

CoReDay 5.11.2019

2. Summary of past decisions regarding coding
and data migration
11.30 – 12:00

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Part 1

Recapitulation of Data migration issues: Reasons and Solutions

Part 2


New variable «Treatment status»: What happened and Why

Mapping **OLD** to **NEW** Datastructure

Guiding principles for **new** data dictionary:

- (1) Intention of the **law**.
 - (2) Goals of NACR/KiKR Public Health **Reporting Concepts**.
 - (3) **Continuation** of existing data collection, whenever possible.
- Non-migrated data are **NOT LOST!**

In contrast to **old NCD**, the **new data dictionary** is a complete list of every registered information.

 A lack of national harmonized coding practices is to be expected for variables which have not been part of the NCD in the past, or have not been the focus of national reporting (i.e. treatments).

CR specific Mapping:

It would NOT be optimal that every CR maps the same way, because CRs interpreted categories of certain variable differently from than CRs. In such cases, national uniform mapping does more wrong than good, and it is better, that the mapping is carried out specific to the individual CR.

CR specific mapping need to be discussed with MS/ED/KM.

The following list of variables with migration problems mainly consists of such variables.

Diagnostic method(s) used

Variable number: 2.8
 Item length: 2
 Item format: Number

Definition

The data item records all diagnostic methods used. The information is mandatory for malignant breast cancer (C50), prostate cancer (C61), and colon and rectal cancer (C18-C20).

| OLD | NEW | Mapping to | Reason |
|---------------------------------------|---|---|---|
| >Knochenmarksentnahme | >Bone marrow aspirate >Bone marrow biopsy | >Bone marrow biopsy | “Knochenmarksentnahme” was German for “Bone marrow biopsy”. Bone marrow aspirate is a novel category. |
| >DCO >DCN | >DCN | >DCN | The information that a death certificate is the ONLY source of information, is not required in this list. That information is coded in the variable “Most valid basis of diagnosis” as code 0 (DCO). |
| >Pre-operative assessment | No longer existing | No mapping envisaged >Clinical examination undefined (depends on CR-specific usage) | Was already lacking in the list of “diagnostic methods used” in Feb_2018 (consensus list of variables after the consultation with CRs): level not essential. Without diagnostic implications. New code 12 for “Imaging NOS” had to be created because Imaging is also an important new code for the variable “most valid basis of diagnosis”. |
| >Biopsy locoregional or of metastasis | >Biopsy locoregional >Biopsy of metastasis | >Biopsy unspecified | Was already lacking in the list of “diagnostic methods used” in Feb_2018 (consensus list of variables after the consultation with CRs): level not essential. |

Registration of «No Treatment» after 1/1/20

NICERStat: Treatment Status

NICERStat_KRG, RSW: CHOP-like code

| ID | EXP | SORT | TEXT_DE | TEXT_EN | TEXT_FR | TEXT_IT |
|----|-----|------|-----------------------|---------------------|----------------------|---------|
| 1 | 1 | 1000 | Abgeschlossen | Ended | Terminé | |
| 2 | 2 | 1010 | Begonnen | Started | Entrepris | |
| 3 | 3 | 1020 | Begonnen-Unterbrochen | Started-interrupted | Entrepris-interrompu | |
| 4 | 4 | 1030 | Geplant | Planned | Prévu | |
| 5 | 5 | 1040 | Verweigert | Refused | Refusé | |
| 6 | 6 | 1050 | Nicht vorgesehen | Not envisaged | Non envisagé | |
| 8 | 8 | 1060 | Keine Therapie | No treatment | Pas de traitement | |
| 9 | 9 | 1070 | Unbekannt | Unknown | Sans renseignement | |

| nbchar | zcode (New CHOP-like end-codes for SWISS CR use only in green) | itemtype | DE | FR | IT | codable | indentlevel | lateralite | Code validated for cancer registration |
|--------|--|----------|--------------------------|---------------|--------------------|---------|-------------|------------|--|
| 1 | CO | T | Massnahmen und Interv... | Procédures et | Procedure e in non | | 1 | | |
| 23701 | 4 ZBB.1F | T | Zusatzaufwand in der Ref | Charge supplé | Risorse supplé | oui | | | Nein/Non/No |
| 23702 | | 998 | Nicht geplante Therapie | | | oui | | | ja/oui/si |
| 23703 | | 999 | Unknown | | | oui | | | ja/oui/si |

CHOP. Die KR, die alte Behandlungscodes topo-spezifisch migrieren wollen, müssen diese Mappings in einem von MS/KM definierten Format formulieren (innerhalb der nächsten beiden Monate).

Part 1

Recapitulation of Data migration issues: Reasons and Solutions

Part 2

Variable «Treatment status»: What happened and Why

First treatment complex code(s) status

Variable number: 7.4.1

Item length: 1

Item format: Number

Definition

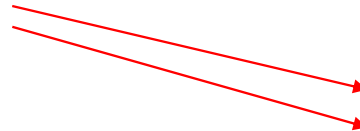
Indicates the status of each treatment as part of the first treatment complex.

Rationale

The data item is used to adjust the evaluation of treatment quality. The information is also used to adjust outcome statistics when evaluating patient survival and other outcomes.

| Code | Label | Description |
|------|-----------------------------|---|
| 0 | Planned | The accompanying treatment is planned as part of the 1 st treatment complex. |
| 1 | Initiated | The accompanying treatment has been initiated. |
| 2 | Completed | The accompanying treatment has been completed. |
| 3 | Stopped prior to completion | The accompanying treatment has been initiated, but stopped prior to completion. |
| 4 | Refused | The accompanying treatment was refused by the patient. |
| 5 | Not envisaged | The accompanying treatment is no longer envisaged (revision of the treatment plan). |
| 6 | Not initiated (unspecified) | The accompanying treatment has not been initiated because of other or unknown reasons. |
| 9 | Unknown | Unknown status of the accompanying treatment (no other code applies). |

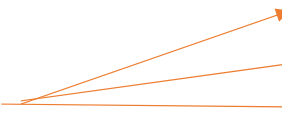
Indispensable



Later additions, based on
Minutes of WG Treatment



Planned, but not initiated. Why?



National usage

The variable is to be submitted to the NACR.

References

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Notes

>More than one status code may be assigned to a specific CHOP or CHOP-like code.

Example 1: a planned treatment that was refused by the patient has status 0 and status 4.

Example 2: a planned local excision of a lesion on the breast which was later decided against for medical reasons has status 0 and status 5.

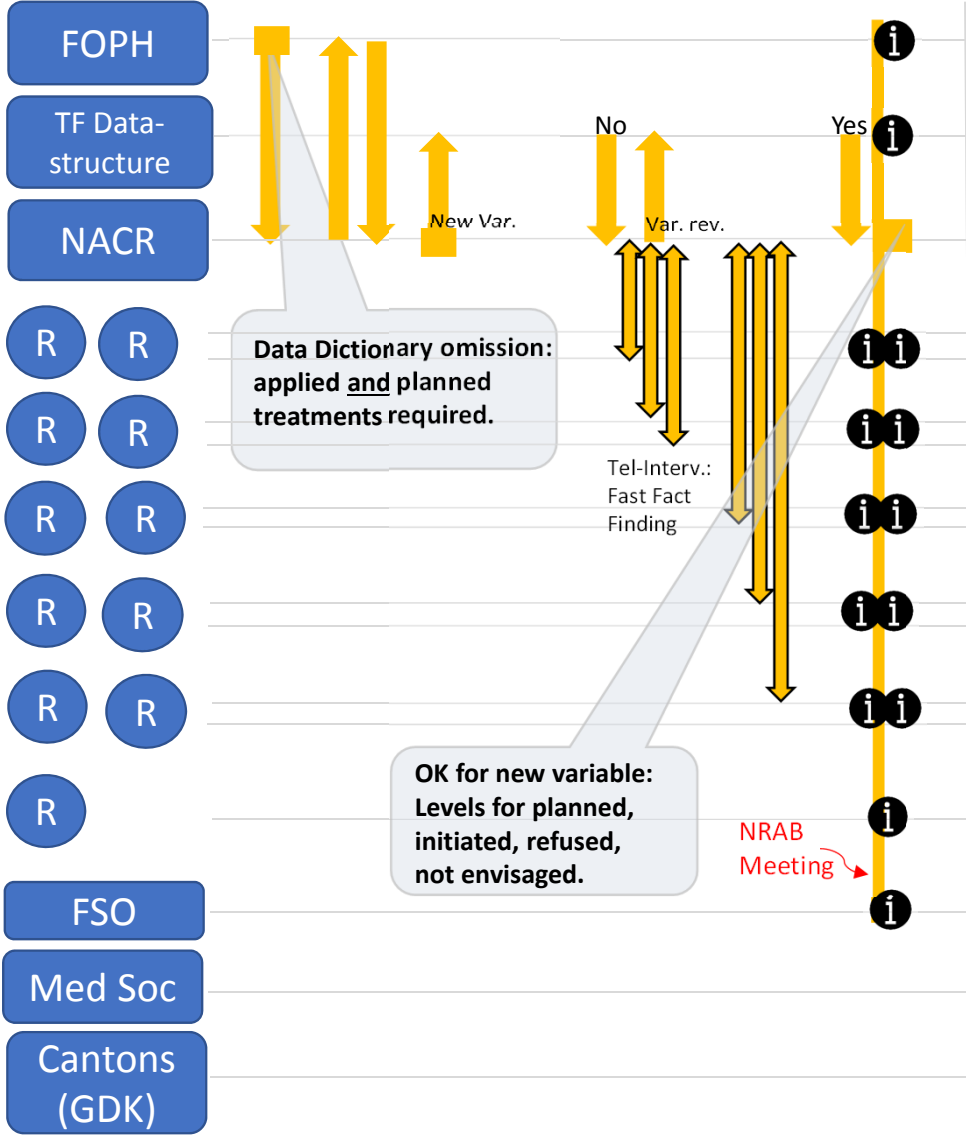
Example 3: a treatment planned, initiated, but stopped prior to completion has status 0, 1, and 3.

>Calendar date of end of treatment in codes 2 (completed) and 3 (stopped prior to completion) are not registered.

August | September

September | October

October | November



August | September

September | October

October | November

w35 w36 w37 w38 w39 w40 w41 w42 w43 w44

FOPH

TF Data-structure

NACR

R R

R R

R R

R R

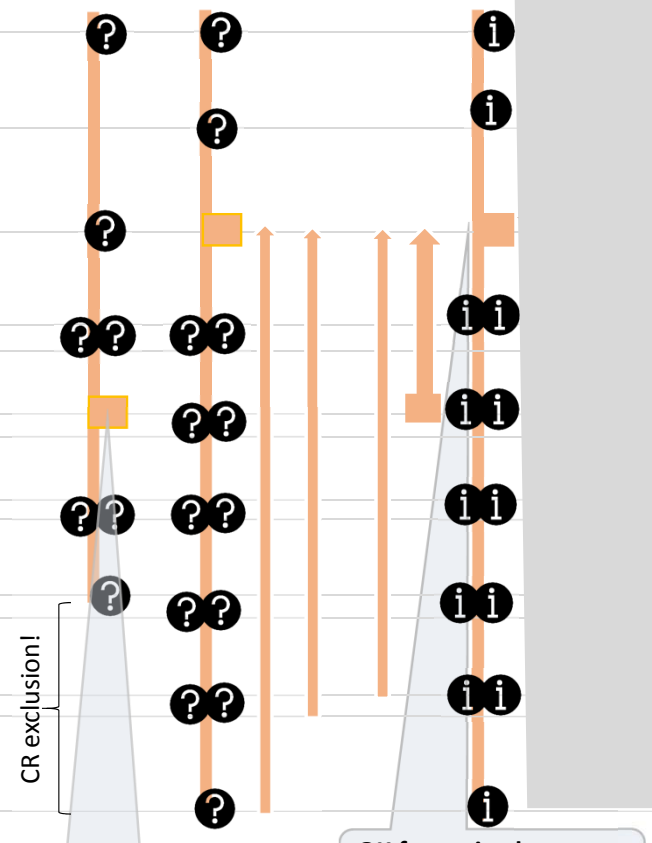
R R

R

FSO

Med Soc

Cantons (GDK)



CR exclusion!

More levels: info if regular treatment completion or not.

OK for revised new variable: more levels.

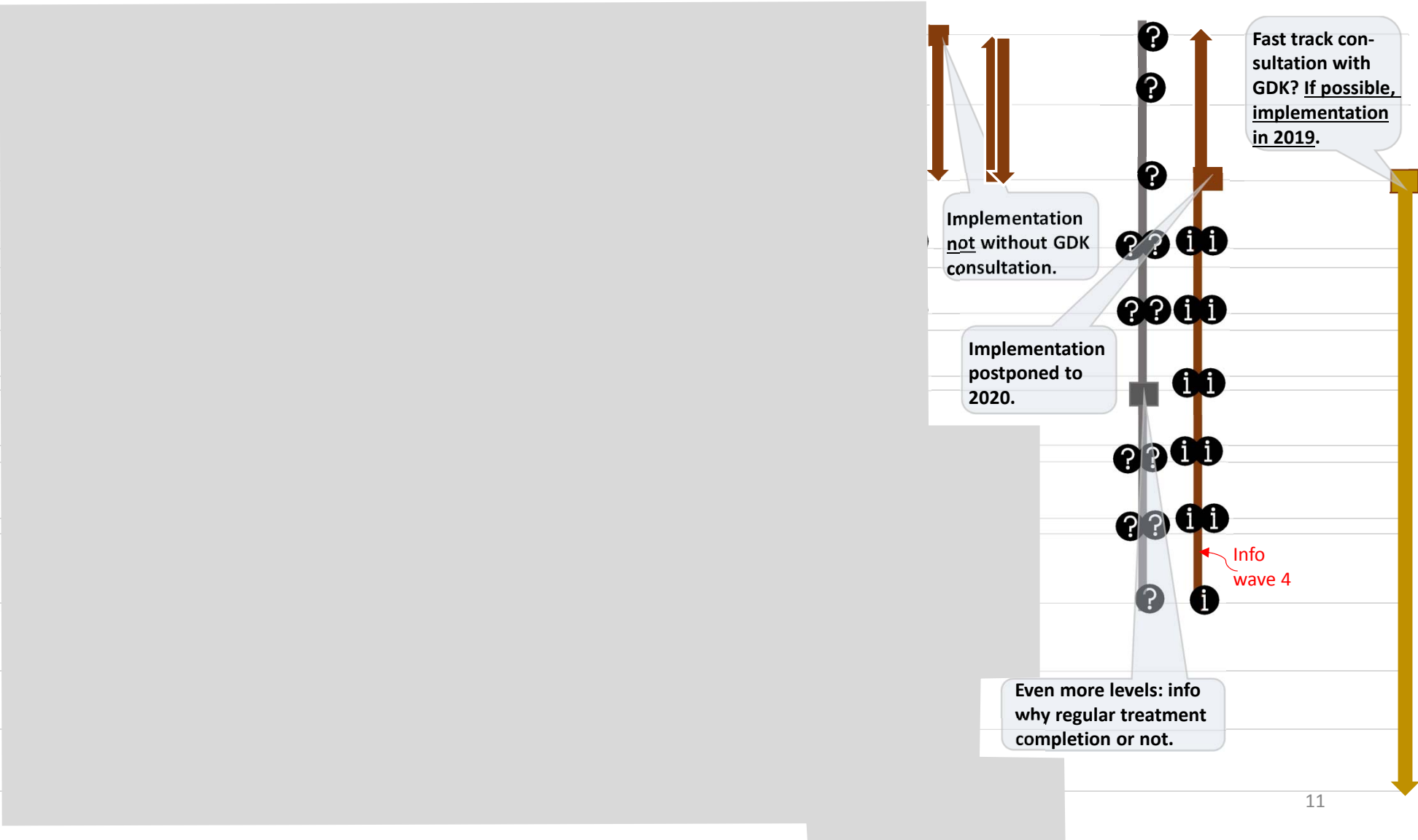
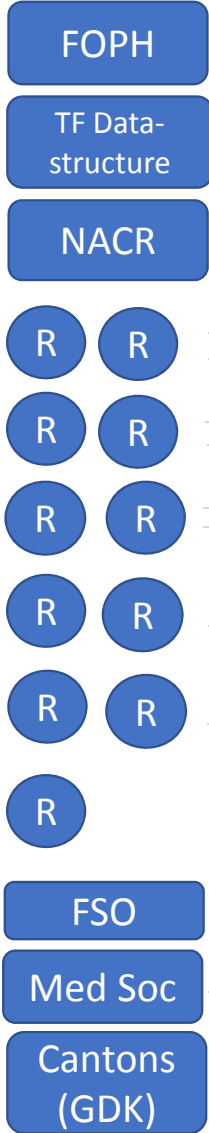


Minutes of 25.1.2017 support more levels

August | September

September | October

October | November



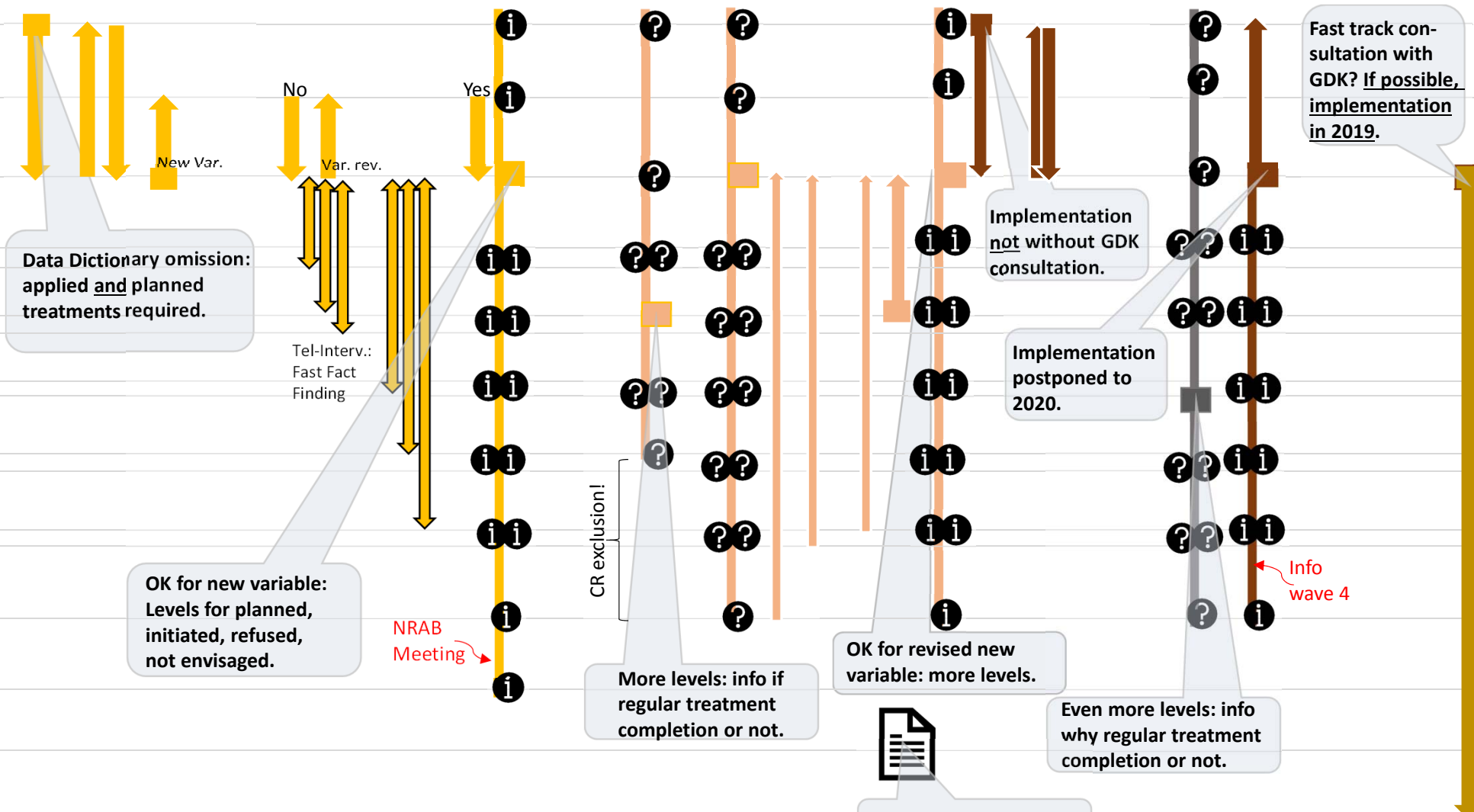
August | September

September | October

October | November



- FOPH
- TF Data-structure
- NACR
- R
- R
- R
- R
- R
- R
- R
- R
- FSO
- Med Soc
- Cantons (GDK)



Data Dictionary omission: applied and planned treatments required.

OK for new variable: Levels for planned, initiated, refused, not envisaged.

CR exclusion!
More levels: info if regular treatment completion or not.

OK for revised new variable: more levels.

Even more levels: info why regular treatment completion or not.

Implementation not without GDK consultation.

Implementation postponed to 2020.

Fast track consultation with GDK? If possible, implementation in 2019.

Minutes of 25.1.2017 support more levels

Learnings Part 2

- Not rely on texts too much: verbal communication about interpretation necessary.
- Optimal balance between «selected» and «all-inclusive» discussions. Mass-mailing is not always the best way to ask for everybody's opinion.
- Requests for modifications must be substantiated with supporting information, i.e. other stakeholders. Requests by CRs should be consolidated among CRs before NACR is contacted.
- There must be definitive time periods, when modifications are under discussion. Later suggestions must be postponed.

END

**Thank you very much
for your attention**

Other slides (Steinbruch)

Page 107, BREAST CANCER: tumour related prognostic factors

The following parameters are missing:

2- Assoziiertes in-situ Karzinom (Lobular, ductal)

All these parameters had been under discussion in the WG Datastructure new law and the first "Vernehmlassung" with Swiss CRs (End of Feb 2019).

To (2): there is now a variable dedicated to presence/absence of in situ tumour components in all types of cancer (Nr. 3.6.2, p57). DCIS/LCIS differentiation in breast cancer was decided as not being of essential importance.

To 5. Look for all localisations used to code metastases AND

To 6. metastases of follow-up using the **codes 12 (multi-systems) and 98 (no metastasis)**

The list of topographies for metastases in the basic data structure is taken directly from the UICC TNM book, because we wanted to be as close to international guidelines as possible wherever possible.

The old category 12 for multi-systems can be mapped to the new code Unknown, meaning that the exact topographies of metastases unknown. It does NOT mean, that it is

unknown whether there are metastases or not. The new variables “Topography of metastases at diagnosis” and “Topography(s) of post-diagnosis metastases” are ONLY coded IF such metastases are found. This means M1 of TNM or variable “type of event” is 3 (metastasis).

To make the descriptive text for category unknown more precise, we add: “..., e.g. poly-metastatic disease”.

The fact of absent metastases (old category 98) is no longer specifically coded in this variable. The new variable is empty (missing) in this case.

Patients having a **civil status code = 5 ("other")**.

This variable of the NCDv4.1 was never intended for national cancer statistics. It remained in the NCD, in spite of attempts to take it out, due to individual cancer registries requests. Therefore, national harmonization of registration practices was not carried out. Civil status has now become part of the basic data structure under the new law and the categories chosen by the working group for data structure are those of the FSO Population and Households statistics. This makes the most sense on the national level. The new category “annulled marriage” is for those rare cases where a marriage was terminated, but not due to divorce or death of the partner. We do not support the uniform mapping of “other” to “annulled marriage” because it is unclear how well “other” fitted to “annulled marriage”, there were likely differences in interpretation between registries. If a national uniform mapping is demanded, then it is better to accept a small information loss and map Other to Unknown (9).

Mapping von 5 auf 9 (?) registerspezifisch klären

Additional question concerning the category “exploratory” for goal of treatment:
The working group Data structure has had discussions because the cancer registries were divided on the usability of this category. The final decision, not to include it, was based on: (1) international guidelines for the definition of such a category were lacking, (2) if exploratory was meant to help diagnose the tumour, then it has no place in the goals of the first treatment complex (which has nothing to do with diagnostics), (3) it was not foreseen as part of the concepts for national cancer monitoring as well as health reporting.

laterality: Differenz alte/neue Kodeliste: neu eingefügte Ausprägung «Unilateral, NOS (unilateral, but unknown whether right or left). Die alten Daten mit einer, aber unbekannter Seite wurden zusammen mit unbekanntem ob uni-oder bilateral als «unknown» kodiert und können somit nur in «unknown» landen.

New variable «treatment status»: 31.8. – 31.10.2019

