



NICER CoreDay Tuesday, 5th November 2019

1. Introduction and Information on KRG 2020

Ulrich Wagner, director NICER & NACR

- In general: NICER / NKRS update
 - Formal changes in structure and processes
- Perspective on development processes (inside out / outside in) of data structure and coding handbook as well as information
- Stakeholder participation & Final process approval by FOPH for «data structure» (legally binding)



In general: NICER/NKRS update

NCC

Contracts FOPH

Contracts EBPI

- [Nicer.org](https://nicer.org)
- nkrs.ch (up to now only linked to [Nicer.org](https://nicer.org))
- onec.ch (« »)
- snrt.ch (« »)
- nacr.ch (« »)



Nationale Krebsregistrierungsstelle
Organe national d'enregistrement du cancer
Servizio nazionale di registrazione dei tumori
National Agency for Cancer Registration

NICER/NKRS update: Data structure



Nationale Krebsregistrierungsstelle
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Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry



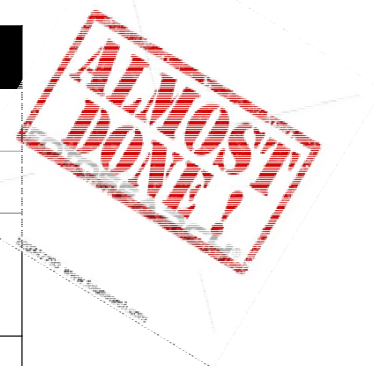
NATIONAL CANCER DATA DICTIONARY

V 1.1



NICER/NKRS update: SCHB

SCHB Kapitel	Sprachen
Entwurf für Inhaltsverzeichnis und Organkapitel	D/F
Teil A - Einführung - Kapitel 1-4	D/F
Teil B - Kommentare zu den Variablen der Basisdaten - Kapitel 1, 2.1, 2.5-2.13	D/F-V1
Teil B - Kommentare zu den Variablen der Basisdaten - Kapitel 2.2, 2.3, 2.4	D/F-V1
Teil C - Kodierungshandbuch für Erwachsene	D/F-V1
CHOP Treatment Coding	D/F-V1
Organkapitel - Brustkrebs	D/F-V1
Organkapitel - Darmkrebs	D/F-V1
Organkapitel - Prostata	D/F-V1
Organkapitel - Hämatologische Tumoren	D/F





NICER/NKRS update: Data publication pillars





NICER/NKRS update: Data Usage Regulation

Data request type	Data classification according to CRA/CRO		
	Personal	Anonymized ¹ (CRO, Art. 30, par 1, 2)	Aggregated (CRO, Art. 30, par 3, 4)
Data request from third parties NO research purpose (CRA, Art. 16) (see 4.2)		X	
Data request for evaluation of diagnosis, treatment quality (CRA, Art. 27) (see 4.3)			X
Data request from third parties research purpose (CRA, Art. 23, CRO, Art. 30) (see 4.4)			X
Patient/patient representative requests own data (FADP, Art. 8) (see 4.5)	X		
International collaboration (CRA, Art. 20) (see 4.6)		X	



NICER/NKRS update: Patients information (& information wave 4)



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Information about the registration of cancer

Why is information about cancer collected?

It's important to collect information about tumours, i.e. cancer and the preliminary stages of cancer. This information helps to improve the diagnosis, treatment and after-treatment care of these diseases. Since January 2020 there has been a law in Switzerland that regulates the registration of information about cancer. This law requires healthcare professionals to send certain information about your disease to the cancer registry. A cancer registry is a kind of table in which all the important information about cancers is entered.

In Switzerland there are Cantonal Cancer Registries and a Childhood Cancer Registry.

- The Cantonal Cancer Registries collect information about cancer in adults aged 20 or older.
- The Childhood Cancer Registry collects information about cancer in children and adolescents under 20 years of age.



Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

What happens to the collected information?

The collected information assists in the fight against cancer.

The Childhood Cancer Registry and the National Agency for Cancer Registration evaluate the information collected throughout Switzerland. This makes it possible to tell, for example, whether:

- cancer occurs more frequently in a certain part of Switzerland,
- certain types of cancer become more or less common over the years,
- certain other diseases accompany cancer.

The Childhood Cancer Registry and the National Agency for Cancer Registration inform the Swiss population about these developments. Doctors, research scientists and politicians can also learn more about cancer in this way. The aim is to help people with cancer. Collecting and evaluating information about cancer brings us one step closer to this goal. The information helps to answer questions, such as:

- How can cancer be detected early in order to increase the chance of a cure?
- How can cancer treatment be improved?

What information is recorded in the cancer registry?

About the person

- your names / your address /
- your date of birth / your gender /
- your insurance number (AHV or OASI number)

This information is required to register your case correctly. It is anonymised (this means it cannot be linked to you) before it is passed on because it is not needed for evaluation purposes.

About the cancer

- what type of cancer you have,
- when and how the cancer was discovered.

About the treatment

- how your cancer is being treated,
- the date your treatment started.

Additional information about breast, bowel or prostate cancer

- whether cancer has already occurred in your family,
- whether you have other medical conditions at the same time.

Additional information about children and adolescents (under 20 years of age)

- whether the children and adolescents have other medical conditions at the same time,
- whether they are being treated, and if so when and how,
- what the result of treatment was (e.g. a cure),
- what tests were performed after the cancer had been treated (to see, for example, whether the cancer returned, or whether there are any negative effects of the treatment).





NICER/NKRS update: Patients information (& information wave 4)

How is this information protected?

Cancer registries follow strict rules when receiving, storing and processing information about you. These strict rules are described in the Cancer Registration Act. For example, this law states how the information is stored, who is permitted to use the information and when the information is deleted. Health insurance providers and employers do not have access to this information. Data protection is in line with the standards and laws that are in effect in Switzerland.

Can I see the information about me in the cancer registry?

You can see everything that is known about you in the cancer registry. If you would like to see the information about you, please write to a cancer registry for details of the procedure.

If you are an adult, the cancer registry in the canton where you live will be happy to assist you. You can find the address of your canton's cancer registry online (address list): www.nacr.ch/en/cancer-registration/cancer-registries. You can also get information from the National Agency for Cancer Registration by e-mail nacr@nicer.org or by phone 044 634 53 74.

For information about children and adolescents you can contact the Childhood Cancer Registry by e-mail kinderkrebsregister@ispm.unibe.ch or by phone 031 631 56 70.

Waiting period

The three-month waiting period begins once you have received this brochure. This waiting period allows you plenty of time to think about whether you agree to your data being registered.

Do you agree to your data being registered?

If so, no further action is needed.

Do you object to your data being registered?

If you don't want your data to be registered, you must inform a cancer registry in writing. To do so, there is a form you can use that is available from your Cantonal Cancer Registry or from the Childhood Cancer Registry. You need to complete and sign it and send it to a cancer registry. You will then receive a letter from the cancer registry confirming that your information will no longer be collected.

If you withdraw permission within the waiting period, your data will not be registered. If you only withdraw permission at a later date, i.e. after the waiting period has elapsed and when the cancer registry has already registered your data, the cancer registry will immediately delete all data concerning your person. Data concerning your disease will remain in the register. However, the person to whom this data belongs will no longer be identifiable. Moreover, after this point in time, no further data concerning yourself or your disease will be registered.

Objecting to your data being collected and used will not affect the way your cancer is treated. You can change your mind at any time and withdraw your objection. If you want to do this, please contact a cancer registry.

How can I find out more about cancer registration, and who can answer my questions?

You can find more information about cancer registration on the websites

- of the Cantonal Cancer Registries (address list): www.nacr.ch/en/cancer-registration/cancer-registries
- of the Childhood Cancer Registry: www.kinderkrebsregister.ch
- of the National Agency for Cancer Registration: www.nacr.ch/en/cancer-registration

For questions about cancer in children and adolescents

- Childhood Cancer Registry (ChCR)
Mittelstrasse 43, CH-3012 Berne
e-mail kinderkrebsregister@ispm.unibe.ch
phone 031 631 56 70

For questions about cancer in adults

- National Agency for Cancer Registration (NACR)
Hirschengraben 82, CH-8001 Zurich
e-mail nacr@nicer.org
phone 044 634 53 74



Nationale Krebsregistrierungsstelle
Organo nazionale di registrazione dei tumori
Servizio nazionale di registrazione dei tumori
National Agency for Cancer Registration

Information über die Registrierung von
Krebserkrankungen

Aktuelle / News
Allgemeines
Patientinnen und Patienten
Krebsregister
Meldepflichtige
Partner im
Gesundheitswesen

Sie als Patientin, oder Patient bzw. als gesetzliche Vertretung (z.B. Eltern) haben das Recht über die Krebsregistrierung informiert zu werden und allenfalls Widerspruch einzulegen. Sie haben auch das Recht, Auskunft über die registrierten Daten zu erhalten.

1. Gibt es eine gesetzliche Grundlage für die Krebsregistrierung?
2. Wer informiert mich als Patientin / als Patient?
3. Über was werde ich als Patientin / als Patient informiert?
4. Wie werde ich als Patientin / als Patient informiert?
5. Nationale Krebsregistrierung, warum?
6. Krebsregistrierung bei Kindern und Jugendlichen – anders als bei Erwachsenen? Warum?
7. Meldepflichtige, kantonale Krebsregister, Kinderkrebsregister, Bundesamt für Statistik, wer sind die? Was machen die und warum?
8. Nationale Krebsregistrierungsstelle, wer ist das? Was macht sie und warum?
9. Welche Daten werden über mich erfasst?
10. Karenzfrist – was bedeutet das?
11. Welche Rechte habe ich als Patientin oder Patient bzw. als gesetzliche Vertretung?
12. Datenschutz – werden meine Daten vertraulich behandelt?
13. Wie bearbeitet das zuständige kantonale Krebsregister meine Daten?
14. Wie lange werden meine Daten gespeichert?
15. Wie werden die schweizweit erfassten Daten genutzt?

Informationsdokumente über die Registrierung von Krebserkrankungen zum Herunterladen

Patienteninformation für Erwachsene, ausführliche Version	PDF / 214KB
Patienteninformation für Kinder und Jugendliche, ausführliche Version	web link
Patienteninformation für Erwachsene, Kinder und Jugendliche, kurze Version	PDF / 101KB

Patients information (& information wave 4)

- Patient information as a compact – short and simple version for the patient handed out by physician – to download
- Patient information extended on the web page (1-15)
- Patient information extended also to download as pdf
- Link to ChCR for patient information kids and adolescent



Der schriftliche Widerspruch muss per Post oder elektronisch an ein kantonales Krebsregister Ihrer Wahl oder an das Kinderkrebsregister geschickt werden¹.

Adresse des Krebsregisters (siehe Adressliste):

Widerspruch gegen die Registrierung von Daten gemäss Artikel 6 des Bundesgesetzes über die Registrierung von Krebserkrankungen (KRG)

Mit diesem Formular nehme ich als Patientin, als Patient oder als gesetzliche Vertretung das Recht wahr, der Registrierung meiner Daten oder der Registrierung der Daten der Person, die ich gesetzlich vertrete, zu widersprechen. Ich fordere damit das zuständige kantonale Krebsregister und/oder das Kinderkrebsregister und die Nationale Krebsregistrierungsstelle auf, noch nicht registrierte Daten zu vernichten und/oder die bereits registrierten Daten zu anonymisieren (dies bedeutet, die Daten können keiner Person mehr zugeordnet werden).

Bitte füllen Sie das Formular mit dem lateinischen Alphabet aus²:

Vorname(n) _____

Nachname(n) _____

Geburtsdatum _____

Geschlecht (freiwillige Angabe) ☐ weiblich ☐ männlich ☐ anderes

Strasse und Hausnr. _____

PLZ/Wohnort _____

Versichertennummer (AHVN13)* _____

* Die persönliche Versichertennummer finden Sie z.B. auf Ihrer Krankenversicherungskarte.

Grund (freiwillige Angabe) _____

Datum _____

Unterschrift Patientin/Patient oder gesetzl. Vertretung

Ein Widerspruch ist nur mit einer Unterschrift gültig.

Nach Erhalt Ihres schriftlichen Widerspruchs informiert das Krebsregister, bei dem Sie Widerspruch eingelegt haben, Sie schriftlich darüber, dass Ihr Widerspruch erfasst wurde.

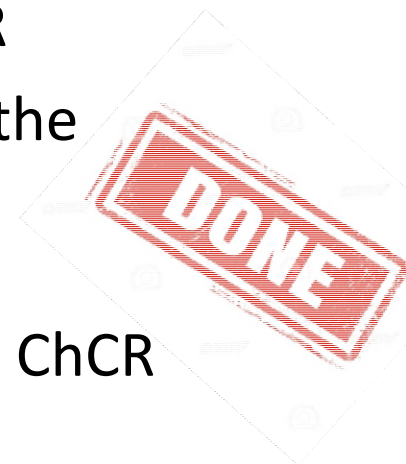
¹ Der Widerspruch kann auch auf elektronischem Wege (Fax oder EMail) erfolgen. Zum Schutz Ihrer persönlichen Daten wird empfohlen, die EMail oder das als Anhang verschickte Widerspruchsdokument zu verschlüsseln.

² Weitere 13 Sprachversionen stehen zum Download bereit auf den Webseiten der kantonalen Krebsregister und des Kinderkrebsregisters.

Originalversion erstellt am 20.09.2019.

Patients information - veto (& information wave 4)

- Veto formular only available as a link to a zip file on the webpages of the CCR and the ChCR
- Described and linked in the patient brochure
- Described as well in the extended version on the ChCR and NKRS website





Obwohl das Krebsregistrierungsgesetz (KRG) erst am 01.01.2020 in Kraft tritt, haben Krebsregister in der Schweiz schon eine 50 jährige Geschichte. 1969 wurde in Basel das erste Krebsregister gegründet.

- ▶ 1. Was ist Krebs?
- ▶ 2. Krebs in der Schweiz
- ▶ 3. Kurze Geschichte der Krebsregistrierung in der Schweiz
- ▶ 4. Das Krebsregistrierungsgesetz (KRG) und die Verordnung
- ▶ 5. Sinn und Zweck der Nationalen Krebsregistrierung und des Krebsregistrierungsgesetzes (KRG)
- ▶ 6. Die Aufgaben der Nationalen Krebsregistrierungsstelle (NKRS) und des Kinderkrebsregisters (KiKR)
- ▶ 7. Umfang der Datensammlung im Rahmen der Krebsregistrierung
- ▶ 8. Die Verarbeitung der Krebsregisterdaten
- ▶ 9. Die Rechte der Patientinnen und Patienten in der Krebsregistrierung
- ▶ 10. Datenschutz
- ▶ 11. Veröffentlichung der Krebsregisterdaten – Die Nationale Krebsstatistik und die Gesundheitsberichterstattung für Krebserkrankungen
- ▶ 12. Links zu den kantonalen/regionalen Krebsregistern und dem Kinderkrebsregister
- ▶ 13. PDF der Patienteninformation in einer langen und in einer kurz vereinfachten Sprachversion stehen als PDF und Link zur Verfügung
- ▶ 14. Weiterführende Informationen

Information of the public

- Minimum requirements: Media release and website
- Together with ChCR
- Collaboration and advise of KLS is welcomed and searched for
- Communication advisor Wolfgang Wettstein died 4 weeks ago
- Planned time: End of november





Formal changes in structure and processes with KRG

On January 1st 2020 (fastest full registration date: April 2nd 2020)

New Set of selected diagnoses to report

Reporting Duty by individuals and organizations

The basic and the supplementary datasets

Patient Information

Patient - Veto

Duty to register for the cantons

New Role for NICER as the NACR (i.e. define coding rules, evaluate and report to cantons)



Perspective on development processes

- inside out / outside in
- Matrix – Organization and their typical conflicts (what and how)
- Different interests in goals with consequences on structure and processes and content out of different history – culture – experience (i.e. “nice to know” vs. “need to know”, is there a real “truth”?, is there a real “wrong”?)
- Questions to answer upfront: who is process owner? Where to lay emphasis? Is a timetable more important than the content? Where to accept delays? When to stop a discussion?



Metachrone Primärtumoren Tumoren

Simultane und metachrone Primärtumoren Tumoren

innerhalb von 42 Monaten auftretende ("synchrone") multiple Karzinome
morphologie (Ausnahme: 1 Herd ist duktal, 1 Herd lobulär, wird als 8522/3-
les und lobuläres Karzinom erfasst, zählt nicht als unterschiedliche
innerhalb einer Brust gelten als ein Primärtumor, wobei der Tumor mit der
ert beim TNM und höchstem Grading dokumentiert wird). Zusätzlich soll b-
den:

nur ein Herd

mehrere räumlich voneinander getrennte Herde in einem

bzw. Abstand ≤ 4 cm)

mehrere Herde in mehreren Quadranten bzw. Abstand > 4 cm

HB alle Altersstufen Variable "(m) Suffix bei pT" und die 4 Grundsatzregel

nose eines neuen Tumors in derselben Brust zu einem späteren Zeitpunkt
tumor als metachroner multipler Primärtumor und wird separat
die 2 Monatsgrenze sollte etwas flexibel gehandhabt werden, z. B. falls
ig Untersuchungen nicht innerhalb von zwei Monaten abgeschlossen sind

distinction between new tumor vs. relapse ne-
further clarified and aligned with international
multiple primary rules. In the everyday coding for



Chloé Sieber

KRZHSG:

Überschrift passt nicht. Vielleicht: Simultane Tumoren



Chloé Sieber

RTTI:

We suggest to take the definition used in TNM:
"Cancer occurring in the same organ that are
identified ≤ 4 month apart, or that are identified at"

Regina Nanieva

Danke, wird auch in SCHB updated



Chloé Sieber

RTTI:

Not contain in data dictionary basis data NKRS. Please
use multiple primary tumor (m suffix only) as defined
in TNM and reported in NKRS basis data ☺

Regina Nanieva

Thanks, will be updated



Chloé Sieber

RTN:

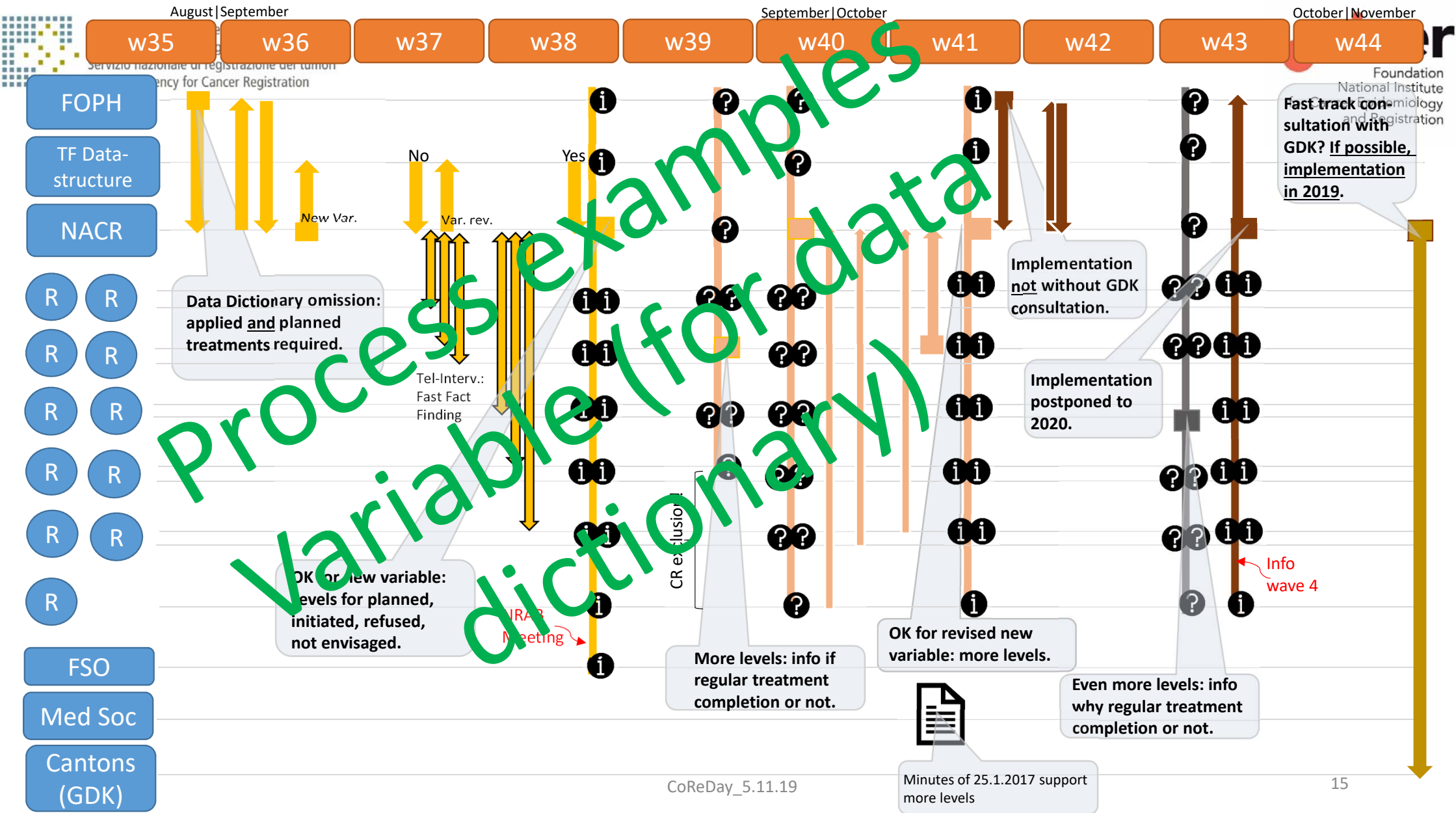
(F) Est-ce que ceci est valable aussi s'il s'agit d'un
cancer in situ qui aurait la même morphologie de la
tumeur invasive ? Il faut préciser ces cas de figures,

Regina Nanieva

Thanks updated. The in-situ tumors of the
same morphology should be recorded as in-
situ components. Will be explained in SCHB.



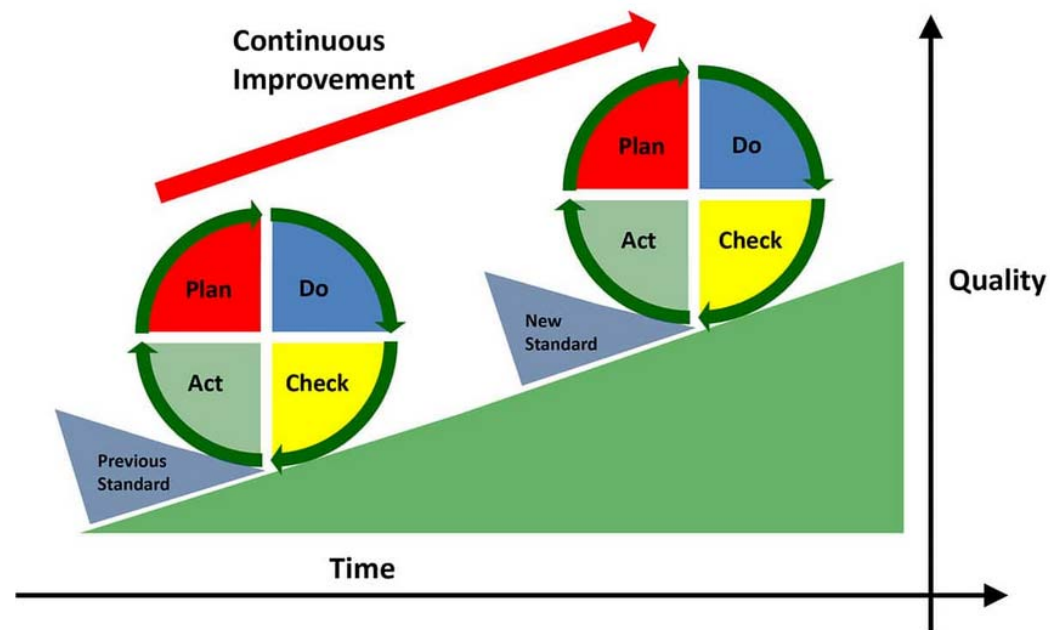
Chloé Sieber





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**done is
better
than
perfect.**





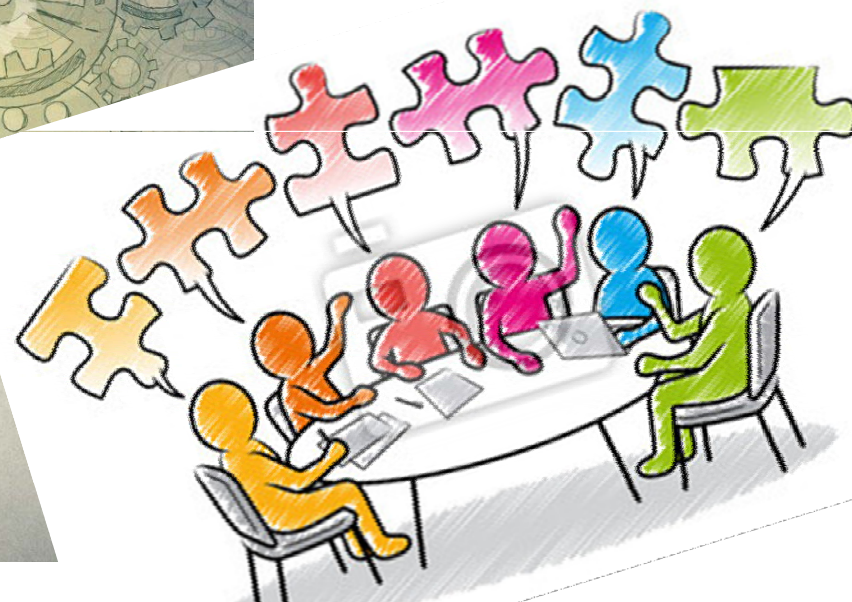
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nicer
Foundation
National Institute
for Cancer Epidemiology
and Registration

Form



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Future Processes and stakeholder participation

- ChCR, CCR, Cantons, FOPH, FSO, Med. Assoc., FMH, H+, Int. Experts
- NSC, State Secretariat for Education, Research and Innovation (SERI), OncoSuisse, SAKK, SPHN, Patient Organisations, Industry....

Process approval by FOPH for «data structure»
(legally binding) / similar processes for others?

- Transparency in participants, processes and decision criteria, ...?
- Content: increase of quality, relevance and evidence, scientific rigour, interpretability, usability for registration and evaluation, ...?
- By delphi procedure with expert opinion or by a group decision, or...?



Process approval by FOPH for «data structure» (legally binding); possible criteria:

- Validation / evaluation concepts based on a formal proposal and a standardized schema
- General
- Interpretability / Usability
- Medical
- Documentation / Coding
- Juridical / ethical
-



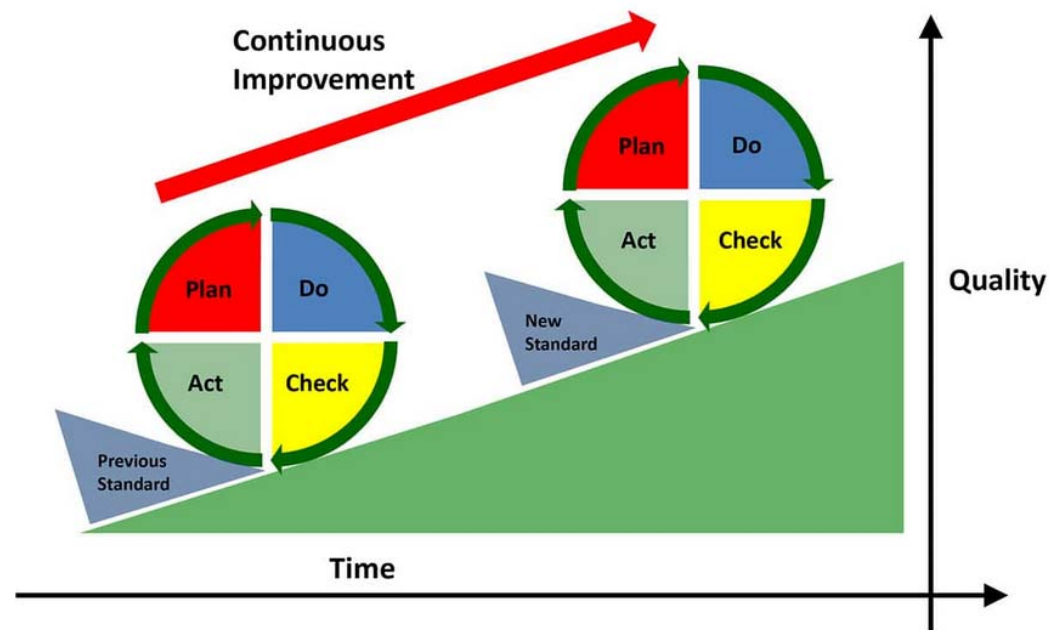
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**done is
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perfect.**





NICER CoreDay Tuesday, 5th November 2019

3. Short group work on process demands

Questions:

- What would be a optimal process for you to participate in the optimization process?
- What is most important for you to judge a new variable of the data structure that you have to register / code (criteria)
 - What is most important for you to judge a coding proposal for a variable (criteria)
 - What information do you need to fully understand and judge a coding proposal ?
 - Is it important if a variable is part of the quality appraisal of a guideline ?
 - Who has to be integrated in such a judgeing process ?