



WASABY

Water and Soil contamination and Awareness on Breast cancer risk
in Young women

D4.1 Survey results

WP4 – Fondazione IRCCS “Istituto Nazionale dei Tumori”

V3 – 21st June 2019

D4.1 Report

WASABY Survey questionnaire to the participating Cancer Registries

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V1	Roberto Lillini	19.04.2018
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1. Background and aims

In the framework of the WASABY Project, the first operative step was devoted to identify the Cancer Registries (CRs) willing to participate to the study. To this aim, the following information was considered:

- Patients data availability: covered area, time range, geo-coding of the information and most disaggregated geographical level by which data were available, cost for organizing and sharing them in the format requested by WASABY;
- Population data availability: as above;
- Availability of socio-economic information and, specifically, deprivation indices (local, national, etc.): as above;
- Maps availability and any cost to be sustained to obtain them;
- Declared interest in participating in the Project;
- Previous experiences in studies connecting cancer and environmental issues with known potential pollution sources in the area covered by every CR;
- Administrative authorities (local and national) of reference for the CRs.

The above was asked via a preliminary questionnaire to 100 European CRs belonging to the European Network of Cancer Registries (ENCR) between the end of 2016 and the start of 2017. 30 CRs from 9 countries declared their interest to participate (Tab. 1).

Tab. 1 – First round (2016-2017) of CRs interested in participating to WASABY.

Nation	Cancer Registry	Nation	Cancer Registry
Belgium	Belgium	Lithuania	Lithuania
Germany	Bremen	Poland	Greater Poland
	Hamburg		Kracow
	Munich		Kielce
	Schleswig-Holstein		Lower Silesia
Italy	Firenze-Prato	Portugal	Silesia
	Friuli Venezia-Giulia		Central Portugal
	Napoli 3 South		Northern Portugal
	Palermo	Slovenia	Slovenia
	Parma	Spain	Basque Country
	Ragusa		Castellon-Valencia
	Siracusa		Girona
	Trento		Granada
	Umbria		Murcia
	Varese	UK	Northern Ireland

The number of CRs declaring their willingness to participate satisfied the number limits (nations and CRs) expressed as objectives in the project proposal presented to the EU Commission.



W A S A B Y

After the EU Commission approved the funding of the WASABY Project, a slightly revised version of the questionnaire was re-submitted to the 30 CRs who were interested in being involved in the study.

This new submission had two aims:

- To better define the sub-areas covered by European CRs for which it would be possible to collect geo-coded residence address (coordinates or small areas such as postal codes). This was necessary to assign to each case the smallest possible area on which the risk would be estimated and to identify the risk areas in as much detail as possible accounting for population characteristics and the socio economic status. Moreover, the decision of sub-areas also depended on the availability or potential availability of a national deprivation index.
- To update the information of the CRs, particularly regarding any changes in CR's staff for the specific project.

After the first WASABY Steering Committee (held in Milan on the 19th of February 2018), five more questions were added to the questionnaire and separately sent to the participating CRs, who already answered to the re-submission.

These five questions mainly dealt with issues regarding privacy and Ethical Committee permissions, due to the single CRs, because the discussion during the Steering Committee remarked that CRs in the same nations could be tied to provide different kinds of permission, in order to share data and analysis for the study.

Therefore, the CRs Survey questionnaire reached its final version, presented in the following paragraph.



2. The Survey questionnaire

FEASIBILITY SURVEY for the DG SANTE PROJECT PP-2-5-2016 WASABY

Water And Soil contamination and Awareness on Breast cancer risk in Young women

IMPORTANT NOTE: THIS IS NOT A DATA REQUEST SURVEY

The survey aims to explore interest and possibility of CR in contributing to the study. CR data handling will be regulated by the responsible ethical committees and in conformity with the EC General Data Protection Regulation (2016/679)

REGISTRY (CR) _____ SURVEY COMPILED BY _____ DATE _____

- In the past, has your CR been involved in studies on environmental pollution and cancer (ex: ca-co, spatial analysis, etc)? Would you be interested to become involved in one study on this topic?
 Yes, and we would be interested Never, but would be interested No, and not interested
- Please indicate below what is the minimum administrative area (from here on, "AREA") on which the CR can estimate incidence rates:
 zip code census block other
 municipalities provinces *please specify* _____
- Please indicate below what is available in your database at date of diagnosis for each incident case:

Residence address	<input type="checkbox"/> Yes	<input type="checkbox"/> Only for selected groups (request for specific studies)	<input type="checkbox"/> No
AREA of residence	<input type="checkbox"/> Yes	<input type="checkbox"/> Only for selected groups (request for specific studies)	<input type="checkbox"/> No
Geocode of residence	<input type="checkbox"/> Yes	<input type="checkbox"/> Only for selected groups (request for specific studies)	<input type="checkbox"/> No
- If none of the above applies, please let us know whether you would be able to collect residence address at date of diagnosis from the General Register Office/ Vital Statistic Office:
 Yes it is possible No it is not possible Our CR is not interested
- What is the name of the official body that defines the AREA in your country? _____
- Do you know which is the average number of inhabitants living in the AREA? _____
- If you were to perform a geo-coding of addresses or analysis by AREA, which would be the body able to link resident address and AREA?
 The CR can perform the link via its ordinary sources and/or software available
 I do not know at the moment, but if the project starts I shall acquire the information
 The CR can perform the link by paying external sources and/or software
 This link is a free of charge activity performed by _____
 This link is performed by paying the activity of _____ (If possible, please provide a cost estimate: _____)
- Please indicate below the answer relevant to your CR:
 data on AREA population are already available at CR per each calendar year
 data on AREA population are already available at CR per sporadic calendar years (ex: census year)
 data on AREA population can be requested free of charge to _____
 data on AREA population are purchasable from _____
Do you have idea of the costs? _____
 I do not know, but if the project starts I will acquire the information
- To your knowledge, is there a deprivation index available for your country?
 No
 I do not know, but if the project starts I will acquire the information
 Yes, it is available at census block level but at the moment our CR does not have in its databases
 Yes, it is available at municipality level but at the moment our CR does not have it into its databases
 Yes, the CR has a deprivation index at municipality/census block level



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10. Please indicate below the answer relevant to your CR

- Maps with AREA boundaries geo-codes are already available at CR
- I do not know, but if the project starts I shall acquire the information
- Maps with AREA boundaries geo-codes can be obtained free of charge from _____
- Maps with AREA boundaries geo-codes are purchasable from _____
Do you have idea of the costs? _____

11. Are there any chemical industries, military bases, or other recognized sources of water/soil pollution present in the area covered by your CR?

- None to my knowledge Yes, but correlation with cancer was never studied
- Yes, correlation with cancer is/it has been under study, yet never with breast cancer in young women
- Yes, correlation with cancer is/ it has been under study (including breast cancer in young women)

12. Please report the calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU). _____

13. Please report the calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection). _____

14. Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.

15. Detail limits in publishing maps (see confidentiality above).

16. Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient? _____

MANY THANKS FOR YOUR TIME AND COLLABORATION!



3. The results of the final Survey questionnaire: the Cancer Registries who confirmed their participation

After the re-submission of the questionnaire, not all the CRs confirmed their participation in the study.

Most of the reasons for this were due to changed conditions in the operating practice, transformations of the CR's identity (i.e., extension of the covered area), changes in privacy rules governing the data privacy and sharing.

The final list of participating CRs is reported below, with a synthesis of available data and corresponding lowest geographical level they can provide (Tab. 2a & 2b).

Twenty four (out of the 30 CRs initially adhering) CRs from 9 countries confirmed their participation and could timely reply to almost all questions. Only the Polish CRs group were not yet allowed to answer to the added 5 questions, as the National Polish Cancer Registry needed to be consulted about Ethical Committee approvals and privacy limit. The information will be provided as soon as possible.

The Parma CR (Italy) could not answer to the five additional questions, due to internal re-organization procedures—occurred after the WASABY Steering Committee. Also in this case, the information will be provided as soon as possible. Two more CRs joined WASABY after the GRELL Meeting in Trento (16th-18 May 2018): Alto Adige (Italy) and Navarra (Spain) and answered to the questionnaire. Also 17 French CRs joined the study after the GRELL Meeting, but they did not answer to the questionnaire, because they will be managed by a local responsible, who will organize the data collection and analysis (according to the WASABY procedures).

Afterwards, two more Polish CRs joined the study (Masovia and Podkarpacie) and, after the 2019 AIRTUM Meeting, also Trapani CR joined the study.

The CRs withdrawing their availability to join the study were: Hamburg and Munich (Germany), Firenze-Prato and Friuli Venezia-Giulia (Italy), Kracow and Lower Silesia (Poland). Afterwards, also the Belgium and Bremen (Germany) CRs left the study, due to internal organisation reasons.

Therefore, at date, a total of 44 CRs (plus the National Polish CR coordinating its local CRs) are involved in the study.

The current numbers of CRs and Nations officially adhering to WASABY fully satisfy the number limits expressed as objectives in the project. The WASABY Coordination Group contacted and stimulated the participation of more ENCR CRs profiting from the opportunity of national and international meetings involving CRs (e.g., GRELL Meeting on the 16th-18th of May 2018 in Trento, Italy).

Therefore, the list and number of participating CRs may still increase, even after the closing of the final list, expected for the end of August (WP4 Milestone M4.2 – Complete list of participating CRs).

Tab. 2a – Final list of CRs interested in participating to WASABY.

Nation	Cancer Registry	Geo-code level (main)	Geo-code linkage by	Reference population available at	Maps available at	SES
Germany	Schleswig-Holstein	Municipality	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	Local deprivation index (until 2009)
Italy	Alto Adige	Census Block	Cancer Registry + WP4	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national index
	Napoli 3 South	x, y coordinates	Cancer Registry + WP4	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national and local index
	Palermo	x, y coordinates	Cancer Registry + WP4	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national and local index
	Parma	Census Block	Cancer Registry	Cancer Registry by calendar year	ISTAT	EDI 2001+national index
	Ragusa	Zip Code/Census Block	Cancer Registry +WP4	Cancer Registry by calendar year	ISTAT	EDI 2001+national index
	Siracusa	Census Block	WP4	Cancer Registry by calendar year	ISTAT	EDI 2001+national index
	Trapani	Census Block	WP4	Cancer Registry by calendar year	ISTAT	EDI 2001+national index
	Trento	x, y coordinates	Cancer Registry + WP4	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national and local index
	Umbria	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national and local index
Varese	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer Registry/ISTAT	EDI 2001+national index	
Lithuania	Lithuania	Eldership	Cancer Registry	Cancer Registry by calendar year	Lithuania Statistics Office	None
Poland	Greater poland	Municipality	To be defined	Cancer Registry by calendar year	Central Bureau of Surveying and Mapping.	National and local deprivation index
	Kielce	Zip Code	External paid resources	Cancer Registry by calendar year	Central Bureau of Surveying and Mapping.	National deprivation index
	Silesia	Municipality	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	National and local deprivation index
	Masovia	Municipality	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	National and local deprivation index
	Podkarpackie	Municipality	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	National and local deprivation index
Portugal	Central Portugal	Parish/Zip Code	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	EDI 2001
	Northern Portugal	Parish	Cancer Registry	Cancer Registry by calendar year	INE	EDI 2001
Slovenia	Slovenia	x, y coordinates	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	EDI (in development)
Spain	Basque Country	Municipality/Census Block	To be defined	Cancer Registry by sporadic calendar year	Cancer Registry	EDI 2001
	Castellon-Valencia	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer Registry	EDI 2001
	Girona	x, y coordinates	External paid resources	Cancer Registry by sporadic calendar year	Purchasable externally	EDI 2001
	Granada	x, y coordinates	External paid resources	Cancer Registry by calendar year	Cancer Registry	EDI 2001
	Murcia	Census Block	External paid resources	Cancer Registry by calendar year	Cancer Registry	EDI 2001
	Navarra	Census Block	To be defined	Cancer Registry by sporadic calendar year	To be defined	EDI 2001
UK	Northern Ireland	Zip Code	Cancer Registry	Cancer Registry by calendar year	Don't know	Local deprivation index

Legenda: ISTAT = Italian National Statistics Office; INE = National Institute of Statistics Portugal; EDI 2001 = European Deprivation Index 2001 (Guillaume et al., 2016).

Tab. 2b – Final list of French CRs interested in participating to WASABY.

Nation	Cancer Registry	Geo-code level (main)	Geo-code linkage by	Reference population available at	Maps available at	SES
France	Gironde	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Poitou-Charentes	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Loire-Atlantique et Vendée	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Haute Vienne	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Calvados	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Manche	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Somme	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Lille et sa région	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Bas-Rhin	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Haut-Rhin	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Doubs et Territoire de Belfort	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Cancers gynécologiques de Côte-d'Or	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Isère	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Hérault	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
	Tarn	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index
Guadeloupe	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index	
Martinique	Census Block	Cancer Registry	Cancer Registry by calendar year	Cancer RegistryFRANCIM	EDI 2001+national index	

Legenda: FRANCIM = Réseau Français des Registres des Cancers; EDI 2001 = European Deprivation Index 2001 (Guillaume et al., 2016).



4. The results of the final Survey: characteristics of the confirmed participating Cancer Registries

The results of the preliminary survey showed different scenarios across the European CRs in terms of data availability and previous experiences in field of spatial analysis. Thus, WP leaders and Steering Committee decided to not to confine the study to one single standardized method for all CRs, but to apply different approaches for each country or CR, according to their available data.

The three main information collected through the questionnaire regarded the geographical level at which data are available, the existence of a socio-economic deprivation index usable by the CR and the presence of confidentiality issues requiring the involvement of a local Ethical Committee.

As for geographical level:

- Municipality: all 44 CRs.
- Zip Code (4 CRs): Ragusa, Kielce, Central Portugal, Northern Ireland. CRs providing completely geo-coded data (x & y) are also able to produce zip code information.
- Census tract or similar information (eldership, parish) (31 CRs): Alto Adige, Parma, Ragusa, Siracusa, Trapani, Umbria, Varese, Lithuania, Central Portugal, Northern Portugal, Basque Country, Castellon-Valencia, Murcia, Navarra and all the French CRs. CRs providing completely geo-coded data (x & y) also could be also able to produce Census tract information.
- X & Y coordinates (6 CRs): Napoli 3 South, Palermo, Trento, Slovenia, Girona, Granada.

As for the presence of a socio-economic deprivation index (Tab. 2):

- EDI was present in its 2001 version (updating), or in development, in 36 CRs, at Census tract level.
- National deprivation indices, at various geographical levels, were available for 15 CRs.
- Local deprivation indices, at various geographical level, were available for 10 CRs.
- Only the Lithuanian CR did not record a deprivation index.

As for differences in Ethical Committee approval:

- Thirteen CRs declared that INT Ethical Committee approval would be enough for their involvement in WASABY: Belgium, Napoli 3 South, Ragusa, Trapani, Varese, Lithuania, Central Portugal, Slovenia, Basque Country, Castellon-Valencia, Girona, Granada, Northern Ireland.
- Seven CRs declared their involvement is linked with the approval of local/specific Ethical Committees: Bremen, Schleswig-Holstein, Siracusa, Trento, Umbria, Northern Portugal, Murcia.
- A small number of CRs (5) were dealing with their referent national and/or local institutions, in order to devise if they need a specific Ethical Committee approval other than the INT one: Palermo, Parma, Greater Poland, Kielce, Silesia.

Another relevant information was the different time range for which the CRs can provide data for the study. In the following graphics (Graph. 1a & 1b), a comparison of the different period are shown.

A synthesis of other relevant information was reported in Table 2.

Information by single CR were reported in the following paragraphs. Also the CRs which originally agreed to participate, filled the questionnaire and retired are reported.

Obviously, in the three-years lifespan of the project, some characteristics may change. In particular the geo-coding of the information could improve at a lower and more detailed geographical level (Census block or x & y coordinates) where not already available, thanks to specific technical intervention inside the WASABY framework.

Graph. 1 – Data availability from the CRs: time range.

CR	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	
Belgium																												
Bremen																												
Schleswig-Holstein																												
Alto Adige																												
Napoli 3 South																												
Palermo																												
Parma																												
Ragusa																												
Siracusa																												
Trapani																												
Trento																												
Umbria																												
Varese																												
Lithuania																												
Central Portugal																												
Northern Portugal																												
Slovenia																												
Basque Country																												
Castellon-Valencia																												
Girona																												
Granada																												
Murcia																												
Navarra																												
Northern Ireland																												
Greater Poland	The 5 Polish CRs received the approval from the National Cancer Registry answer. They will process and analyse data by themselves, sharing only the results.																											
Kielce																												
Silesia																												
Masovia																												
Podkarpackie																												

CR	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
Gironde																											
Poitou-Charentes																											
Loire-Atlantique et Vendée																											
Haute Vienne																											
Calvados																											
Manche																											
Somme																											
Lille et sa région																											
Bas-Rhin																											
Haut-Rhin																											
Doubs et Territoire de Belfort																											
Cancers gynécologiques de Côte-d'Or																											
Isère																											
Hérault																											
Tarn																											
Guadeloupe																											
Martinique																											



4.1 Belgium Cancer Registry

CR's Director: Liesbet Van Eycken (elizabeth.vaneycken@kankerregister.org). **WASABY referents:** Julie Francart (Julie.Francart@registreducancer.org) and Kris Henau (Kris.Henau@kankerregister.org).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	18931 (range: 58 – 510610).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI in development.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2004-2016.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes (Municipality).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Concerning the privacy and confidentiality aspects, 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 delay the final response.
Detail limits in publishing maps (see confidentiality above).	No limits in mapping municipality data, if Privacy Commission will allow to send data.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





4.2 Bremen Cancer Registry

CR's Director and WASABY referent: Sabine Luttman (luttmann@bips.uni-bremen.de).

Question	Provided information
Geo-code level (smallest unit - SU).	Urban District (Bremen).
SU dimension (average number of people)	66189.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	Local index (until 2009) and EDI in development.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2004-2013.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	For aggregated data on municipality unit only an approval from local government, which usually takes 3-4 weeks. On small area unit (Urban District) it would need to aggregate on a 10 year time period and an approval from local Ethic Committee is needed. Very small number (< 5) in some small areas are expected (leading to potential data anonymization).
Detail limits in publishing maps (see confidentiality above).	As above.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	As above





4.3 Schleswig-Holstein Cancer Registry

CR's Director: Alexander Katalinic (Alexander.Katalinic@uksh.de). **WASABY referent:** Ron Pritzkeleit (Ron.Pritzkeleit@uksh.de).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	2474 (range: 5 – 78263).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	Local index (until 2009) and EDI in development.
Previous studies in the area, connecting cancer outcomes and environmental issues.	No experiences.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2000-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	Permanent small changes but population data and incidence data can be converted to a unique area status/mapping status.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Assuming that the data used is either anonymized or aggregated, in both cases there should be no problems with confidentiality. This should be pointed out for EC approval.
Detail limits in publishing maps (see confidentiality above).	There is no problem to publish rates or smoothed rates. It could be a problem for small municipalities for numbers.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.4 Alto Adige Cancer Registry

CR's Director: Guido Mazzoleni. WASABY referent: Andreas Bultako (andreasklaus.bulatko@sabes.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	Globally 526000 people .
Geo-code linkage by:	To be defined.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study (including breast cancer in young women).
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1995-2013.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems might arise.
Detail limits in publishing maps (see confidentiality above).	Municipality level.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval must be informed.



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4.5 Napoli 3 South Cancer Registry

CR's Director: Mario Fusco (mariofusco2@virgilio.it). **WASABY referent:** Francesca Maria Vitale (mafravi86@libero.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block.
SU dimension (average number of people)	170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national and local deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1997-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2001, 2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems will not arise.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.6 Palermo Cancer Registry

CR's Director: Francesco Vitale (francesco.vitale@unipa.it). **WASABY referents:** Rosanna Cusimano (rosanna.cusimano@unipa.it) and Maurizio Zarcone (registrotumoripalermo@unipa.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality (probably Census block).
SU dimension (average number of people)	Census block: 170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national and local deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2001-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2001, 2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Still to be defined.
Detail limits in publishing maps (see confidentiality above).	Still to be defined.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Still to be defined.





W A S A B Y

4.7 Parma Cancer Registry

CR's Director: Maria Michiara (michiara@ao.pr.it). **WASABY referent:** Paolo Sgargi (psgargi@ao.pr.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block (but only for Parma municipality).
SU dimension (average number of people)	170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	ISTAT.
SES and deprivation index.	EDI and national deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2001-2013.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2001, 2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Still to be defined.
Detail limits in publishing maps (see confidentiality above).	Still to be defined.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Still to be defined.



W A S A B Y

4.8 Ragusa Cancer Registry

CR's Director and WASABY referent: Rosario Tumino (rtumino@tin.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Zip Code and x & y coordinates.
SU dimension (average number of people)	Zip Code: 26766.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	ISTAT.
SES and deprivation index.	EDI and national deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1998-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes (x & y coordinates).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems will not arise.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.9 Siracusa Cancer Registry

CR's Director: Anselmo Madeddu (rtp@ausl8.siracusa.it). **WASABY referent:** Francesco Tisano (rtp@asp.sr.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality (but they will move towards Census block).
SU dimension (average number of people)	Census block: 170 (range: 1 – 3386).
Geo-code linkage by:	They must identify someone inside or outside the CR to perform geo-coding.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	ISTAT.
SES and deprivation index.	EDI and national deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2003-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Local Ethical Committee approval is needed.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval is needed.





W A S A B Y

4.10 Trapani Cancer Registry

CR's Director: Giuseppa Candela (candelag@inwind.it). **WASABY referent:** Tiziana Scuderi (trusyit@yahoo.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality (but they will move towards Census block).
SU dimension (average number of people)	Census block: 170 (range: 1 – 3386).
Geo-code linkage by:	They must identify someone inside or outside the CR to perform geo-coding.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	ISTAT.
SES and deprivation index.	EDI and national deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2002-2011.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems will not arise.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.



4.11 Trento Cancer Registry

CR's Director and WASABY referent: Silvano Piffer (Silvano.Piffer@apss.tn.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block.
SU dimension (average number of people)	170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national and local deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2003-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Local Ethical Committee approval is needed.
Detail limits in publishing maps (see confidentiality above).	There is a problem of confidentiality, given the municipal disaggregation of Trentino and the consequent possibility of identifying cases for municipalities with few inhabitants.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval is needed.



W A S A B Y

4.12 Umbria Cancer Registry

CR's Director and WASABY referent: Fabrizio Stracci (fabrizio.stracci@unipg.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block and x & y coordinates.
SU dimension (average number of people)	Census block: 170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national and local deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2001-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2001 and 2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Confidentiality issues in conferring nominative and coordinated data without approval of the Ethical Committee and of the Region.
Detail limits in publishing maps (see confidentiality above).	No limits.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval.



W A S A B Y

4.13 Varese Cancer Registry

CR's Director: Giovanna Tagliabue (Giovanna.Tagliabue@istitutotumori.mi.it). **WASABY referents:** Paolo Contiero (Paolo.Contiero@istitutotumori.mi.it) and Giovanna Tagliabue (Giovanna.Tagliabue@istitutotumori.mi.it).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block and x & y coordinates.
SU dimension (average number of people)	170 (range: 1 – 3386).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI and national deprivation indices.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, correlation with cancer was studied, also breast cancer was considered, but not yet specifically in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1990-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2001 and 2011 (Census data collection).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems will not arise.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.14 Lithuania Cancer Registry

CR's Director and WASABY referent: Ieva Vincerževskienė (ieva.vincerzevskiene@nvi.lt).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	58117 (range: 2400 – 554300).
Geo-code linkage by:	They must identify someone inside or outside the CR to perform geo-coding.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Lithuania National Statistics Office.
SES and deprivation index.	No deprivation index is available.
Previous studies in the area, connecting cancer outcomes and environmental issues.	None.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1990-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes (municipality).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Problems will not arise.
Detail limits in publishing maps (see confidentiality above).	Problems will not arise.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





4.15 Greater Poland Cancer Registry

CR's Director: Maciej Trojanowski (maciej.trojanowski@wco.pl). **WASABY referent:** Łukasz Taraszkiewicz (lukasz.taraszkiewicz@wco.pl).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	25000.
Geo-code linkage by:	They must identify someone inside or outside the CR to perform geo-coding.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Central Bureau of Surveying and Mapping.
SES and deprivation index.	National and/or local deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	Waiting for reply by the National Cancer Registry (NCR).
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	Waiting for reply by the National Cancer Registry (NCR).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Waiting for reply by the National Cancer Registry (NCR).
Detail limits in publishing maps (see confidentiality above).	Waiting for reply by the National Cancer Registry (NCR).
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Waiting for reply by the National Cancer Registry (NCR).





W A S A B Y

4.16 Kielce Cancer Registry

CR's Director: Stanislaw Gozdz (stanislaw.gozdz@onkol.kielce.pl). **WASABY referent:** Ryszard Mezyk (Ryszard.Mezyk@onkol.kielce.pl).

Question	Provided information
Geo-code level (smallest unit - SU).	Zip code.
SU dimension (average number of people)	To be defined.
Geo-code linkage by:	External paid resources.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Central Bureau of Surveying and Mapping.
SES and deprivation index.	National deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	Waiting for reply by the National Cancer Registry (NCR).
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	Waiting for reply by the National Cancer Registry (NCR).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Waiting for reply by the National Cancer Registry (NCR).
Detail limits in publishing maps (see confidentiality above).	Waiting for reply by the National Cancer Registry (NCR).
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Waiting for reply by the National Cancer Registry (NCR).





W A S A B Y

4.17 Silesia Cancer Registry

CR's Director and WASABY referent: Marcin Motnyk (Marcin.Motnyk@io.gliwice.pl).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality.
SU dimension (average number of people)	101759 (range: 35684 – 304362).
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	National and/or local deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	Waiting for reply by the National Cancer Registry (NCR).
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	Waiting for reply by the National Cancer Registry (NCR).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Waiting for reply by the National Cancer Registry (NCR).
Detail limits in publishing maps (see confidentiality above).	Waiting for reply by the National Cancer Registry (NCR).
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Waiting for reply by the National Cancer Registry (NCR).





WASABY

4.18 Central Portugal Cancer Registry

CR's Director: Manuel António Silva. **WASABY referent:** Joana Antunes Lima Bastos (3603@ipocoimbra.min-saude.pt).

Question	Provided information
Geo-code level (smallest unit - SU).	Zip code for this specific study.
SU dimension (average number of people)	To be defined.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	None.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1998-2011.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	The last census was in 2011 and the other one before was in 2001. There was a reorganization of Portuguese smallest sub-area of residence (freguesia) in 2012.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.19 Northern Portugal Cancer Registry

CR's Director: Maria José Bento (mjbento@ipoporto.min-saude.pt). **WASABY referent:** Luis Antunes (luis.antunes@ipoporto.min-saude.pt).

Question	Provided information
Geo-code level (smallest unit - SU).	Parish.
SU dimension (average number of people)	1088.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	INE.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2003-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	Data will be aggregated by parish (smallest geographical area available). There have been some changes in the number and composition of these units over time but distribution of parishes used in the census 2011 will be used.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	Local Ethical Committee approval.
Detail limits in publishing maps (see confidentiality above).	Local Ethical Committee approval.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval.





W A S A B Y

4.20 Slovenia Cancer Registry

CR's Director: Maja Primic Žakelj (MZakelj@onko-i.si). **WASABY referents:** Tina Žagar (TZagar@onko-i.si) and Vesna Zadnik (vzadnik@onko-i.si).

Question	Provided information
Geo-code level (smallest unit - SU).	X & Y coordinates.
SU dimension (average number of people)	It depends on the area radius around the coordinates.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1998-2015.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes (x & y coordinates).
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.21 Basque Country Cancer Registry

CR's Director: Arantza Lopez De Munain Marques (arantza-lopez@euskadi.eus). **WASABY referent:** Nerea Larrañaga (n-larranaga@euskadi.eus).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality. Census block available from 2014.
SU dimension (average number of people)	Census block: 1500.
Geo-code linkage by:	They must identify someone inside or outside the CR to perform geo-coding.
Reference population available at:	Cancer Registry by sporadic calendar year.
Maps available at:	To be identified by CR.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Correlation with cancer is/it has been under study, yet never with breast cancer in young women.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2005-2015 (Census bock: 2014-2015).
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes in the study period.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.22 Castellon-Valencia Cancer Registry

CR's Director: Consol Sabater Gregori (sabater_congre@gva.es). **WASABY referents:** Paloma Botella (botella_pal@gva.es) and Fernando Almela (almela_fer@gva.es).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block.
SU dimension (average number of people)	1500.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2005-2014.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 Census.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.



4.23 Girona Cancer Registry

CR's Director: Rafael Marcos-Gragera (rmarcos@iconcologia.net). **WASABY referent:** Marc Saez (marc.saez@udg.edu).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block and x & y coordinates.
SU dimension (average number of people)	1500.
Geo-code linkage by:	External paid resources.
Reference population available at:	Cancer Registry by sporadic calendar year.
Maps available at:	Purchasable externally.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1994-2014.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	2011 Census.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.24 Granada Cancer Registry

CR's Director and WASABY referent: María José Sánchez Pérez (mariajose.sanchez.easp@juntadeandalucia.es).

Question	Provided information
Geo-code level (smallest unit - SU).	Municipality (x & y coordinates could be attempted).
SU dimension (average number of people)	5473 (range: 134 – 237540).
Geo-code linkage by:	External paid resources.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2004-2013.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes in the study period.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	No confidentiality problems.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





W A S A B Y

4.25 Murcia Cancer Registry

CR's Director: Carmen Navarro Sánchez (carmen.navarro@carm.es). **WASABY referent:** María Dolores Chirlaque López (mdolores.chirlaque@carm.es).

Question	Provided information
Geo-code level (smallest unit - SU).	Census block.
SU dimension (average number of people)	1500.
Geo-code linkage by:	Cancer Registry and External paid resources.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	Cancer Registry.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Environmental studies were performed, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2003-2007.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes in the study period.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	In small areas only is possible to publish more than 5 cases.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval.





W A S A B Y

4.26 Navarra Cancer Registry

CR's Director: Eva Ardanaz (me.ardanz.aicua@cfnavarra.es). **WASABY referent:** Marcela Guevara (mp.guevara.eslava@navarra.es).

Question	Provided information
Geo-code level (smallest unit - SU).	Basic Health zones and zx & y coordinates.
SU dimension (average number of people)	11000 (varying from 1300 to 22000 people).
Geo-code linkage by:	To be defined.
Reference population available at:	Cancer Registry by sporadic calendar year.
Maps available at:	To be defined.
SES and deprivation index.	EDI.
Previous studies in the area, connecting cancer outcomes and environmental issues.	Yes, but correlation with cancer was never studied.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	2009-2012.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	To be defined.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	There could be confidentiality problems for very small geographic areas, and also for rare cases.
Detail limits in publishing maps (see confidentiality above).	There could be confidentiality problems for very small geographic areas, and also for rare cases.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	Local Ethical Committee approval.





W A S A B Y

4.27 Northern Ireland Cancer Registry

CR's Director and WASABY referent: Anna Gavin (A.Gavin@qub.ac.uk).

Question	Provided information
Geo-code level (smallest unit - SU).	Zip code.
SU dimension (average number of people)	4342.
Geo-code linkage by:	Cancer Registry.
Reference population available at:	Cancer Registry by calendar year.
Maps available at:	External provider to be identified
SES and deprivation index.	Local deprivation index.
Previous studies in the area, connecting cancer outcomes and environmental issues.	None.
The calendar years by which the CR can provide incidence data at the most disaggregated geographic level (exact x and y coordinates or SU).	1993-2016.
The calendar year by which such geographic level has changed (e.g., census tract changes between two different Census data collection).	No changes in the study period.
Any confidentiality problems likely to arise if/when pursuing the approval to the Ethical Committees, locally.	No confidentiality problems.
Detail limits in publishing maps (see confidentiality above).	There may be some copyrights to be acknowledged when publishing maps.
Do you think your institute will require a specific EC approval for the participation in this project or will the INT EC approval be sufficient?	INT Ethical Committee approval is enough.





5. Conclusions and next steps

The survey enabled to collect information on data available each CR interested to participate. Based on the findings, two major deliverables will be produced: a protocol for CR on data collection on breast cancer and a model to map cancer incidence.

CRs will need to provide the list of first invasive breast cancer cases (coded as C50 according to the ICD-10) diagnosed during a specific period (to be defined separately for each participating CR, e.g. since 1990), together with age at diagnosis (or 5-year age groups), morphology and data on the place of residence at the time of diagnosis (exact x and y coordinates or smallest possible sub-area of residence).

More specifically:

- Residence at smallest possible sub-area level for each cancer case, on the date of diagnosis. Some CRs already have this detail and no additional work is needed. CRs that now cannot provide such information will be helped with operative intervention (in terms of education and practical actions) by WP4, after an exploration aimed to evaluate the efficacy of the intervention.
- Female population data by 5-year age groups, calendar year within time period and sub-area on which the incidence data would be estimated. Sub-areas refer to the smallest geographical area for which required data are available and may differ between countries.
- Shape files for the area covered by CR and sub-areas are usually provided by the national mapping authority. Centroids of the sub-areas are calculated from GIS software from given shape files.
- Pollutants indicators by sub-area (for those CRs involved in the pilot environmental study, as reported in the WASABY Project).

A detailed description of the actions that every CR is expected to accomplish the WASABY tasks, will be presented in the Protocol for CR data collection and Ethical Committees (Deliverable D4.2) due at the end of May 2018 (M5).

Moreover, a complete list of participating CRs will be presented at the end of August (Milestone M4.2), possibly including additional CRs, contacted between May and July 2018.

Indeed, a key element in the reflection of EDI construction is the smallest geographical entity for which census data are available in the country concerned. This information will give for each country the scale to which the incidence data must be geo-coded in order to account for deprivation. WP5 will try to retrieve this information from the relevant institutions in each country. Only once this information is available, the management of the geo-coding work in each country will be possible. To have optimal conditions for the EDI construction in each country, information on all the geographical area available for each country (administrative and non-administrative) and the link between them is also needed. So, WP5 proposes to elaborate a technical point on census level availability for each country and then send a questionnaire to WASABY contacts involved in EDI construction to have information about geographical unit in their country. That will give for each country the scale of EDI construction which will be the largest scale needed for geo-coding cases to account for deprivation in further analyses.





W A S A B Y

References

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