

# E-NNOVATE: Electronic innovations in cancer registration

Sharing knowledge to accelerate progress with the launch of the global DHIS2 oncology module

## The E-NNOVATE PROJECT

With electronic medical records (EMRs) becoming more common, greater opportunities have emerged for them to be used as a data source for PBCRs. To explore this issue, international partners have collaborated to form the E-NNOVATE Project. The goal is to develop a global tool that connects PBCRs to [DHIS2](#), a health information system that is widely used in low- and middle-income countries.

### Overview

The E-NNOVATE project is based on creating efficiencies. Health facilities using DHIS2 have already committed resources to storing patient information in a common electronic format. To make use of this investment, and the change in medical reporting practices that accompanies it, a Beta cancer module in DHIS2 has been developed. Led by the Rwanda National Cancer Registry, the DHIS2 Oncology module contains the necessary data fields for a PBCR. Moreover, the module incorporates IARC edit checks to increase data quality by flagging incompatible entries in real time. Completed records can then be transferred directly to the PBCR, avoiding re-entry of cases. This has been further enhanced by the development of an interface with CanReg5, a free and open-source software for cancer registry management used in many countries.

One of the most difficult tasks in electronic medical records is to make sure that what works in one setting can work elsewhere. Using implementation science approaches and the existing structures of the GICR, the DHIS2 Oncology module is being tested so that a robust solution can be made available to any country that wishes to use it. The Caribbean Public Health Agency has led this component by examining features related to installation, operation. This includes customizing the module to the core variable dataset recommended for Caribbean PBCRs, pilot testing the module in PBCRs in the region, and partnering with the Organization of Eastern Caribbean States (OECS) to develop a centralized cancer registry for interested Member Countries of the OECS. A global release of the DHIS2 Oncology module and accompanying resource material is planned for December 2023.

### Background

Cancer patients experience different outcomes depending on where they live. This includes many preventable and premature deaths, financial hardship for families, and heavy losses to society. Cancer control planning can help mitigate the impact. With quality cancer data, countries can know where to invest and can monitor the impact of their efforts. Population-based cancer registries (PBCRs) collect data on all new cancer cases in a defined population to produce key indicators about the cancer burden. This information guides decision-making in cancer control and aids our understanding of the causes of cancer for respective countries. While collecting the necessary data for PBCRs is challenging in lower resource settings it has been demonstrated to be feasible. In recent decades, rapid technology advancements have offered the potential for leapfrog solutions, in which PBCRs can demonstrate efficiencies by moving directly to digital systems and away from cumbersome paper-based methods. Through the framework of the [Global Initiative on Cancer Registry Development \(GICR\)](#), the [International Agency for Research on Cancer \(IARC\)](#) has brought together key partner organizations to develop new tools that support the sustainable development of PBCRs.



### Factors For Success

#### PARTNERSHIPS

Bringing focus to a common problem by convening diverse groups and skills offers a strong basis for a solution. Coordinated by IARC together with [Vital Strategies](#), work on the project is divided among the partner organizations, supported in part by the [Bloomberg Philanthropies Data for Health Initiative](#), to create a faster and more efficient result. The partners include the [Rwanda Ministry of Health](#), the [Rwanda Biomedical Centre](#), the [African Cancer Registry Network/IARC Sub Saharan Hub for Cancer Registration](#), the [University of Oslo](#), and the [Caribbean Public Health Agency/IARC Caribbean Hub for Cancer Registration](#), and the [OECS](#). Each partner is accountable to the others and brings unique strengths to the project.

#### KNOWLEDGE TRANSFER

The project will make use of knowledge transfer techniques to create peer-learning opportunities. Documenting what has worked and what proved to be difficult will help to transfer lessons to others. Scientifically studying the process in an organized way around the world will reduce the time needed for implementation and strengthen the tool. DHIS2 and CanReg5 are both free and open-source software, meaning that their programming code is available for others to view and modify as needed. Regional experts in CanReg5, as part of the GICRNet – a network of IARC–GICR trainers on cancer registration topics – will be available as local support. The GICR framework and the project partners will be available to widely disseminate results.

#### INNOVATION

Searching for new answers to problems relies on a degree of curiosity and a willingness to explore different approaches. The E-NNOVATE project incorporates this principle to create forward-thinking solutions in the field of cancer registration that can be easily shared throughout the world.

#### COUNTRY LED:

While the project benefits from many partners working together, decisions about how to implement the project rest fully with each country. Local collaborators will be tasked with driving results while international partners are there to provide support.

### OUTCOMES

The project will achieve several key outcomes. With the integration of electronic medical records, data collection will be standardized. The same formats and definitions will be used throughout, eliminating problems such as incompatible records from within the same country. Unique identifiers are a prerequisite for electronic medical records, so their inclusion in the cancer registry brings the benefit of reducing inconsistencies when linking records of the same person. Electronic data capture will produce efficiencies in time, freeing up cancer registry staff to devote efforts to other tasks and avoid duplication brought on by using paper-based forms. Validation of information using built-in cross-checks will help to increase the quality of data, making the registry of greater value to its stakeholders.

### IMPACT

Creating an application that links a cancer registry to electronic medical health records in a country will improve the way cancer data is captured as well as its value and usability. The solution can be applied to any country in the world using DHIS2, and with further investment, can be adapted to other disease surveillance systems. Unlike most other information technology advances, the DHIS2-CanReg application will be free and open-source. In addition, a network of experts has volunteered their time to support new users globally. The model of the GICR is one that builds on the experiences of others, so as new users are added and gain the needed competencies, they will be asked to share what they learned with others.

Beyond the immediate impacts, the larger goal of the project is to better inform cancer control. High-quality local cancer data can point decision-makers to where action is needed. It provides policymakers the information they need to implement prevention and control strategies. Tracking key indicators that a cancer registry produces – such as the number of new cases, the profile of cancer in each population, and survival differences over time – gives a roadmap of where to invest and a gauge of how the health system is functioning overall. Countries that have a strong cancer registry can plan, implement and monitor cancer strategies that ultimately lessen the risk of developing cancer and improve the lives of those with cancer. The E-NNOVATE project offers a way to fast track the benefits of electronic medical records to countries that need support.

