厚生労働科学研究費補助金（がん対策推進総合研究事業）
（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、昨年度作成した調査票を精査・修正し、国際がん登録協議会（International Association of Cancer Registries）へ事前調査を行った。来年度は、事前調査のフィードバックを基に最終化した調査票を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。

B. 研究方法

本年度は、国際がん登録協議会（International Association of Cancer Registries）へ最新版の調査票を送付し事前調査を行った（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／ゲノム情報データ(Biobank or genomic information database)
- 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)

事前調査を基に最終化した調査票を、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。来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：

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添付1

Overview of public use of cancer data
Questionnaire

1

Contents

1. Respondents' contact information

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 description

2.1.1.Registry type:

- ☐ Population-based
- ☐ Hospital-based
- ☐ No registry in the country

2.1.2.Area covered by PBCR

.....

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

.....

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

.....

2.1.5.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?

2.1.6.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
- ☐ Other detailed clinical information
- ☐ Socio economic status of patients

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/ Academic society
- ☐ Private organization (e.g. NGO, pharmaceutical 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 record individual data to the database?

- ☐ Yes
- ☐ No

2.2.4.If informed consent is not required for 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.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

2.3.2.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 data1	Anonymised individual data2	Aggregated data
National/ Local Government			
Research/ Education			
Private organization			
Mass media			
Others			

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

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

.....

- ☐ No

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

.....

2.3.5.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

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

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ Yes, under certain conditions

  .....
- ☐ No

3. Cancer screening

3.1. Data description

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

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

- ☐ Yes
- ☐ No

3.1.2.Is there an integrated database for cancer screenees?

- ☐ Yes
- ☐ No

3.2. Conditions of the data

3.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization/ Academic society
- ☐ Private organization (e.g. NGO, pharmaceutical company)
- ☐ Others, please explain

  .....

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

☐ Yes

☐ No

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

☐ Yes

☐ No

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

.....

3.3. Conditions of the data usage

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

☐ Yes

☐ No

3.3.2.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 data1	Anonymised individual data2	Aggregated data
National/ Local Government			
Research/ Education			
Private organization			
Mass media			
Others			

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

☐ Yes

☐ Yes, annnonymised data only

☐ Yes, under certain conditions

.....

☐ No

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

.....

3.3.5.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

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

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

3.3.9.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

4.2.1.To whom do the data belong?

- ☐ National/ Local Government
- ☐ Research group/ Researcher
- ☐ University, Hospital, etc.
- ☐ Medical organization/ Academic society
- ☐ Private organization (e.g. NGO, pharmaceutical company)
- ☐ Others, please explain

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

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

.....

4.3. Conditions of the data usage

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

- ☐ Yes
- ☐ No

4.3.2.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 data1	Anonymised individual data2	Aggregated data
National/ Local Government			
Research/ Education			
Private organization			
Mass media			
Others			

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

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

  .....
- ☐ No

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

.....

4.3.5.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

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

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

4.3.9.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 insurance type:

- ☐ National
- ☐ Private
- ☐ No health insurance system in the country

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

.....

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/ Academic society
- ☐ Private organization (e.g. NGO, pharmaceutical 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 record individual data to the database?

- ☐ Yes
- ☐ No

5.2.4.If informed consent is not required for 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.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

5.3.2.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 data1	Anonymised individual data2	Aggregated data
National/ Local Government			
Research/ Education			
Private organization			
Mass media			
Others			

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

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

  .....
- ☐ No

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

.....

5.3.5.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

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

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ Yes, under certain conditions

  .....
- ☐ No

6. Biobank or genomic information database

6.1. Biobank or genomic information database type

6.1.1.Biobank type:

- ☐ Population-based
- ☐ 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/ Academic society
- ☐ Private organization (e.g. NGO, pharmaceutical 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 record individual data to the database?

- ☐ Yes
- ☐ No

6.2.4.If informed consent is not required for 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.Is a specific law regulating data use in force?

- ☐ Yes
- ☐ No

6.3.2.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 data1	Anonymised individual data2	Aggregated data
National/ Local Government			
Research/ Education			
Private organization			
Mass media			
Others			

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

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

  .....
- ☐ No

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

.....

6.3.5.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

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

.....

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ No

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

- ☐ Yes
- ☐ Yes, under certain conditions

  .....
- ☐ No

7. Census or other socio-economic status database

7.1. Availability of data

7.1.1. What kind of other clinical databases are available in the country? If any, please add lines to describe.

	Non-anonymised individual data linkable to other data 1	Anonymised individual data indirectly linkable with geographical information 2	Anonymised individual data 2	Aggregated data
Eating habit				
Smoking habit				
Alcohol intake				
Individual/ Household income				
Education				
Marital status/ parity				
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.

8. Other clinical database

8.1. Availability of data

8.1.1.What kind of other clinical databases are available in the country? If any, please add lines to describe.

	Non-anonymised individual data linkable to other data 1	Anonymised individual data indirectly linkable with geographical information 2	Anonymised individual data 2	Aggregated data
Academic society-based clinical database				

[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.

9. Data linkage

9.1. Linkable database

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

	Cancer registry	Cancer screening	Mortality	Health insurance claim	Biobanks or genomic info	Census or SES	Other clinical data		
Cancer registry									
Cancer screening									
Mortality									
Health insurance claim									
Biobanks or genomic info									
Census or SES									
Other clinical data									

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

11. Barriers to conduct a research

11.1. Privacy legislation

11.1.1. Have you experienced barriers to use the cancer research related 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 research related data due to technical issues (e.g. mistype of names recorded in XX database was evident and not completely linkable)?

☐ Yes, please explain

.....

☐ No

11.3. Legal or ethical issues

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