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«They say things are happening at the border, but nobody knows which border» (Mark Strand)

New economic challenges for managing disease prevention and monitoring

by **Pablo Collazzo – Mauro Romanelli – Paola Briganti – Paolino Fierro – Davide de Gennaro**

Abstract: *Managing disease prevention and monitoring its progression benefits professionals facing the challenge of acquiring new knowledge and information for fighting the many diseases that negatively affect the life of people in areas such as public health systems, families, economic and business systems. From economic and operational points of view, Cancer Registries as organisations managing information by collecting, storing, reporting and interpreting data to improve cancer monitoring which is needed to plan health policies evaluation and design. Sustaining the role of the Cancer Registry as information system for fighting against cancer relies on paying attention on regulatory and ethical aspects with regard to the protection of confidential data, understanding and meeting the organisational challenges, learning from theory and practice emerging from the comparison of international experiences, bringing together voluntary, private initiatives of associations and public programs for sustaining the relevance of gathering and collecting data, information for knowledge about managing prevention and monitoring of the disease as core competence for driving public health systems towards sustainable development. Regulatory and organizational infrastructures help improve both information and knowledge management and design and implement effective measures and initiatives leading to efficacy in preventing and monitoring cancer disease as support to medical scientific research for cancer cure.*

Summary: *1. Introduction. – 2. Managing disease prevention systems. – 3. Disease registries as organisation: regulation and ethical aspects – 4. Managing information and knowledge – 5. International experiences and practices – 6. The Airtum as organisational form and coordinating mechanism. – 7. A case study for improving the disease prevention and monitoring. – 8. Conclusions.*

1. Managing disease prevention and monitoring helps professionals facing the challenge of acquiring new knowledge and information for fighting against many diseases that negatively affect the lives of people in terms of public health systems costs. Cancer Registries as organisation responsible for ensuring effective collection, storage, reporting and interpretation of data help to improve cancer monitoring and build new knowledge for disease treatment, analysis, prevention and monitoring which

can in turn drive improved health policy planning, evaluation and design. The aim of this study is to investigate how Cancer Registries may operate as systems for gathering, collecting and managing information to create new knowledge base with regards to cancer disease prevention and monitoring. The study relies on archival and qualitative data drawn by considering the Cancer Registries as organisations and information sources for managing disease prevention, monitoring and control. A literature review on the international experiences and practices is presented. Finally, to facilitate the study aims, the data gathering and collection concerning the role of the AIRTUM *Associazione Italiana Registri Tumori* as an organisational form for coordinating the activities related to cancer prevention and analysis, and the case study represented by the *Terra dei Fuochi (The Land of Fires)* as laboratory and case study highlighting the need to strengthen and improve the Cancer Registries as informational sources for knowledge improvement, sharing and creation will be examined.

The study is organised as follows. Following this introduction, in the second section, some considerations on management systems for disease prevention are presented. In the third section, the features of Cancer Registries as organisations with regards to regulatory and ethical aspects of the treatment of confidential data are presented. In the fourth section, the role of Cancer Registries as organisations managing information and knowledge for disease prevention is elucidated. In particular, the analysis explores international experiences and practices; to explain the role, the goals and the task of AIRTUM as organisational form and mechanism of coordination for the activities related to the cancer prevention and monitoring. Also in this section, the *Terra dei Fuochi (The Land of Fires)* as case study is discussed, as an experiment to improve the role and value of Cancer Registries to better manage and share information and knowledge for improving the cancer prevention.

2. Chronic diseases such as heart conditions, cancer, diabetes, chronic respiratory disease, or visual and auditory defects contribute significantly to premature deaths and disabilities, and thus heavily affecting the quality of life of individuals[1], particularly those in disadvantaged socio-economic people[2].

Generally, the chronic illness originates at an early age, but can take decades before becoming clinically apparent, thus requiring long term care. It is at this latter stage that the disease offers the opportunity for analysing, studying and finding solutions for prevention and monitoring, and efficacy in its cure. Employing medical record systems may lead to major health care savings while improving individuals' health, even if benefits may materialize themselves at a later stage[3] and prevention systems are still poorly implemented[4].

Prevention systems deal with the continuous monitoring of the distribution and progression of a disease incidence in a population through systematic data collection, analysis and evaluation of morbidity, mortality and other relevant data, as well as the disclosure of information to everyone who contributed to the system and to everyone who needs to know about the issues[5].

Monitoring systems allow researchers to classify and categorise diseases to provide a useful overview to address these issues and offer results that permit healthcare professionals to develop plans to be targeted at specific interventions and to evaluate their effectiveness over time. The international cases about general disease prevention systems, structures, methods and techniques encompass a range of monitoring and prevention models (epidemiological data collection, analysis, interpretation, prevention

initiatives ranging from information and training to the population to specific diagnostic services on the territory).

The automated telephone communication systems (ATCS), unidirectional (one-way, non-interactive voice communication), interactive voice response (IVR) systems, ATCS with additional functions such as access to an expert to request advice (ATCS Plus) and multimodal ATCS, where the calls are delivered as part of a multi-component intervention, contribute to improve and increase healthcare effects in terms of immunisation, screening, and compliance medications and tests[6].

3. The Cancer Registry is both an organisation and the process to systematically collect, store, analyze, interpret and report data of persons suffering from the disease, in order to improve cancer control, and evaluate and compare the effects of health policies and practices on this disease. Hospital-based Cancer Registries provide readily accessible information on patients with cancer in terms of the treatment they receive and the results. Population-based Cancer Registries help gather data and produce statistics on cases of cancer concerning a population in a well-delimited geographical area, providing a framework to appreciate and assess an effective cancer control and impact with regards to epidemiological aspects which helps define public health priorities, based on etiological studies[7]. Cancer Registries as valuable database and information systems should help evaluate the impact of cancer prevention, screening and treatment programs, and improve the cancer planning, focusing significantly on the quality of life and meeting the needs of patients[8].

Ensuring better health care implies prevention, control and measurement as a registration determinant. Cancer registration may rely on voluntary or compulsory notification of patients' outcomes resulting from legislation or from an administrative act in virtue of an executive healthcare authority. Designing an effective cancer registration service requires the development of appropriate guidelines to protect patient confidential data to promote high quality of data and to use those data to benefit patients and monitor cancer control advancing medical research[9]. Confidential data permit the identification of an individual or patient's condition. Personal data should be processed lawfully, fairly, in a transparent manner in relation to the data subject; collected for specific, explicit and legitimate purposes, adequate, relevant and limited to what is necessary, and kept for no longer than necessary, processed in a manner that ensures confidentiality and protection against unauthorised or unlawful processing against accidental loss, destruction or damage[10]. The guidelines on confidentiality, in this context, and the ethics for Cancer Registries should provide specific measures in order to ensure the preservation of personal data[11]. Worldwide guidelines developed since 1991 (IARC[12]) and European guidelines (ENCR[13]) developed since 1992 have defined the measures needed to ensure the protection of privacy (patients, doctors and the hospitals), specifying which is considered confidential information. Cancer Registries should follow the same standards about how to identify and manage confidential data. Providing an adequate legal framework helps the effectiveness of the Cancer Registries by ensuring privacy to protect the confidentiality of the personal data as the more important threat to cancer registration[14], an ethical issue to be considered in terms of completeness and accurateness of registry data to minimize risks of loss of privacy and breaches to confidentiality facilitating planning and implementation of public health programs and research activities[15]. Regulations and directives should help bring together measures for both data and information protection and exchange for producing new knowledge and scientific results in terms of therapies, diagnostic and prevention[16].

4. Appreciating cancer survival allows health care providers and policy makers to evaluate the effectiveness of health management systems. According to the World Health Organisation (WHO), 16 million of new cancer cases per year will be by 2020, seventy per cent in developing countries, largely resulting from growing environmental pollution and unhealthy eating styles, along with extreme working conditions in the exploitation of land natural resources, such as gold, diamonds or petroleum.

The WHO conducted a study on the frequency and characteristics of latent or overt carcinomas in specific body areas, by employing Cancer Registries. Introducing worldwide Cancer Registries for comparison data collected helped solve disagreements in diagnosis and increase the effectiveness of cancer care and cure[17].

Cancer Registries as information management systems should help to improve knowledge and information sharing about cancer disease evolution, diagnosis and prevention. It is valuable to consider the international experiences and practices in comparison with the organisational form implemented for the collection and management of data and information. Cancer Registries help to support strategic decision processes regarding complex issues, such as the definition, implementation, and improvement of care protocols for diseases, often characterised by incomplete and confused epidemiological data, and information about etiology, dynamics and effective treatments with sustainable side effects by patients. Cancer Registries collect data and information on all cancers in all residents of a given area (single city, entire region, province or nation territory). ‘Specialised’ Cancer Registries collect data and information on specific tumours (the colon–rectum, lung, breast, etc.) or on specific age groups (all childhood tumours, etc.)[18]. Cancer Registries foster knowledge creation and information management through cooperation at inter-organisational levels. Scientific expertise and skills, information technology management systems represent strategic resources^[19] leading Cancer Registries to be considered as decisional support systems helping to learn how to make decisions facing and solving difficult and not structured problems[20]. By using flexible data processing systems for advancing scientific and organisational learning, and improving the processes for cancer prevention and treatment, the knowledge on cancer information management and monitoring proceeding coherently with a double-loop learning[21].

5. Information on different cases of cancer emerged in the first half of the twentieth century and continuously grew over time. Cancer Registries, which originally focused on analysing cancer’s patterns and trends on patient survival, developed in order to plan and evaluate activities of cancer control and care based on comparability, validity and timeliness of the log data[22]: comparability refers to understand a comprehensive review about the registration procedures under place; validity as examined through numerical indices; timeliness refers to specific rules for abstraction and register signaling[23].

In the 1970s best practices were developed and laid down by national agencies based on detailed programmatic criteria (United States, Northern Europe and Japan). In Southern Europe countries, Cancer Registries developed in 1990s, as a spontaneous scientific rationale of individual clinicians, pathologists, epidemiologists and public health doctors arising from their commitment as physicians, to improve the knowledge about the disease and better understanding the causes and mechanisms of cancer development^[24], in response to significant growth of cancer diseases in the past few decades[25].

Cancer Registries allow professionals to specifically record incidence, mortality and the prevalence of cancer. Inequality in cancer prevention and monitoring emerge in low-and middle-income countries (LMICs) leading to a continuing cycle of poverty. High-income countries (HICs) mostly have population screening programmes (for example, cervix, breast and bowel cancer); however, in LMICs 70% of patients do not have access to adequate cancer cures (vaccine, radiotherapy). Socioeconomic status tends to influence the possibility of survival. It is necessary to invest in the training of oncologic surgeons particularly in LMICs, in acquiring and managing methods to control and prevent the cancer by developing adequate population-based cancer registries[26]. The United Nations (UN) has set rules to improve global cancer registries adoption to monitor the epidemiological data, which is aimed at bridging the clinical and global gap[27].

Attention should be paid to the reliability of Cancer Registries in terms of completeness and precision of data[28]. For example, while between 1990 and 1996, the Finnish Cancer Registry had recorded, the morbidity of 4.922 patients with pancreatic cancer with 89 surviving for at least five years, Carpelan–Holmström and colleagues[29](2005) showed that the data were inaccurate and only 10 patients survived for at least five years.

It is arguably necessary to effectively plan an active research program tracking records and statistics of cancer cases[30]. Some experiences and attempts emerged over time. The EUROPREVAL[31] is a European project for studying cancer by highlighting and evaluating the differences between countries, in terms of epidemiological evidence and effectiveness of care. EUROPREVAL is based on 38 Cancer Registries in 17 European countries, providing data on almost 3 million patients diagnosed with cancer between 1970 and 1992. Standardised procedures were used for collecting and validating data by identifying large geographical, gender and wealth differences within and among countries. Many types of tumours have a higher prevalence in Sweden, Switzerland, Germany and Italy, while showing lower trend in Poland, Estonia, Slovenia and Slovakia. Breast cancer accounted for 34% of all women's cancers and colorectal cancer was prevalent in about 15% of males.

Within richer European countries both a greater presence of cancer cases and a lower number of deaths emerge[32]. Introducing and employing Cancer Registries therefore helps achieve positive results in terms of improvement in health techniques[33]. Higher levels of cancer survival are shown (Australia, Canada and Sweden). Intermediate levels were apparent (Norway) and lowest levels were (Denmark, England, Northern Ireland and Wales).

Analyses tend to check the validity of the cancer registry (Norway, between 2001 and 2005). It has been shown that the routines involved were reasonably accurate, close-to-complete and timely[34]. With regard to the Sweden, the quality of data provided by the hospitals and the state was confirmed in relation to a study of 13,434 cancer patients (1995-2003)[35]. In Japan, a computerised system has been developed with the aim of reporting cases of pancreatic cancer[36]. In Iran, Cancer Registries, as constructed on regional basis, gathering and collecting data about 3,500 cancer patients, provided interesting information[37].

6. In Italy there are no mandatory prescriptions for storing data related to the diagnosis of the cancer treatment. The AIRTUM^[38] (Associazione Italiana Registro dei Tumori), aims at actively seeking, storing and making information available for scientific study and research. The AIRTUM working group (2013) showed 4.473 new cases of malignant neoplasie on children and adolescents between 2003 and 2008.

The Association of Italian Cancer Registries, established as AIRT in Florence in 1997, aims at coordinating the 43 regional Cancer Registries providing data and information on the type of cancer diagnosed, the name, address, age and sex of the patient, the clinical conditions, the medical treatments and the evolution of the disease with regard for 28 millions patients, corresponding to 47% of the total resident population.

The association through its connection with equivalent bodies in Europe and worldwide supports the research, the editorial output and methodological development of various Cancer Registries.

Since 2006 AIRTUM has aimed to enable the comparison of epidemiological data for cancer between the different parts of the country; to survey and measure oncological pathology in terms of mortality, incidence and survival; to examine trends over time and to compare the results obtained with those observed in other countries. The objectives of the AIRTUM are: to make available to health service bodies and the scientific community, data on incidence, mortality, survival and prevalence data for tumours in Italy in order to facilitate research, disease prevention and oncologic welfare planning to stimulate data analysis so as to shed light on the frequency of cancer in Italy; to contribute to the planning of new initiatives in data registration and their evaluation; to foster the standardisation of registration techniques; to promote a national and international network; to represent and safeguard, at home and abroad, the professional interests of researchers and technical assistants in Italian cancer registries; to improve the usage of data registration through guidelines enabling the standardisation of results and the setting up of a forum for sharing recent epidemiological research.

The activities of AIRTUM are focused on establishing a national database for the estimation of frequency indicators for cancer in Italy using the information collected from accredited cancer registries; to continuously assess the quality of the data collected from associated cancer registries; to stimulate, promote and support study and research and conduct the editorial work by disseminating publications based on the national database; to organise training courses designed especially for the staff of cancer registries; to organise the collection of funds and materials to promote and support research activities; to organize seminars and conventions and to collaborate with organisations, bodies, institutions and national and international foundations with similar or complementary aims.

Today, AIRTUM plays a significant role in managing and sharing data and information with regards to cancer care. The Italian Health Ministry mandatorily imposed a duty on to public and private hospitals to keep all records about the diagnosis and treatment of tumours: the Cancer Registries permit to collect information about those sick with cancer resident in a specified area known as *population registries*, and gather data about the tumours of all residents in a specific area which could be a single city, an entire region or province, or the area covered by an ASL (Azienda Sanitaria Locale – local public bodies providing health services); including data of people affected by a specific type of tumour, named *specialised registries on a single type of tumour* (for example, tumours of the colon, the rectum and breasts), or belonging to a *specific age group* (for example, children aged 0 to 14, and adolescents aged 15 to 19).

The data from Cancer Registries are essential for research about the causes of cancer, the evaluation of the efficacy of treatments, the planning of preventive interventions and scheduling expenditure on health services. 34 Cancer Registries cover a quarter of the Italian population. The information collected includes the type of tumour diagnosed, the name, address, the age and sex of the patient, the clinical

circumstances in which the cancer was found, the current treatment and treatment history, and the development of the disease[39].

Cancer registries collect the data from hospitals, family doctors, local health authorities (ASL), and regional health agencies. The main sources are: *hospital discharge notes* holding a summary of every patient admission; *anatomical and pathological cytology archives* generally ensuring the highest level of accuracy of the diagnosis of individual cases following international coding rules with a great acquisition of the characteristics of neoplasms (morphology of the cancer, biological structure, grading and classification); *clinical records* disclosing case data that computer processing is often not able to achieve, consulted at the hospital, and, rarely, with the treating doctor; along with *death certificates* all accounting for the main sources for information acquisition.

Cancer Registries are created by the initiative of doctors and professionals operating in the public health system. Such initiative is voluntary rather than mandatory. The diffusion of Cancer Registries is not homogeneous in Italy. In Southern Italy, there are fewer Cancer Registries (32% in 2013) in comparison to North Western (41%), Eastern (69%) and Central Italy (26%). Recently, the Health Ministry promoted programmes in order to encourage to extend the registration in all regions of Italy.

The organisational structure and governance of AIRTUM, as determined in the Statute, is articulated in: *Members; Organs and Commissions*.

The *Members* are researchers and technical personnel of Cancer Registries, citizens and people interested in health information systems. *Members* can vote, be elected as officers and participate in all the activities of the assembly.

As for the *Organs of the Association: The Assembly of Members* (ordinary or extraordinary) is chaired by the Secretary and convened at least every year. The ordinary assembly approves the budget and annual accounts, discusses and approves a programme of activities and appoints the members of the *Board of Directors* and of the *Audit Office*.

The *Board of Directors* consists of 8 members *pro bono*, elected by the Assembly before the beginning of the year and remaining in charge for two years, potentially re-electable. The *Board of Directors* is responsible for making strategic choices as agreed by the Assembly in terms of designation of collaborators, drawing up the budget and annual accounts, presenting an annual report of the Association's scientific endeavour, and convenes the Assembly of Members, appointing delegates for workgroups and committees and conducting the business of the Association. The Board of Directors elects the Association's Secretariat and treasurer from among the board members. To accredit a new registry, a board meeting may be enlarged to include the directors of all Italian Cancer Registries.

The *Secretariat* consists of the Secretary and two Vice-secretaries. The Secretary is the legal representative of the Association, responsible for all administrative matters drawing up contracts and signing correspondence for and on behalf of the Association.

The *Audit Office*, consisting of two members of the Association checks the regular keeping of accounts and accounting documentation.

The *Commissions* are grouped and specialised for specific matters and affairs (database, financial, accreditation, publications, press and web, quality of cancer registries, education, international relations). The *Commissions* have to present an annual programme comprising the objectives and activities, the account of the activities performed to be debated and discussed in the annual assembly of the Association.

The AIRTUM *database*, available online and periodically hosted by the ISPO (Institute for Oncologic Research and Prevention, Florence), is the main national archive on cancer data, collating all tumour data, collected by the individual accredited registries.

There are specific rules that govern the accreditation of a Cancer Registry. The Board for assessment appointed by AIRTUM will issue a written judgement within three months of receiving the documents and material discussed below. It reserves the right to request further information that, if necessary, will be inspected at the offices of the applicant registry.

The Cancer Registry, to secure accreditation, must submit incidence data covering at least three consecutive years, and the production and submission by the applicant registry of complete documentation and materials indicated in the AIRTUM Statute. The cases are codified by the individual registries following the International Classification of Diseases (ICD-O 3) before being submitted to the national database. Their quality is checked before and after being submitted to the database. Analyses of quality indicators show a high level of completeness and validity of the collected data, and give reassurance of the comparability of the different areas. The high quality of the data produced by AIRTUM is suggested by its regular inclusion in international publications on cancer, such as cancer incidence or Eurocare 4, Cancer in Five Continents.

7. Many factors, particularly the biological ones and life conditions, affect human health[40]. Historically, the Italian region of Campania was known as *Campania Felix* by virtue of the fertility and fruitfulness of its territory[41]. Recently, a large urban and rural area of 1.076 km² and comprising more than two million and four thousands of inhabitants (ISTAT, 2013) between the cities of Naples and Caserta was negatively renamed by local, national, and international mass media as *Terra dei Fuochi* (*Land of Fires*) because of toxic and black smoke trails ascending to the sky as a result of the incineration of toxic waste burned down along not particularly busy road arteries, and as a territory in which criminal economic activities developed by activating an illegal waste cycle that produced large scale pollution to the environment[42].

The Italian government intervened by identifying 32 municipalities in the province of Naples and 23 municipalities in the province of Caserta as the *Terra dei Fuochi* and passing the law n. 6/2014 in conversion of the Decree n. 136/2013 in order to solve the so-called *waste emergency* having a very negative impact on public health and the natural environment by the contamination of farmland and creating danger for agro-food products within the Campania region. An Inter-Ministerial Committee was set up, from which a specific Commission was placed in charge of coordinating a program aimed at protecting health, safety, site reclamation and economic revitalization of the territories in question. The Campania region was called upon to define the type of examinations for the cancer prevention and the control of the health status of the resident population in the municipalities concerned, without any cost for patients; it was also determined to update the epidemiological study “Sentieri” by the Higher Institute of Health[43].

The epidemiological picture of people living in the 55 municipalities of Campania within the *Land of Fires* was characterised by a higher incidence of cancer in for male (11%) and female (9%) compared to the national average; the mortality rate for male (9%) and female (7%) tends to exceed the the national average according to the data provided by Istituto Superiore della Sanità (2016).

As of 2017, there are seven accredited Cancer Registries supplying data and information on 71% of the population living in the Campania region, whilst the national average covers only 52% of the population of any given region. They are monitoring 20% more of cancer cases in comparison with the Italian average, and cover 100% of the cases in the *Terra dei Fuochi* area, excluding the city of Naples. Moreover, the Campania Region is the third Italian region in adopting and obtaining the accreditation from AIRTUM of an Infantile Cancer Registry of regional coverage, tracking all new cancer cases occurring in the age range of 0–19 years. At present, the Campania Infantile Cancer Registry is the one with the highest percentage of supervised children and youngsters in Italy. The AIRTUM has activated three Cancer Registries in Naples, Salerno and Caserta. The first two, set up in 1996 and 1997 respectively, are already part of the AIRTUM network and they are accredited; the Cancer Register in Caserta, set up in 2012, is completing its first registration, relating to the data for the 2008-2010 triennium. In addition, AIRTUM has recently set up the Regional Cancer Registry Network with the aim of ensuring, in coming years, a cancer register for each province of Campania region.

8. Cancer Registries tend to emerge as important organisational forms for managing data and information that support the initiatives and the efforts of public health systems to control, prevent, analyse and battle cancer, a disease that slashes people's lives, while impacting the structure of costs and spending within public health systems.

The Italian experience suggests that AIRTUM as a mechanism of coordination helps Cancer Registries better develop important functions and performing the task by strengthening their role and contribution. Prevention is typically better, more useful and less costly than providing a cure. Managing disease prevention and monitoring helps the development of a public health system and creating communities and public awareness on the importance to gather, collect, interpret and analyse data and information to anticipate and prevent the negative consequences of cancer.

New forms of regulatory and formal, international and national governance are arguably necessary to discipline the activities of the Cancer Registries so as to effectively fight cancer disease by providing useful data, inputs and outputs leading to improved public health policies, while encouraging private and public-sector cooperation and collaboration for sustainable economic growth. Bringing together voluntary, private initiatives of associations and public programs for sustaining the collecting data, for the prevention and monitoring of the disease is seen as a core competence for driving public health systems towards greater impact and efficiency. Providing adequate regulatory and organizational infrastructure helps improve both information and knowledge management and design and implement effective measures and initiatives leading to efficacy in preventing and monitoring cancer disease as support to medical scientific research for cancer cure.

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