厚生労働科学研究費補助金（がん対策推進総合研究事業（がん政策研究事業））
分担研究報告書

医療情報収集・提供の仕組みの国際比較

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研究要旨

がん登録等の推進に関する法律（がん登録推進法、平成25年法律第111号）に基づき集められた全国のがんの罹患の情報（全国がん登録情報）は、がんに係る調査研究やがん対策の企画立案又は実施のために利用できる。2019年から国立がん研究センターでは、「全国がん登録　情報提供の窓口」を開設し、全国がん登録情報の利用申請を受け付けていており、今後当該情報の利活用はさらに進むことが予想される。

そこで、本分担研究の目的は、任期となる三年間を通して、欧米におけるがん登録データを含む医療情報収集・提供・利用状況を調査し、調査結果を基に、我が国でのあり方を提言することである。

昨今の情報保護の厳格化を踏まえ、とりわけ欧州を中心に、がん登録情報を初めとする医療情報の収集方法及び研究や行政利用での提供方法を調査した結果は、我が国のあり方に参照できる。欧州で取り入れられているデータの提供方法、その安全性と簡便性、さらに利用方法や利用範囲について今後確認していきたい。

本年度は、調査票を作成した。調査票は、国際がん登録協議会（International Association of Cancer Registries）や欧州がん登録ネットワーク（European Network of Cancer Registries）のネットワークを介し、来年度より各国の統計担当者へ配布する。来年度の報告書では、調査結果を基に、諸外国における医療情報集・提供・利用状況についてまとめたい。本調査により、我が国の医療情報提供の仕組みを検討する上で、有益な基礎情報が収集できる。

A. 研究目的

がん登録等の推進に関する法律（がん登録推進法、平成 25 年法律第 111 号）に基づき集められた全国のがんの罹患の情報（全国がん登録情報）は、がんに係る調査研究やがん対策の企画立案又は実施のために利用できる。2019 年から国立がん研究センターでは、「全国がん登録　情報提供の窓口」を開設し、全国がん登録情報の利用申請を受け付けており、今後当該情報の利活用はさらに進むことが予想される。

そこで、本分担研究の目的は、任期となる三年間を通して、欧米におけるがん登録データを含む医療情報収集・提供・利用状況を調査し、調査結果を基に、我が国でのあり方を提言することである。

B. 研究方法

本年度は、調査票を作成した（添付 1）。調査項目は 10 項目から成り、以下の通りである：

- がん登録の仕組み (Cancer Registry Data)
- がん検診制度(Cancer Screening)
- 死亡データ(Mortality Database)
- 健康保険の請求データ(Health Insurance Claim Data)
- バイオバンク(Biobank)
- 人口動態調査(Census or other socio-demographic database)
- その他の臨床系データについて (Other clinical database)
- データリンケージについて(Data linkage)
- データ利用に関して(Data usage)
- 調査を実施する上での課題 (Barriers to conduct the research)

調査票は、国際がん登録協議会（International Association of Cancer Registries）や欧州がん登録ネットワーク（ European Network of Cancer Registries）のネットワークを介し、各国における統計担当者へ来年度より配布する。

C. 研究結果

昨今の情報保護の厳格化を踏まえ、とりわけ欧州を中心に、がん登録情報を初めとする医療情報の収集方法及び研究や行政利用での提供方法を調査した結果は、我が国のあり方に参照できる。次年度より実施する調査結果を基に、欧州で取り入れられているデータの提供方法、その安全性と簡便性、さらに利用方法や利用範囲について今後確認していきたい。

D. 考察

本調査票を基に、医療情報の収集や提供の仕組みについて国際比較を行うことが可能になるであろう。過去に、Siesling (2015)は、欧州におけるがん登録の仕組みの整理を行っている。本調査を実施することにより、より幅広い国々におけるがん登録ならびに医療情報の仕組み、その提供方法や利用状況を把握することが可能である。

我が国の医療情報提供の仕組みを検討する上で、これらの情報は有益な基礎情報となることが期待される。

E. 結論

本分担研究では、欧米におけるがん登録データを含む医療情報の収集・提供・利用状況を調査する。10 項目から構成される調査票を、来年度より各国の統計担当者へ配布し、回答を収集する。調査結果は、来年度以降の報告書で纏める。本調査により、我が国の医療情報提供の仕組みを検討する上で、有益な基礎情報が収集できる。

F. 健康危険情報
なし

G. 研究発表
なし

H. 知的財産権の出願・登録情報
1. 特許取得
なし
2. 実用新案登録
なし
3. その他
なし

参考文献：

Siesling S. Louwman W.J. Kwast A et al. Use of cancer registries for public health and clinical research in Europe: Results of the European Network of Cancer Registries suevry among 161 population-based cancer registries during 2020-2012. Eur J Cancer. 2015 Jun;51(9):1039-49.

謝辞：
調査票の作成および分担研究の遂行にあたって終始指導いただきました国立がん研究センター 松田智大先生に、深く感謝の意を表します。

添付1

Overview of public use of cancer data
Questionnaire

Contents

1. Contact

1.1. Contact information

1.1.1.Please enter your name

.....

1.1.2.Please enter your email address

.....

1.1.3.Name of the institute

.....

1.2. Sharing the answers

Below, please select the level of sharing of identified answers to the other questions contained in this questionnaire.

*1.2.1.Other IACR members **

- ☐ Yes
- ☐ No

*1.2.2.Unrestricted public **

- ☐ Yes
- ☐ No

1.3. Do you have any comments to add before the submission of this questionnaire?

.....

2. Cancer registry data

2.1. Data collection

2.1.1.Registry type:

- ☐ National
- ☐ Regional
- ☐ Hospital-based
- ☐ No registry in the country

2.1.2.Area covered by PBCR

.....

2.1.3.Please indicate the year that the registry activity started in the country

.....

2.1.4.Please indicate the current or most recent estimation of area covered by the registry (in km2):

.....

2.1.5.Please enter the current or most recent estimation of the size of the population covered by the registry (in number of inhabitants)

.....

2.1.6.Please enter the year of reference for the number of inhabitants provided

.....

2.1.7.How is the data for the cancer registry retrieved or submitted:

- ☐ Via the treating doctors manually (physical notification form)?
- ☐ By data entry by designated professionals in the cancer registry?
- ☐ Via automatic submission from electronic health care records?
- ☐ Via electronic submission from (e.g.) pathology laboratories or hospital records systems?

2.1.8.Please describe how the follow-up items below are collected in your registry:

- ☐ Vital status
- ☐ Date of follow-up
- ☐ Cause of death
- ☐ Distant metastasis
- ☐ Recurrence
- ☐ Treatment after the first course of treatment

2.2. Conditions of the data

2.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.

- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

  .....

2.2.2.Does the law (or any subsidiary regulations) on privacy apply to the data collection?

- ☐ Yes
- ☐ No

2.2.3.Under this law (regulation), is informed consent required for a government, doctor, hospital or researcher, to submit individual data to the database?

- ☐ Yes
- ☐ No

2.2.4.If informed consent is not required for cancer registration, what other data privacy procedure (if any) is being used (e.g. because the data are collected anonymous)?

.....

2.3. Conditions of the data usage

2.3.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

  .....

2.3.2.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

2.3.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			

Others			

2.3.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

- ☐ Yes
- ☐ Yes, annnonymised data only
- ☐ Yes, under certain conditions

  .....

- ☐ No

2.3.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

2.3.6.How long does it take to use the data generally from the date of application?

- ☐ Within a month
- ☐ A couple of months
- ☐ Longer than that

2.3.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

2.3.8.Is it free of charge to use the data?

- ☐ Yes
- ☐ No

2.3.9.Is there any onsite center to use the data?

- ☐ Yes
- ☐ No

2.3.10. Are you allowed to share and publish anonymised data on single individuals?

- ☐ Yes
- ☐ Yes, under certain conditions

  .....

- ☐ No

3. Cancer screening

3.1. Data collection

Please indicate the modalities of screening programmes for any of the tumour types listed below, if carried out in your registration area:

	Organisation		Is "method of detection in relation to screening" used in your registry? (1)		Any access to the screening database (directly or through record linkage)?	
	Invitations	Opportunistic	Yes	No	Yes	No
Breast cancer						
Cervical cancer						
Ovary cancer						
Colorectal cancer						
Prostate cancer						
Malignant Melanoma						
Lung cancer						
Other cancer						

1 According to the ENCR recommendations http://www.encr.com.fr/detection.pdf

3.1.1.Are there screening programs for other cancer sites in your registration area?

……

3.1.2.Do you routinely use the PBCR data for quality control of cancer screening?

- ☐ Yes
- ☐ No

3.1.3.Is there an integrated database for cancer screenees?

- ☐ Yes
- ☐ No

3.1.4.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

……

3.1.5.Does the law (or any subsidiary regulations) on privacy apply to the data collection?

- ☐ Yes
- ☐ No

3.1.6.Under this law (regulation), is informed consent required for a government, doctor, hospital or researcher, to submit individual data to the database?

- ☐ Yes
- ☐ No

3.1.7.If informed consent is not required for cancer registration, what other data privacy procedure (if any) is being used (e.g. because the data are collected anonymous)?

.....

3.2. Conditions of the data usage

3.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

.....

3.2.2.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

3.2.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			
Others			

3.2.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

- ☐ Yes
- ☐ Yes, annnonymised data only

☐ Yes, under certain conditions

.....

☐ No

3.2.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

3.2.6.How long does it take to use the data generally from the date of application?

☐ Within a month

☐ A couple of months

☐ Longer than that

3.2.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

3.2.8.Is it free of charge to use the data?

☐ Yes

☐ No

3.2.9.Is there any onsite center to use the data?

☐ Yes

☐ No

3.2.10. Are you allowed to share and publish anonymised data on single individuals?

☐ Yes

☐ Yes, under certain conditions

.....

☐ No

4. Mortality Database

4.1. Data collection

4.1.1.Mortality data coverage:

- ☐ National
- ☐ Regional
- ☐ Hospital-based
- ☐ No mortality data in the country

4.1.2.Area covered by the mortality database

.....

4.1.3.Please indicate the year that the mortality data activity started in the country

.....

4.1.4.Please describe the procedure to collect death certificates to make up the database

.....

4.1.5.Does the law (or any subsidiary regulations) on privacy apply to the data collection?

- ☐ Yes
- ☐ No

4.1.6.Under this law (regulation), is informed consent required for a government, doctor, hospital or researcher, to submit individual data to the database?

- ☐ Yes
- ☐ No

4.1.7.If informed consent is not required for data collection, what other data privacy procedure (if any) is being used (e.g. because the data are collected anonymous)?

.....

4.2. Conditions of the data usage

4.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

.....

4.2.2.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

4.2.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			
Others			

4.2.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

- ☐ Yes
- ☐ Yes, annnonymised data only
- ☐ Yes, under certain conditions

  .....

- ☐ No

4.2.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

4.2.6.How long does it take to use the data generally from the date of application?

- ☐ Within a month
- ☐ A couple of months
- ☐ Longer than that

4.2.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

4.2.8.Is it free of charge to use the data?

- ☐ Yes
- ☐ No

4.2.9.Is there any onsite center to use the data?

- ☐ Yes
- ☐ No

4.2.10. Are you allowed to share and publish anonymised data on single individuals?

- ☐ Yes
- ☐ Yes, under certain conditions

  .....

- ☐ No

5. Health Insurance Claim Database

5.1. Health insurance claim type

5.1.1.Health insuran type:

- ☐ National
- ☐ Regional
- ☐ Private
- ☐ No health insurance database in the country

5.1.2.Please describe the procedure to collect health insurance claim to make up the database

.....

5.2. Conditions of the data

5.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

  .....

5.2.2.Does the law (or any subsidiary regulations) on privacy apply to the data collection?

- ☐ Yes
- ☐ No

5.2.3.Under this law (regulation), is informed consent required for a government, doctor, hospital or researcher, to submit individual data to the database?

- ☐ Yes
- ☐ No

5.2.4.If informed consent is not required for cancer registration, what other data privacy procedure (if any) is being used (e.g. because the data are collected anonymous)?

.....

5.3. Conditions of the data usage

5.3.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.

☐ Medical organization

☐ Private company

☐ Others, please explain

.....

5.3.2.Is a specific law regulating data use in force?

☐ Yes

☐ No

5.3.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			
Others			

5.3.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

☐ Yes

☐ Yes, annnonymised data only

☐ Yes, under certain conditions

.....

☐ No

5.3.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

5.3.6.How long does it take to use the data generally from the date of application?

☐ Within a month

☐ A couple of months

☐ Longer than that

5.3.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

5.3.8.Is it free of charge to use the data?

☐ Yes

☐ No

5.3.9.Is there any onsite center to use the data?

☐ Yes

☐ No

5.3.10. Are you allowed to share and publish anonymised data on single individuals?

☐ Yes

☐ Yes, under certain conditions

.....

☐ No

6. Biobank

6.1. Biobank type

6.1.1.Biobank type:

- ☐ National
- ☐ Regional
- ☐ Hospital-based
- ☐ Academic
- ☐ No biobank in the country

6.1.2.Please indicate the year that collection of samples in the biobank started in the country

.....

6.2. Conditions of the data

6.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company
- ☐ Others, please explain

  .....

6.2.2.Does the law (or any subsidiary regulations) on privacy apply to the data collection?

- ☐ Yes
- ☐ No

6.2.3.Under this law (regulation), is informed consent required for a government, doctor, hospital or researcher, to submit individual data to the database?

- ☐ Yes
- ☐ No

6.2.4.If informed consent is not required for cancer registration, what other data privacy procedure (if any) is being used (e.g. because the data are collected anonymous)?

.....

6.3. Conditions of the data usage

6.3.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.

☐ Medical organization

☐ Private company

☐ Others, please explain

.....

6.3.2.Is a specific law regulating data use in force?

☐ Yes

☐ No

6.3.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			
Others			

6.3.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

☐ Yes

☐ Yes, annnonymised data only

☐ Yes, under certain conditions

.....

☐ No

6.3.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

6.3.6.How long does it take to use the data generally from the date of application?

☐ Within a month

☐ A couple of months

☐ Longer than that

6.3.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

6.3.8.Is it free of charge to use the data?

☐ Yes

☐ No

6.3.9.Is there any onsite center to use the data?

☐ Yes

☐ No

6.3.10. Are you allowed to share and publish anonymised data on single individuals?

☐ Yes

☐ Yes, under certain conditions

.....

☐ No

7. Census or other socio-demographic database

7.1. Availability of data

	Non-anonymised individual data linkable to other data1	Anonymised individual data2	Aggregated data
Eating habit			
Smoking habit			
Alcohol intake			
Household income			
Education			
Profession			

[1]Individual data in which the full identity of the patient has at least a key ID even the original identifiable variables are remove, e.g. the name and address, date of birth, etc., and it remains possible to link the record to the other database individually

[2]Individual data in which the identity of the person has been disguised by removal of a part or all identification, e.g. the name and address, date of birth, etc., and impossible to link the record to the other database individually. However, the data have geographical information to realize ecological studies.

7.1.1.Population data type:

- ☐ Census
- ☐ Civil registration
- ☐ Other estimation

7.1.2.Please describe kind of the database

.....

7.2. Conditions of the data usage

7.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization
- ☐ Private company

☐ Others, please explain

.....

7.2.2.Is a specific law regulating data use in force?

☐ Yes

☐ No

7.2.3.Who are authorized to use the individual data other than published aggregated numbers?

(1 Yes, 2 No, 3 Other)

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
National/ Local Government			
Research/ Education			
Private company			
Mass media			
Others			

7.2.4.Are foreigners allowed to use the individual data other than published aggregated numbers?

☐ Yes

☐ Yes, annnonymised data only

☐ Yes, under certain conditions

.....

☐ No

7.2.5.Are there any other conditions for data usage (i.e. only for academic use, have to be a member of a research team, etc.)?

.....

7.2.6.How long does it take to use the data generally from the date of application?

☐ Within a month

☐ A couple of months

☐ Longer than that

7.2.7.Please describe the procedure to have an access to the data (i.e. online application)

.....

7.2.8.Is it free of charge to use the data?

☐ Yes

☐ No

7.2.9.Is there any onsite center to use the data?

☐ Yes

☐ No

7.2.10. Are you allowed to share and publish anonymised data on single individuals?

- ☐ Yes
- ☐ Yes, under certain conditions

  .....
- ☐ No

8. Other clinical database

8.1. Type of data

8.1.1.What kind of other clinical databases are available in the country?

	Non-anonymised individual data linkable to other data[1]	Anonymised individual data[2]	Aggregated data
Genetic information of cancer patients			
Academic association based clinical database			

8.1.2.Please indicate the year that collection of samples in the biobank started in the country

.....

9. Data linkage

9.1. Linkable database

9.1.1.Which of the listed data are individually linked to each other in your country? For each of the used data sources please indicate the type of inquiry best describing the current practice.

	Cancer registry data	Cancer screening data	Mortality data	Health insurance claim	Biobanks	Census	Hospital records	Pathology or other laboratories
Cancer registry data								
Cancer screening data								
Mortality data								
Health insurance claim								
Biobanks								
Census								
Hospital records								
Pathology or other laboratories								
Pharmacists								
Research studies								

1=Nationally, 2=Regionally, 3=Project-based

9.2. Linkage center

9.2.1.Are there organizations specialized in linkage of several individual database?

☐ Yes

☐ No

10. Data usage

10.1. Data usage in health policy

10.1.1. Please describe the contribution of your registry to the description of cancer burden or evaluation *of cancer control by selecting the applicable answer below:*

	Routine, regular, frequent	Occasional, ad- hoc	Never
Cancer control in general			
Cancer incidence rates			
Cancer survival			
Cancer mortality rates			
Development of national cancer control strategies			
Evaluation of national cancer control strategies			
Clinical audits on diagnosis/staging			
Clinical audits on treatment			
Clinical audits on waiting times			
Clinical audits on multidisciplinary care			
Evaluation of adherence to clinical guidelines for diagnosis			
Evaluation of impact of clinical guidelines for diagnosis			
Evaluation of adherence to clinical guidelines for treatment			
Evaluation of impact of clinical guidelines for treatment			
Improvement of cancer care projects			
Cancer screening evaluation			
Evaluation of radiation systems use			
Evaluation of usage of Computed Axial Tomography (CT)			
Evaluation of usage of Positron Emission Tomography (PET)			
Evaluation of usage of magnetic resonance technique			

1=Nationally, 2=Regionally, 3=Project-based

10.1.2. Please select the status of the private sector's use of each data item in the following list (Some of the questions are duplicated from the previous sections, but please kindly answer them again):

	A. Private sector can use without application	*B. Private sector can use with application*	*(if the answer is A or B) Can private sector can use non-anonymous data?*	*No, private sector cannot use.*
Cancer incidence rates				
Cancer survival				
Cancer mortality rates				
Staging at diagnosis				
Initial treatment data				
Subsequent treatment data				
Recurrence / progression rates				
Biomarker testing rates				
Biomarkers				
Census or other socio-demographic database				

10.1.3. (showing the data for those its answer for 10.1.2. is A or B above) Does the private sector need to pay for using the data?

	Yes	No
Cancer incidence rates		
Cancer survival		
Cancer mortality rates		
Staging at diagnosis		
Initial treatment data		
Subsequent treatment data		
Recurrence / progression rates		
Biomarker testing rates		
Biomarkers		

Census or other socio-demographic database		

10.1.4. (showing the data for those its answer for 10.1.2. is A or B above) Can private sector use the data for themselves (e.g. to make business decisions) or do they need to make the data public and give it back to society at large?

	Private sector can use for their own usage	Private sector should publish the data
Cancer incidence rates		
Cancer survival		
Cancer mortality rates		
Staging at diagnosis		
Initial treatment data		
Subsequent treatment data		
Recurrence / progression rates		
Biomarker testing rates		
Biomarkers		
Census or other socio-demographic database		

10.1.5. (showing the data for those its answer for 10.1.2. is A or B above) Can the private sector use the data to apply for approval of a drug or medical device?

	Yes, private sector can use the data for apply approval	No, private sector cannot use the data for apply approval
Cancer incidence rates		
Cancer survival		
Cancer mortality rates		
Staging at diagnosis		
Initial treatment data		
Subsequent treatment data		
Recurrence / progression rates		
Biomarker testing rates		

Biomarkers		
Census or other socio-demographic database		

11. Barriers to conduct a research

11.1. Privacy legislation

11.1.1. Have you experienced barriers to use the cancer data due to privacy legislation (e.g. PIN is not allowed to be used in medical research)?

☐ Yes, please explain

.....

☐ No

11.2. Technical issues

11.2.1. Have you experienced barriers to use the cancer data due to technical issues (e.g. only initial of the names recorded in XX database)?

☐ Yes, please explain

.....

☐ No

11.3. Technical issues

11.3.1. Please provide a short description (with examples) of any legal or ethical problems in public usage of cancer data, in cancer control planning/evaluation, quality control of medical acts and research?
