

**VIRTUAL MOBILITY (VM)
GRANT REPORT**

This report is submitted by the VM grantee to VNS Manager, who will coordinate the approval on behalf of the Action MC.

Action number: CA18117

VM grant title: Creation of a standard template for cancer registries for rare gynaecological malignancies

VM grant start and end date: 20/9/2021 to 20/10/2021

Grantee name: Rita Micallef

Description of the outcomes and achieved outputs (including any specific Action objective and deliverables, or publications resulting from the Virtual Mobility).

The objective of this study was to compile a template for a new database for the collection of rare gynaecological cancer cases within diverse cancer registries within the EU and other participating countries.

Two-hour meetings have been held online via Zoom every Tuesday throughout the VM grant period (21st September, 28th September, and 5th, 12th and 19th October 2021), in collaboration with two Maltese gynaecological professors, a Maltese pathologist, the public health consultant in charge and the manager of the Malta national cancer register as well as the Irish partners, namely Dr Sharon O'Toole and Dr James Beirne from Trinity College Dublin and St James' Hospital in Dublin. In one of the meetings, consultation was held also with Prof C Simon Herrington from Edinburgh, UK who is the expert on the WHO classification of cancers of the female genital tract.

During the first meeting a presentation of the data collection methods and diverse data sources used by the Maltese National cancer registry was given. During the following meetings ,discussions and plans were made regarding how the questionnaire will be set up to make it easy for the recipients to fill it in. Tick boxes were used throughout this questionnaire. The best way of how it will be

disseminated was discussed and different platforms were explored. A decision was taken to use Google forms.

The questionnaire was first validated internally with the aim of eventually distributing it to cancer registries from across the 30 countries forming part of this GYNOCARE COST Action. A generic email was set up so that the participants can submit their data flow process sheet through this email and can be accessed by the whole team. The next step is to apply for ethics approval, and then the survey will be distributed in the next grant period.

Description of the benefits to the COST Action Strategy (what and how).

Data compilation is a highly complex but extremely significant process. The aim of this data compilation is needed to measure the number of rare cancer cases, to monitor trends, take necessary actions for prevention of risk factors to minimise the disease, to introduce screening programmes and plan for the necessary treatment. Eventually this is also important when planning clinical trials for novel treatment. This is essential to address all the main objectives of the GYNOCARE COST Action, as it will explore how and what data is being collected specifically for rare gynaecological malignancy, and eventually aim to harmonise cancer registries in the EU and beyond.

Methods of which type of data coding is being used is of high importance, as there might be some variation in the way that pathologists will define the type of disease. The different data flow processes is also important to ensure that all available data is collected. The availability of complete and accurate rare cancer data will lead to improvement of healthcare and expand knowledge about diseases whilst ensuring that ongoing study and research regarding rare cancer treatment will be more efficient and effective. This may thus lead to prolonging survival and quality of life. The population would also be made more aware of risk factors and would thus seek to adopt lifestyles. Studies are still ongoing to find the cause, the risk factors, and the appropriate treatment of this disease, but to continue in the appropriate direction data compilation must be complete, accurate, measurable and comparable.

Auditing of the methods and standards for data compilation used by diverse cancer registries will be made once the questionnaire is answered. This will help to assess and evaluate the effectiveness, efficiencies, accuracy, comparability, validity and timeliness of the data compiled. A holistic perspective regarding the quantitative and qualitative dimensions of data auditing will be presented.

Sufficient regards will be granted to the culture of the respective cancer registers under review. High attention will also be given regarding ethical issues and confidentiality.

Description of the virtual collaboration (including constructive reflection on activities undertaken, identified successful practices and lessons learned).

Brainstorming was done over a series of five 2-hour online meetings by different experts related to the field of rare gynaecological cancers hailing from different countries. This included pathologist, general gynaecologists, gynae-oncologists, public health and health information specialists, data manager and ethics/legal expert. This series of meetings over a 5 week period was very helpful in helping keep focus especially in designing the questionnaire and to ensure that all major problems are tackled.

One of the questions is the responsibility and occupation of the participant in charge of the cancer register. The major problem in the development and maintenance of cancer statistics is the lack of appropriately and adequately trained personnel to fulfill the necessary functions in the registry. The collecting, storage, analysis, interpretation and utilization of cancer data require high level of training at all levels. Pathologists, oncologists and epidemiologist or statisticians are very rare, and they are especially busy particularly at this time of the ongoing COVID-19 pandemic. Obviously, one cannot analyse the data collected without the appropriate equipment and well skilled human resources. All different methods that are being used in these Cancer Registries, will be investigated and analysed. This will help to ensure that data compilation is complete, accurate and valid and is being processed in a timely manner.

The fact that these meetings could be held online at a time when all the participants in the VM mobility were available, has certainly helped in allowing the compilation of this important piece of work, which otherwise would have been difficult to achieve so successfully in such a relatively short period of time, especially taking in consideration how busy the people involved are, particularly at this time.