

WASABY Meeting at GRELL Meeting (Trento, 17th May 2018)

On the occasion of the GRELL Meeting 2018 (<https://www.grell-network.org/next-meeting>) a meeting with several cancer registrars involved in WASABY, and representatives of WASABY WP4, 5 and 7, was organised.

The WASABY management team wishes to thank the GRELL organizers in Trento for the great hospitality.

List of participants

CRs	Representatives
Belgium	Julie Francart
Alto Adige	Andreas Bulatko
Palermo	Sergio Mazzola
Trento	Maria Gentilini, Roberto Rizzello
Umbria	Fabrizio Stracci
Varese	Paolo Contiero
Central Portugal	Joana Antunes Lima Bastos
Northern Portugal	Luis Antunes
Basque Country	Nerea Larrañaga, Arantza Lopez De Munain Marques
Girona	Rafael Marcos Gragera
Granada	María José Sánchez Pérez, Miguel Rodriguez-Barranco

WASABY partners	Representatives
Fondazione IRCCS "Istituto Nazionale Tumori" – WP4	Martina Bertoldi, Roberto Lillini , Milena Sant
Caen University – WP5	Elodie Guillaume, Ludivine Launay, Guy Launoy
Fondazione IRCCS "Istituto Nazionale Tumori" – WP7	Paolo Contiero

Agenda

1. General observations to the project from the partners and the participating Cancer Registries: issues, suggestions, etc.
2. Data availability and smallest geographic unit: how can we improve the CRs geo-coding? Role of the WASABY WP4 (Data management), WP5 (Deprivation index) and WP6 (Spatial Analysis Methods) in helping the Cancer Registries to improve it.
3. European Deprivation Index: what variables and at what geographic level are they available? What years of availability?
4. The local Ethical Committee approvals: what we are doing and what we have to do?
5. Organizing and sending the datasets: when?
6. Discussion about pollutants: discussion what about institutions that have databases on pollutants in the Cancer Registry's area?
7. WASABY cross-fertilization with other projects: using the European Deprivation Index for survival and outcome studies on breast cancer.

Report

1. General observations to the project from the partners and the participating Cancer Registries: issues, suggestions, etc.

The participants expressed satisfaction for the project communication process between WPs and CRs; this should be maintained in that it assure a major involvement of CRs in the project.

A new CR will join the WASABY project: the Alto Adige Cancer Registry.

WP5 referent, Guy Launoy and his team reported about the WP's next action: a short survey will be sent to participating CRs in order to define the geographical level of availability of the socio-economic information coming from every National Census (Census Tract, Municipal Code, etc.).

The survey will be prepared and administered by WP5 and made available along with its results on the WASABY web site.

The data collection protocol was presented again to the CRs in order to stimulate a possible further discussion about the document current version. No observations were raised during the meeting participants agreed that any additional changes may be sent up to the end of May 2018.

2. Data availability and smallest geographic unit: how can we improve the CRs geo-coding? Role of the WASABY WP4 (Data management), WP5 (Deprivation index) and WP6 (Spatial Analysis Methods) in helping the Cancer Registries to improve it.

Problems about geo-coding at smallest geographic level (census tract and/or x&y coordinates) were underlined by Belgium, Trento and, partially, by Central and Northern Portugal.

Belgium: two aspects were underlined. Firstly the possibility to geo-code cases at census tract level is conditioned by the privacy and confidentiality aspects (about this issue, the discussion were developed in point 4). Secondly, as numerous small and very small municipalities (under 2000 inhabs.) exist in the country, a similar approach to that applied for the Schleswig-Holstein CR (cases geo-coded at municipality level) may be adopted.

A similar situation was presented by the Trento CR: geo-coding at census tract and x& y level could be possible only after Local Ethical Committee approval. There is a problem of confidentiality, given to the municipal disaggregation of Trento province and the consequent possibility of identifying cases for census tracts with very few inhabitants. This aspect is common also to the numerous very small municipalities of the province.

For these reasons, also in the Trento CR, a mixed geo-coding strategy could be discussed in the next steps of the project.

The 2 CRs from Portugal: geo-coding will be defined at parish level, because of the geographic and demographic dimension of the census tracts, which is larger than the ones in the other countries. Parishes (smaller than census tract) should be a more reliable choice also for the definition of the deprivation index.

Martina Bertoldi expressed the WP4 intention to produce a brief document, useful to help CRs performing geo-coding for the first time in completing this procedure. The preparation of such document will involve the collaboration of Martina Bertoldi (Fondazione IRCCS "Istituto Nazionale Tumori" – WP4) and the Palermo and Umbria CRs, and drafts will be shared with WP5 and WP6 so to obtain a supporting document homogenous for all those involved in the project. This document will be used as a specific chapter of the deliverable D6.2 - Practical manual for CR's personnel.

The availability to work together by web tools and/or organize specific meetings in the single CRs to improve the knowledge and ability in the geo-coding procedures was confirmed as an aim of the project.

3. European Deprivation Index: what variables and at what geographic level are they available? What years of availability?

The WP5 team underlined the importance of defining geographic and time scale availability of socio-economic data for each participating country.

In the next weeks, WP5 will produce and send a new survey to all CRs, devoted to collect such information.

Meanwhile, WP5 will collect the 2011 census data from the countries where the European Deprivation Index was already developed by 2001 data, in order to update such index.

4. The local Ethical Committee approvals: what we are doing and what we have to do?

The WP4 team communicated that the project obtained the INT Ethical Committee approval. Some registries reported the need to obtain the approval of local Ethical Committees or Commissions revising privacy and confidentiality issues.

The Belgium CR informed that the requirements in Belgium are very strict. It is possible that a specific request must be submitted to the Privacy Commission to obtain authorization before transferring the data. These discussions will take some time and will need a very detailed request, possibly in French language. Guy Launoy and the other WP5 participants offered their help in producing this request: they will work together with the Belgium CR in order to speed up the procedure.

The Trento CR also reported the need for local approval of the study due to a problem of confidentiality, given by the municipal disaggregation of Trento province and the consequent possibility of identifying cases for Municipalities/census tracts with few inhabitants. They will start the procedure as soon as possible, but it is difficult to estimate when an answer will be given.

Also the Umbria CR have confidentiality issues in conferring nominative and coordinated data without approval of the Ethical Committee and of the Region. No limits for data at census tract level.

The Northern Portugal CR were activating the procedure for obtaining their local Ethical Committee approval.

WP4 and WP5 representatives are available to helping to speed up procedures, where needed.

5. Organizing and sending the datasets: when?

The deadline of CR data sending was confirmed as 31st of March 2019.

The WP4 team encouraged the CRs to send their dataset as soon as they have completed the different procedures (geo-coding, locals approvals, etc.), in order to speed up the analyses.

Specific issues regarding analysis procedure and confidentiality problems will be discussed separately with the single CRs, if needed.

6. Discussion about pollutants: discussion what about institutions that have databases on pollutants in the Cancer Registry's area?

WP7 leader, Paolo Contiero (Fondazione IRCCS "Istituto Nazionale Tumori" – WP7), introduced the topic of the pollutants databases at European level, their main characteristics and limits. He proposed the possible exploration of existing local dataset so to improve information on pollutants.

The CRs representatives declared their interest and availability for exploring the existence and characteristics of such datasets and a discussion arose around how these could be used in the study in consideration on possible differences and non-standardization.

The group decided to proceed also with this exploration, reserving the use of these databases for areas where European databases should prove useless. In this occasion, WP4 leader highlighted that comparisons between CR areas are not relevant for the WASABY project.

WP7 will collect the information about the various environmental datasets and will evaluate their utility in the study.

7. WASABY cross-fertilization with other projects: using the European Deprivation Index for survival and outcome studies on breast cancer.

Finally, Milena Sant underlined the relevance of interaction between WASABY and other European project, already existing or to be proposed as new projects to the EU Commission or inside the different countries.

In particular, the information collected in WASABY and the estimation of the European Deprivation Index (EDI) for a major number of countries (or calendar years) could be very useful in survival and high-resolution studies, considering specific pathological and clinical variables, geo-coded residence of the patients, etc.