Union | Medium to high | 97:306-103-226 | – | Non-adherence to international standards; low visibility | Technical support; training; resources in Russian |
| Armenia                 | High                           | 306:226                                       | NCD plan, 2016–20               | Non-adherence to international standards; low visibility; no software | Site visit with IAEA and recommendations, 2012 |
| Azerbaijan              | High                           | 166:124                                       | Mostly hospital-based cancer registries | On-site training of the registry team at ICMR Cancer Registry, 2016 |
| Georgia                 | High                           | 208:164                                       | No                             | Mostly hospital-based cancer registries; inadequate funding | Site visit with IAEA and recommendations, 2014 |
| Kazakhstan              | High                           | 282:217                                       | Yes, 2012–16                    | Non-adherence to international standards | Site visits (Global Initiative for Cancer Registration and IAEA) and recommendations, 2016; basic cancer registration course, Astana, 2014 |
| Kyrgyzstan              | Medium                         | 152:129                                       | NCD plan, 2013–20               | Lack of commitment to cancer registration; unclear location; inadequate funding | Site visits and recommendations, 2015 and 2016; technical support setting up CanReg5 system |
| Tajikistan              | Medium                         | 129:112                                       | Yes, 2010–15                    | Poorly developed infrastructure; no funding for cancer registration | Site visits and recommendations, 2012; IAEA Programme of Action for Cancer Therapy |
| Turkmenistan            | Medium                         | 159:133                                       | NCD plan, 2014–20               | No information | No country-specific activities |
| Uzbekistan              | Medium                         | 97:103                                        | No                             | Mostly hospital-based cancer registries | Site visit and recommendations, 2013 |

*(Table continues on next page)*
IARC and the northern African registries have a long history of collaboration. After the establishment of the IARC Regional Hub, country assessments were done and recommendations provided to Algeria, Egypt, Libya, and Morocco. Morocco also hosted the Annual Scientific Conference of the International Association of Cancer

| Human Development Index | History of cancer registration | Cancer incidence (age-standardised rate per 100 000) [world standard] | National cancer-control plan | Main challenges | Global Initiative for Cancer Registry Development actions (2012–16) |
|-------------------------|-------------------------------|-------------------------|-----------------------------|---------------|---------------------------------------------------------------|
| (Continued from previous page) | | | | | |
| **Western Asia†** | | | | | |
| | | | | | |
| Gulf countries | High to very high | From the USA, Surveillance, Epidemiology, and End Results based programme | 79-113 81-135 | — | — |
| | | | | | |
| Bahrain | Very high | National cancer registry, data on nationals in CI5 volumes IX-XI | 113:122 | Yes, 2010–20 | Lack of mortality data, registration of non-nationals |
| | | | | | |
| Kuwait | Very high | National cancer registry data on both nationals and non-nationals in CI5 volumes V-XI | 90:123 | Yes, 2013-18 | Low-quality mortality data |
| | | | | | |
| Oman | High | Cancer registry since 1996 | 79:92 | No | Low quality of mortality data, inadequate funding, few staff |
| | | | | | |
| Qatar | Very high | National cancer registry, data on nationals in CI5 volumes X and XI | 103:135 | Yes, 2011–16 | Registration of non-nationals |
| | | | | | |
| Saudi Arabia | Very high | National cancer registry, data on nationals for Riyadh in CI5 volumes X and XI | 86:103 | Yes, 2014–25 | Registration of non-nationals; registration outside the Riyadh region |
| | | | | | |
| United Arab Emirates | Very high | Hospital-based cancer registry in Tawam hospital, Abu Dhabi, plan to introduce PBCR | 84:127 | NCD plan, 2012–21 | Hospital-based cancer registries; retention of staff |
| | | | | | |
| Yemen | Low | Aden Cancer Registry | 81:81 | No | Armed conflicts |
| | | | | | |
| **Other western Asia†** | | | | | |
| | | | | | |
| Cyprus | High | National cancer registry since 1998, data in CI5 volumes IX-XI | 218:198 | Yes, 2009 | Inadequate funding |
| | | | | | |
| West Bank and Gaza Strip | Medium | Former Middle East Cancer Consortium registry, since 1998 | 150:143 | No | Scarce infrastructure; location unclear; few trained staff |
| | | | | | |
| Iraq | Medium | Cancer registry established in 1976, CanReg4 software | 145:132 | NCD plan, 2013-17 | Armed conflicts; little training |
| | | | | | |
| Israel | Very high | National cancer registry, data in CI5 volumes II-XI | 318:259 | In preparation | Better use of hospital information systems; training new staff |
| | | | | | |
| Jordan | High | Former Middle East Cancer Consortium registry, since 1996, data in CI5 volume XI | 153:158 | No | Scarcity of mortality data, large proportion of refugee populations |
| | | | | | |
| Lebanon | High | National pathology-based registration | 204:193 | NCD plan, 2016–20 | Pathology-based cancer registration |
| | | | | | |
| Syria | Medium | Cancer registry using CanReg4 software | 148:145 | No | Armed conflicts |
| | | | | | |
| Turkey | High | Regional cancer registries in CI5 volumes IX-XI | 258:162 | Yes, 2013-18 | Questionable quality of mortality data |

CI5=Cancer Incidence in Five Countries; EMRO=Eastern Mediterranean Regional Office; PBCR=population-based cancer registry; IAEA=International Atomic Energy Agency; NCD=non-communicable diseases.

*Based on world standard population. †Summary indicators not presented as the region is very diverse.

Table: Cancer registration setting and development in countries within the North Africa, Central and West Asia Hub
Registries in 2016 and included 47 registry participants across the northern Africa region. From 2014, action plans for cancer surveillance in the region have been developed in partnership with WHO EMRO.

Central Asia
The five central Asian countries that formed part of the former Soviet Union (Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan), until its breakdown in 1991, are distinct in their ethnic composition, languages, and religion. In the years that followed the dissolution of the Soviet Union, each nation initially showed declines in gross domestic product and public health spending, with Tajikistan faring the worst of the five countries as a result of a civil war that lasted 6 years.21,24 The different attitudes of countries toward market economies and information sharing have also reflected on the degree of optimal utilisation of available development funds. Hence, programmatic aid and direct budgetary assistance by donors were welcomed in Tajikistan and Kyrgyzstan, but less in Turkmenistan and Uzbekistan. Kazakhstan appears the most open to unrestricted competition for development funds and is currently the only country in the region with a high HDI (table).8,23,25 Health-care systems in central Asian countries stem from the Soviet Semashko model, which is characterised by a largely centralised state-controlled system with universal access to health care, often with many staff, while not being necessarily efficient in terms of health outcomes and quality of care provided.28 One of the characteristics of this system is universal coverage by specialised care at the primary level, with oncologists in charge of cancer prevention and follow-up leading to high-quality surveillance.27 The obligatory reporting of health statistics involves the compilation of predefined forms in the medical statistics office of a hospital, which are then processed by a medical statistician, a profile that is unique to the former Soviet Union countries. Cancer incidence data are then reported from regional to national oncology centres and subsequently to the Ministry of Health in what is often in an aggregated, commonly paper-based, format.

However, as the countries changed in the post-Soviet era, cancer registration procedures diverged from common standards resulting in loss of comparability across the region and internationally. An additional challenge shared with formerly communist European countries is the perception that a cancer registry is a regime-affiliated administrative body. This perception might have partly led to the low status of cancer registry physicians, resulting in poor visibility of cancer registry data, and a lack of opportunities to sustain and to expand cancer surveillance activities as a consequence. The absence of high-quality cancer data in central Asia is worth noting (table), except for the project-based data from Kyrgyzstan covering 1986–87, which are published in CI5 volume VI.1 Registrations in Kyrgyzstan only recommenced in 2015 as a project of the country’s Ministry of Health, in collaboration with WHO EURO. Kazakhstan has the longest population-based incidence series in the region, dating back to 2004, and currently has the most developed cancer surveillance system in central Asia. By contrast, Tajikistan still has no infrastructure for efficient cancer registration, Uzbekistan’s cancer registration is hospital-based, and Turkmenistan has only just introduced software to commence cancer registration.

Estimates of the cancer burden in central Asia are based on the mortality data available from the WHO mortality database for all five countries.29 Although the estimated regional incidence in 2012 was comparatively low (168 per 100,000 men, 148 per 100,000 women), the estimated number of new cancer cases was over 80,000, which is projected to increase 60% by 2030 based on demographic changes.24 The observed cancer profiles align with those in many low to medium HDI countries, with a high residual burden of infection-related cancers, in particular stomach cancer in both sexes, and cervical cancer as the second most common cancer in women in central Asia.10 Cancer-control efforts are gathering momentum, with Kazakhstan introducing a cancer-control plan for 2012–16, and Kyrgyzstan adopting the National Program on Prevention and Control of NCDs.22 A common feature of these plans is to introduce hospital information systems that encompass all mandatory cancer statistics notifications, and make provision for cancer registry data. Although the value of hospital information systems is well established, maintaining access to other independent data sources, such as mortality data, is essential to ensure robust population-based data collection is feasible.28

The IARC Regional Hub’s activities in the region have focused on establishing links with the cancer surveillance community, and provides training and materials in Russian. The first IARC cancer registration course in the Russian language was held in Astana in 2014, from which learning resources in Russian and recommendations for cancer registration in the former Soviet Union, the Astana Recommendations,32 were developed. A further cancer registration course with WHO EURO was held in Bishkek, Kyrgyzstan, in 2016. At the national level, site visits were completed and recommendations provided to Uzbekistan, Kazakhstan, and Kyrgyzstan, which was the first country to implement the Russian version of the CanReg5 software developed by IARC.31

Western Asia
Western Asia is a diverse region including countries in the Middle East, as well as countries of the Caucasus, previously in the former Soviet Union. Although the development of surveillance systems has been thwarted by conflict and population migration in many countries in this region, several cancer registries including the national registry in Israel and subnational registries in Turkey (including Izmir, the host of the Hub) have
managed to sustain high-quality data.14 High-quality PBCRs from western Asia, mostly subnational, were included in the CI5 volume XI.10 In the whole region, the projected cancer incidence is expected to increase by approximately 75% over two decades, with over 746,000 new cases predicted in 2030.1 Because of the marked difference in HDI and corresponding cancer profiles relative to the rest of the region, the Gulf region is described separately.5,30

**Gulf countries**

Other than Yemen, each country has a high or very high HDI and is characterised by major immigration, particularly of men of working age. Despite cancer care being available in both public and private sectors, access to care is variable particularly for non-nationals who form a large proportion of the population, and for whom health-care indicators are frequently missing.14-16

The oldest cancer registry in the Gulf is the Kuwaiti Cancer Registry, with data registered from 1979–2012 compiled in CI5 volumes V to XI. Other registries in the region developed in the 1990s, with national data from Oman published in CI5 volume IX, and data for Bahraini, Qatari, and Saudi (Riyadh) populations included in volumes X and XI.31 In 2011, a report on 10-year cancer incidence among nationals of the Gulf Cooperation Council states (1998–2007) was published by the Gulf Centre for Cancer Control and Prevention.27

The inadequate availability or low quality of mortality data, partly due to rapid burial tradition, is shared by most Arabic countries, yet a particular challenge in the region is the registration and follow-up of non-nationals as they frequently return to their home countries for additional work-up and treatment.7 Thus far, only Kuwait has been able to provide high-quality cancer data for nationals and non-nationals for their country.31 In this region, cancer registrars are commonly non-nationals, which leads to a large staff turnover. Still, the only countries that have not published population-based data are the United Arab Emirates and Yemen. Several countries—such as Qatar, Saudi Arabia, and United Arab Emirates—have initiated the use of new software systems within broader health information systems, but no systematic assessment of data quality has been made thus far.

GLOBOCAN 2012 has estimated just under 37,000 new cancer cases and 21,300 cancer deaths annually for this region of 70 million in the seven Gulf countries (Bahrain, Kuwait, Oman, Qatar, Saudi Arabia, United Arab Emirates, and Yemen). Despite the low number of new cancer cases, the cancer burden is expected to double over the next decades according to population projections,7 while an increased adoption of western lifestyles is likely to augment current incidence rates,15,16-20 with obesity prevalence and physical inactivity, notably among women, among the highest in the world for this region.29

Cancer incidence patterns in the Gulf countries differ accordingly from those observed in the rest of western Asia, with colorectal cancer the most common cancer in men and the third most common cancer in women, whereas haematological malignancies are the second most common cancer in both sexes.7,21-23 The Health Ministers’ Council for the Gulf Cooperation Council states played a leading role in cancer-control initiatives in the Gulf countries, emphasising the importance of cancer-control planning at its 43rd conference, which was held in Geneva, 1997. The conference was followed by the development of a 10-year strategy (2010–20).41 At the national level, most Gulf countries have cancer plans that include cancer surveillance.22

In addition to the action plan with the WHO EMRO, training activities and research collaborations are planned in the Western Asia region. The IARC Regional Hub for cancer registration in North Africa, Central and West Asia also has an active role in supporting the registries in advocating legislation for cancer registration and obtaining access to death certificates and data sources from within the private sector. Many other countries in western Asia have ongoing conflicts, with large numbers of refugees and internally displaced people (table). A registry assessment workshop in Iraq, convened by WHO EMRO in Erbil in 2016, with participation of cancer registry professionals from all regions, provided a good model to support building cancer registry infrastructure in the near future.

**Conclusion**

The opportunities for establishing a viable national cancer surveillance system are closely linked to a country’s stage of development, with countries that have a very high or high HDI tending to have oncology care infrastructure already in place, along with readily accessible information on patients via electronic rather than paper-based medical records.19 Although several examples of high-quality surveillance systems from low-income countries are available,9 a specific problem in northern Africa, and in central and western Asia, remains the political instability and low government accountability, impeding access to universal health care and evidence-based cancer-control planning.8 Armed conflicts and migrations are making cancer care and cancer surveillance even more challenging, and have resulted in either the cessation of operations (eg, Benghazi, Libya, and Aden, Yemen) or the inability of long-established cancer registration systems, such as that in Iraq, to produce high-quality data.19,24 The protracted conflicts and an unprecedented number of 65.6 million forcibly displaced people worldwide,46 imposes a need to develop mechanisms to extend cancer care and surveillance to both displaced and host populations.46

In view of the widespread adoption of western lifestyles, and the projected rise in cancer due to population ageing and growth, the cost of inaction is high. Steps should be taken now to build capacity for cancer registration across
the northern Africa, and central and western Asia region, to facilitate networking, and to sensitise governments and other stakeholders to the indispensability of cancer surveillance for cancer control. Linking with WHO and UN targets and frameworks for monitoring NCDs at a national level, providing concerted efforts to accelerate the availability of regional and national PBCR through the Global Initiative for Cancer Registry Development partnership, is translating into a global effort that can enable cancer data to inform and to measure the impact of cancer action.

Contributors
All authors contributed to the preparation of this Series paper, reviewed the manuscript, and approved the final version. AZ and FB were responsible for the conceptualisation; and AZ was responsible for writing the manuscript.

Declaration of interests
We declare no competing interests.

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