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*In March 2008, the nationwide virtual tumourbank project was launched by the Belgian Minister of Health, Ms. Laurette Onkelinx (initiative 27 of the Belgian Cancer Plan). The Belgian Virtual Tumourbank (BVT network) encompasses the tumour biobanks from eleven Belgian university hospitals ([click here](#) for the list) that collect and store residual human tumour samples locally. In order to facilitate the search for tumour samples scattered among different Belgian institutions, data collected at sample level is made available for researchers via the online BVT catalogue (BVTc) application. A high quality of the data on the tumour samples requested by scientists for research in oncology is guaranteed by automatic and manual controls performed by the BVT project team at the Belgian Cancer Registry.*

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## RARE CANCERS IN THE BVT CATALOGUE

**This third newsletter highlights the rare cancers available in the online BVT catalogue! The BVT catalogue can facilitate the search for tumour samples scattered among different local biobanks, especially for rare cancers. If you want to know if the specific samples for your research are available in our catalogue, please request full access so you can browse freely through all available sample data and locate the matching samples for your study!**

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## WHAT ARE RARE CANCERS?

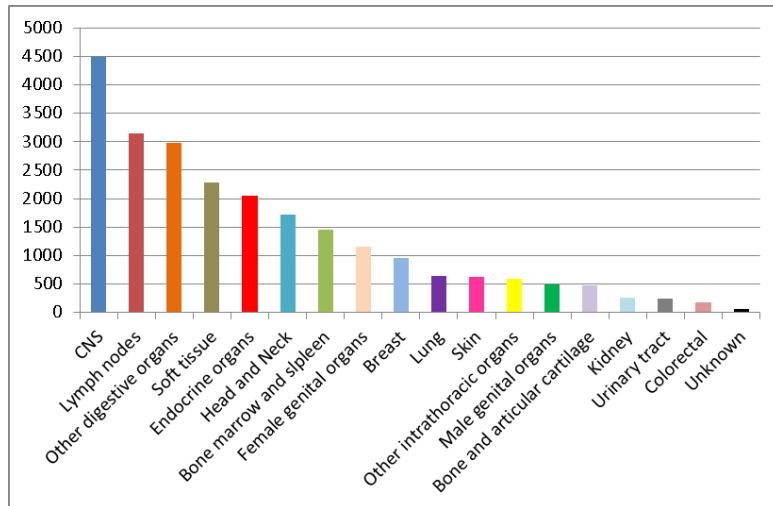
Rare cancers have been defined as cancers with an incidence rate lower than 6 per 100,000 per year for both sexes by the RARECARE project (<http://www.rarecare.eu/>). This European project quantified the burden of rare cancers in Europe and showed that rare cancers pose an important challenge in Europe. In 2014 the Belgian Cancer Registry has published a report on rare cancers in the Flemish region (for more information [click here](#)).

The selection of rare cancers in the current newsletter is based on the RARECARE cancer list, a list of common and rare cancers that has been made publicly available ([click here](#)). The definition of each tumour entity is done based on a combination of morphology and topography codes according to the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3).

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## WHICH RARE CANCERS ARE AVAILABLE?

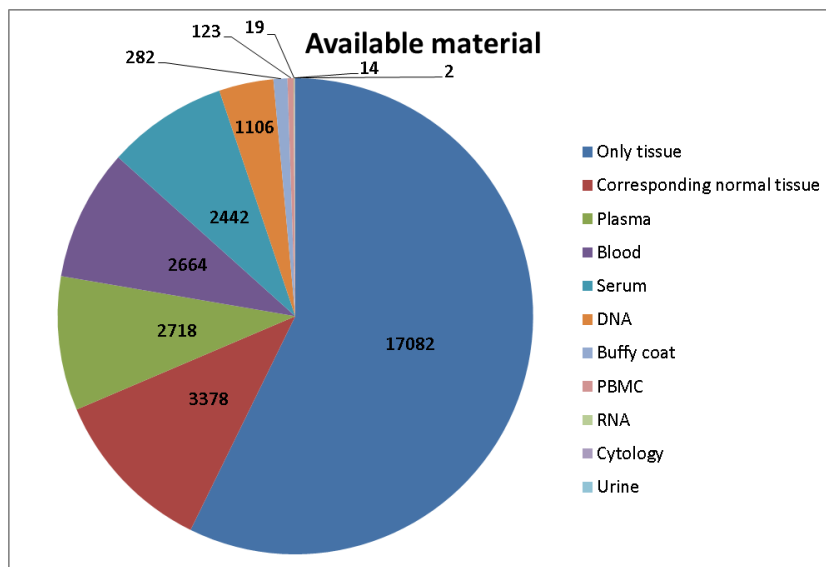
In total, 84,307 registrations were available in the BVT catalogue at the moment of selection (March 2018). Based on the criteria proposed by the RARECARE project, **23,847** registrations from **12,043** patients with rare cancers could be retrieved in the BVTc. The majority of the registrations concern male patients (13,199 or 55.3%) while 10,648 of the registrations (44.7%) concern female patients.



The most common sample localisation of the rare cancers in the BVTc is the central nervous system (18.8%). Lymph nodes and other digestive organs (like stomach, liver and pancreas) complete the top three of sample localisations with 13.2% and 12.5% respectively. As expected Head and Neck tumours are numerous present as well in the catalogue (7.2%).

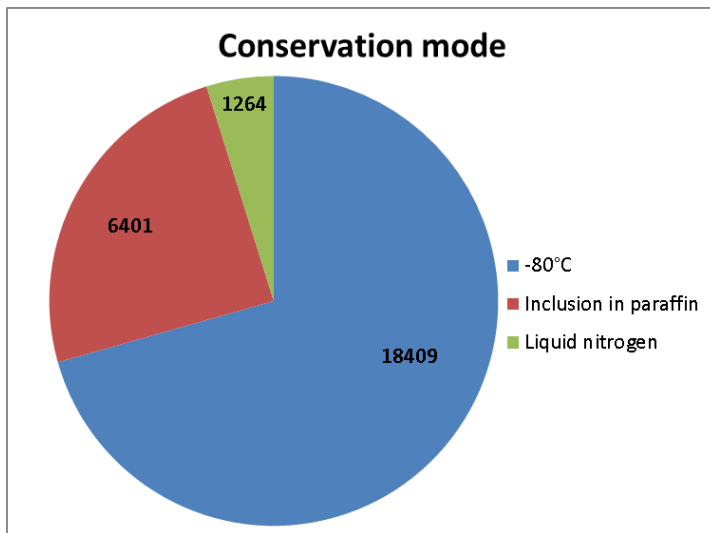
Figure 1: Overview of the localisation of primary tumour samples of rare cancers in the BVTc

## STORAGE OF SAMPLES FROM RARE CANCERS



For 57.3% of the registrations, only residual tumour tissue is stored. For some patients, also additional types of material are stored at the local biobanks and registered in the BVT catalogue. The most common type is corresponding normal tissue: 11.3% of the registrations. Blood (8.9%), plasma (9.1%) and serum (8.2%) are also available in some local biobanks.

Figure 2: Overview of other available material stored at the local biobanks



More than 70% of the registrations (18,409) are stored at -80°C, 24.6% are included in paraffin (6,401) and 4.9% are stored in liquid nitrogen (1,264). Conservation delay, the time between excision and fixation or freezing of the sample, is less than 30 minutes for 18% of the registrations. For 7,254 registrations (30%) the conservation delay is more than 30 minutes.

**Figure 3:** Conservation mode for rare cancers available at the BVT catalogue

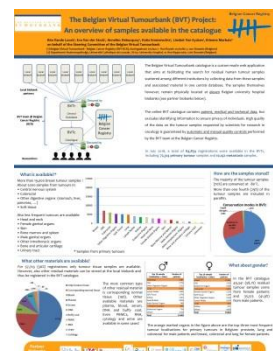
## SPREAD THE WORD....

Flyers on the BVT project have been distributed at the Belgian Week of Gastroenterology (21-23<sup>rd</sup> February, Antwerp), BSMO annual meeting (23-24<sup>th</sup> February, Oostende), OncoPoint meeting (28<sup>th</sup> February, Gent), Oncoforum (9<sup>th</sup> June, Leuven) and the Europe Biobank Week (4-7<sup>th</sup> September, Antwerp).



The Belgian Virtual Tumourbank team was present at the first Belgian Biobank Day (23<sup>rd</sup> March 2018, Gent) organised by BMMRI.be and gave a presentation on quality control of data.

The Belgian Virtual Tumourbank team presented a poster at the Europe Biobank Week (4-7<sup>th</sup> September 2018, Antwerp) in the category “Data sharing in biobanking – Discoveries, Novelties, Realities”.



- ➔ The BVT team likes to be informed about upcoming meetings where the BVT project can be presented or if you would like to receive BVT flyers for distribution in your institution.

For information on sample availability, [click here](#).

To gain full access to the online BVT catalogue, please follow the procedure indicated [here](#).

For further information: [www.virtualltumourbank.be](http://www.virtualltumourbank.be)  
[biobank@kankerregister.org](mailto:biobank@kankerregister.org) or [biobank@registreducancer.org](mailto:biobank@registreducancer.org)

Do you wish to be kept informed in the future? Click [here](#).  
 Click [here](#) if you do not wish to receive our information any longer.  
 Belgian Cancer Registry | Brussels | [www.kankerregister.org](http://www.kankerregister.org)