



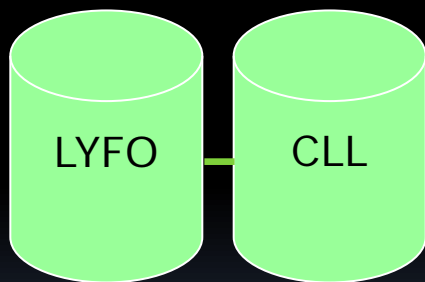
LYFO DATABASEN STATUS 2022

Den hæmatologiske fællesdatabase

- 1983 Lymfom vest Danmark
- 1999 Lyfo bliver national
- 2000 Akut Myeloid Leukæmi
- 2005 Akut Lymfatisk Leukæmi
- 2005 Myelomatose
- 2005 Etablering af KMS-database
- 2008 Kronisk Lymfatisk Leukæmi
- 2010 MDS/Myeloproliferativ sygdom
- 2013 MGUS og Amyloidose

6 Databaser i 4 DMCGer

DLG



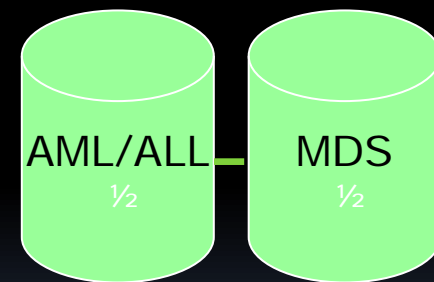
DMSG



DSKMS



ALG



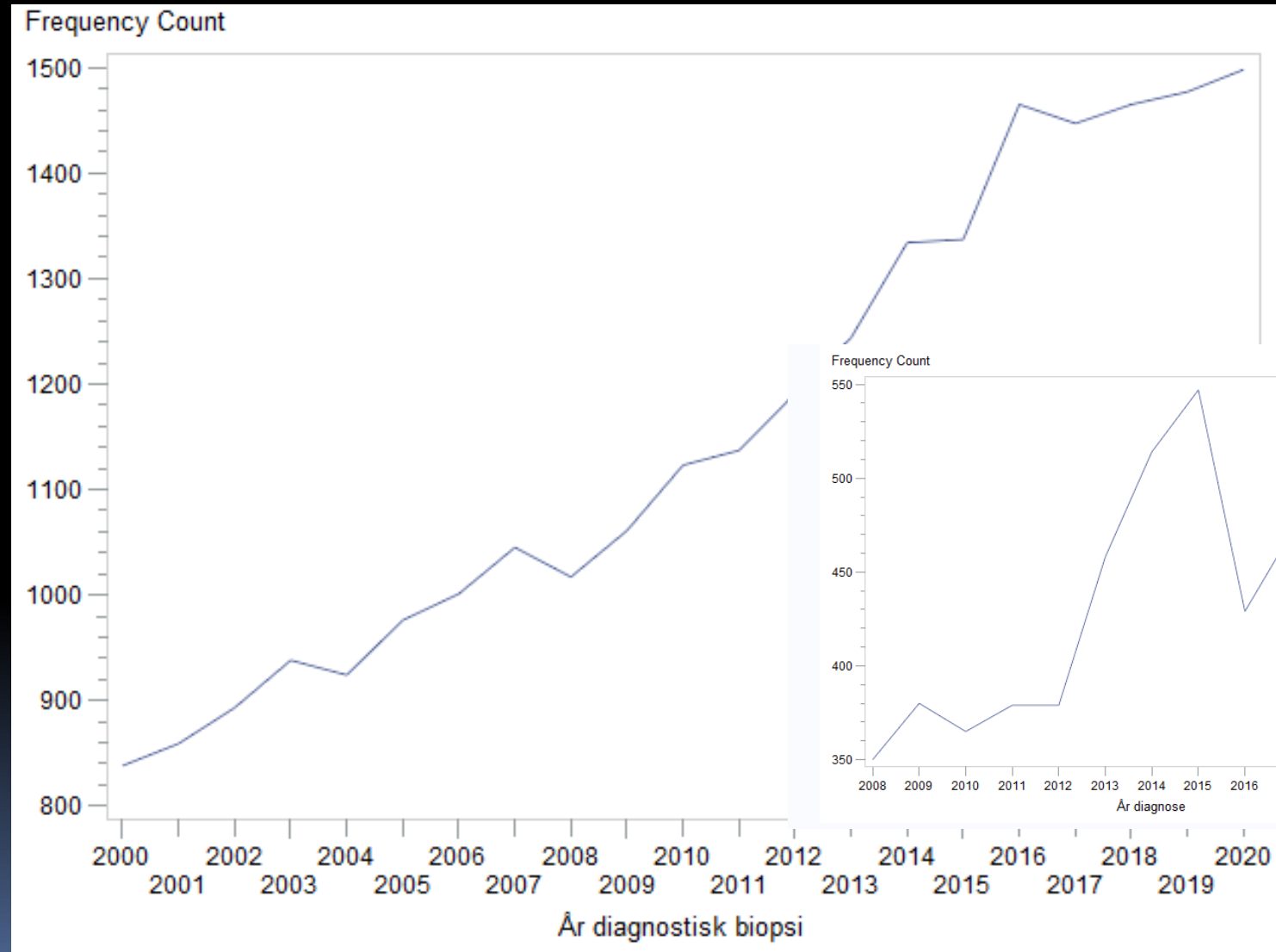
WHO klassifikation 4. udgave

- Chronic lymphocytic leukaemia/small lymphocytic lymphoma
- Monoclonal B-cell lymphocytosis
- B-cell prolymphocytic leukaemia
- Splenic marginal zone lymphoma
- Hairy cell leukaemia
- Splenic B-cell lymphoma/leukaemia, unclassifiable
- Splenic diffuse red pulp small B-cell lymphoma
- Hairy cell leukaemia variant
- Lymphoplasmacytic lymphoma
- IgM Monoclonal gammopathy of undetermined significance
- Extranodal marginal zone lymphoma of mucosa-associated lymphoid tissue (MALT lymphoma)
- Nodal marginal zone lymphoma
- Paediatric nodal marginal zone lymphoma
- Follicular lymphoma
- In situ follicular neoplasia
- Duodenal-type follicular lymphoma
- Paediatric-type follicular lymphoma
- Large B-cell lymphoma with IRF4 rearrangement
- Primary cutaneous follicle centre lymphoma
- Mantle cell lymphoma
- Leukaemic non-nodal mantle cell lymphoma
- In situ mantle cell neoplasia
- Diffuse large B-cell lymphoma (DLBCL), NOS
- T-cell/histiocyte-rich large B-cell lymphoma
- Primary diffuse large B-cell lymphoma of the CNS
- Primary cutaneous diffuse large B-cell lymphoma, leg type
- EBV-positive diffuse large B-cell lymphoma, NOS
- EBV-positive mucocutaneous ulcer
- Diffuse large B-cell lymphoma associated with chronic inflammation
- Fibrin-associated diffuse large B-cell lymphoma
- Lymphomatoid granulomatosis
- Primary mediastinal (thymic) large B-cell lymphoma
- Intravascular large B-cell lymphoma
- ALK-positive large B-cell lymphoma
- Plasmablastic lymphoma
- Primary effusion lymphoma
- HHV8-associated lymphoproliferative disorders
- Multicentric Castleman disease
- HHV8-positive diffuse large B-cell lymphoma, NOS
- HHV8-positive germinotropic lymphoproliferative disorder
- Burkitt lymphoma
- Burkitt-like lymphoma with 11q aberration
- High-grade B-cell lymphoma
- High-grade B-cell lymphoma with MYC and BCL2 and/or BCL6 rearrangements
- High-grade B-cell lymphoma, NOS
- B-cell lymphoma, unclassifiable, with features intermediate between DLBCL and classic Hodgkin lymphoma

- T-cell prolymphocytic leukaemia
- T-cell large granular lymphocytic leukaemia
- Chronic lymphoproliferative disorder of NK cells
- Aggressive NK-cell leukaemia
- EBV positive T-cell and NK-cell lymphoproliferative diseases of childhood
- Systemic EBV+ T-cell lymphoma of childhood
- Chronic active EBV infection of T- and NK-cell type, systemic form
- Hydroa vacciniforme-like lymphoproliferative disorder
- Severe mosquito bite allergy
- Adult T-cell leukaemia/lymphoma
- Extranodal NK/T-cell lymphoma, nasal type
- Intestinal T-cell lymphoma
- Enteropathy-associated T-cell lymphoma
- Monomorphic epitheliotropic intestinal T-cell lymphoma
- Intestinal T-cell lymphoma, NOS
- Indolent T-cell lymphoproliferative disorder of the gastrointestinal tract
- Hepatosplenic T-cell lymphoma
- Subcutaneous panniculitis-like T-cell lymphoma
- Mycosis fungoides
- Sezary syndrome

- Primary cutaneous CD30-positive T-cell lymphoproliferative disorders
- Lymphomatoid papulosis
- Primary cutaneous anaplastic large cell lymphoma
- Primary cutaneous peripheral T-cell lymphomas, rare subtypes
- Introduction
- Primary cutaneous gamma delta T-cell lymphoma
- Primary cutaneous CD8-positive aggressive epidermotropic cytotoxic T-cell lymphoma
- Primary cutaneous acral CD8-positive T-cell lymphoma
- Primary cutaneous CD4+ small/medium T-cell lymphoproliferative disorder
- Peripheral T-cell lymphoma, NOS
- Angioimmunoblastic T-cell lymphoma and other nodal lymphomas of T follicular helper (TFH) cell origin
- Angioimmunoblastic T-cell lymphoma
- Follicular T-cell lymphoma
- Nodal peripheral T-cell lymphoma with TFH phenotype
- Anaplastic large cell lymphoma, ALK-positive
- Anaplastic large cell lymphoma, ALK-negative
- Breast implant-associated anaplastic large cell lymphoma
- Nodular lymphocyte predominant Hodgkin lymphoma
- Classic Hodgkin lymphoma
- Nodular sclerosis classic Hodgkin lymphoma
- Lymphocyte-rich classic Hodgkin lymphoma
- Mixed-cellularity classic Hodgkin lymphoma
- Lymphocyte depleted classic Hodgkin lymphoma

Incidente tilfælde/år



Skemaflow

1983-2004

Registrering

3-års Follow up

5-års Follow up

Diagnose
Performance
Lab data

Behandling
Relaps
Død

Relaps
Død

2005 → Relaps &

Registrering

1. linie
behandling

2.-linie
behandling

Follow-up

Diagnose
Performance
Lab data

Behandling
Respons

Behandling
Respons

Evt Død og
sygdom
status

Indtastnings-skema

Udfyldelse.

LYFO1: Registrering (v2.0) > Print Slet Gem Gem & forlad Indlever Indlever & forlad ?

LYFO1: Registrering (v2.0)

Histologi & Patologi

Dato for diagnostisk biopsi(?) Vis kalender

WHO histologikode(?)

-> Kodelabel

Diskordant lymfom(?) Ja Nej

Stadium (Ann Arbor)(?)

B-symptomer(?) ja nej Uvist

Max. tumordiameter, nøjagtig mål (?)
(cm, max een decimal.
-1 hvis uoplyst)

Performance status WHO(?)

Anden malign sygdom(?) Ja Nej Uoplyst

Bopæl ved diagnose

Kommunekode (2007 ff)(foretrækkes)(?)

Region (2007 ff)

Behandling

Iværksat eller planlagt behandling(?) Ja "Wait-and-watch" strategi. Nej Uvist

• Dato for start af behandling eller beslutning om "wait-and-watch" Vis kalender

• Ingen behandling"

Sygdomslokalisation(?)

Kun nodalt
 Kun ekstranodalt
 Primært nodalt, sekundært ekstranodalt
 Primært ekstranodalt, sekundært nodalt

Rhinopharynx Nej Ja

Waldeyers svælgring Nej Ja

Tonsilla Palatina Nej Ja

Hals, Øvre Nej Ja

Supraclaviculært Nej Ja

Infraclaviculært Nej Ja

Axiller Nej Ja

Mediastinum Nej Ja

Lungehili Nej Ja

Retroperitoneum Nej Ja

Tarmkrøst(?) Nej Ja

Pelvis Nej Ja

Ingvinale Nej Ja

Milt Nej Ja Uoplyst

Knoglemarv Nej Ja Uoplyst

Biokemi

(Skriv -1 (minus een) i nedenstående felter hvis Uoplyst)

Måleenheder der vises(?) Kun fra dit sygehus (+ evt. indtastede) Vis alle slags måleenheder

Hæmoglobin (mmol/L)(?)

Thrombocytter (mia/L)(?)

Leukocytter (mia/L)(?)

Lymfocytter (mia/L)(?)

Lymfocytter (%)(?)

Albumin (mikromol/L)(?)

Calcium, ioniseret Ca++ (mmol/L)(?)

Creatinin (mikromol/L)(?)

Bilirubin (mikromol/L)(?)

ALAT (U/L)(?)

Basisk Fosfatase (U/L)(?)

Basisk phosphatase-værdien over øvre reference Ja Nej

LDH (U/L)(?)

LDH-værdien over øvre referencegrænse Ja Nej

Beta 2 microglobulin (nmol/L)(?)

Immunglobuliner

• IgA (g/L)(?)

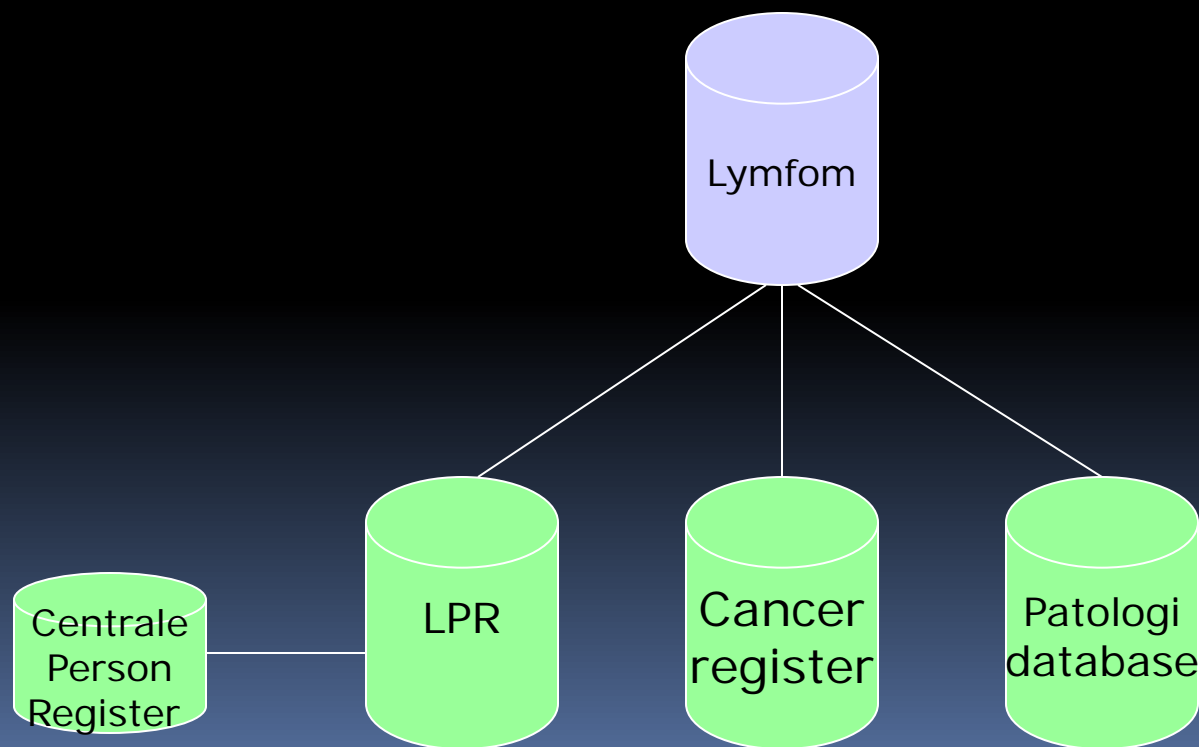
• IgG (g/L)(?)

• IgM (g/L)(?)

• M-Protein

Høj indberetningsfrekvens forudsætning for databasens validitet

- Samkøring af centrale registre
- Opdaterede lister 10 årligt/LIS



Completeness of 11 LYFO variables

Variable	All (1706)	Random (364)	DLBCL (169)	Hodgkin (672)	CNS (370)	PTCL (141)
Lymphoma subtype	99.9	100	98.3	100	99.5	99.3
Date of diagnosis (± 14 days)	100	100	100	99.7	100	100
Ann Arbor Stage (1-2/3-4)	100	100	100	99.5	100	100
Performance status (0-1/2-4)	99.0	99.2	100	NA	98.4	99.3
LDH above upper limit	95.7	96.5	100	NA	92.0	98.6
Extranodal involvement	100	100	NA	NA	NA	NA
Planned treatment	99.7	98.1	NA	NA	NA	NA
Chemotherapy	99.3	98.4	100	NA	100	NA
Immunotherapy	98.9	98.3	100	NA	98.9	NA
Radiotherapy	98.1	96.4	98.1	NA	99.7	NA
Albumin	94.4	NA	NA	94.4	NA	NA

Positive Predictive value (PPV)

Variable	All (1706) PPV(%) ½	Random (364) PPV	DLBCL (159) PPV	Hodgkin (672) PPV	CNS (370) PPV	PTCL (141) PPV
Lymphoma subtype	98.5	96.7	94,8	100,0	99.5	99.3
Date of diagnosis (±14 days)	94.5	96.4	87.8	93,6	98.9	89.4
Ann Arbor Stage (1-2/3-4)	93.4	92.8	91.2	97,0	90.2	87.9
Performance status (0-1/2-4)	97.5	98,1	90.6	NA	100	97,1
LDH above upper limit	97.5	96.1	98.7	NA	100	93.5
Extranodal involvement (0-1/>1)	95.3	95.3	NA	NA	NA	NA
Planned treatment	97.5	97.5	NA	NA	NA	NA
Chemotherapy	99.2	98.9	100	NA	99.5	NA
Immunotherapy	98,2	97.2	99.4	NA	98.6	NA
Radiotherapy	97.1	96.9	93.0	NA	99.2	NA
Relapse	96.6	94.7	NA	NA	100	NA
Albumin	87,1	NA	NA	87,1	NA	NA


Indikatorer

2005-15

- **Resultatindikatorer:**
 - Antal nye sygdomstilfælde, iværksatte behandlinger og recidiv
 - Mortalitet 30, 90 og 180 dage efter iværksat behandling.
 - Antal patienter som opnår komplet eller partiel remission på 1. linie behandlingen.
 - Estimeret Kaplan-Meier overlevelse efter hhv 1, 3 og 5 år.
- **Procesindikatorer**
 - Tidsrum fra diagnose til 1. behandlingsdato for patienter der behandles
 - Andel patienter inkluderet i klinisk behandlings protokol
 - Andel patienter med sikker prognostisk index dvs. alle faktorer der indgår foreligger (IPI,IPS,FLIPI,MIPI,PTL-IPI,....)



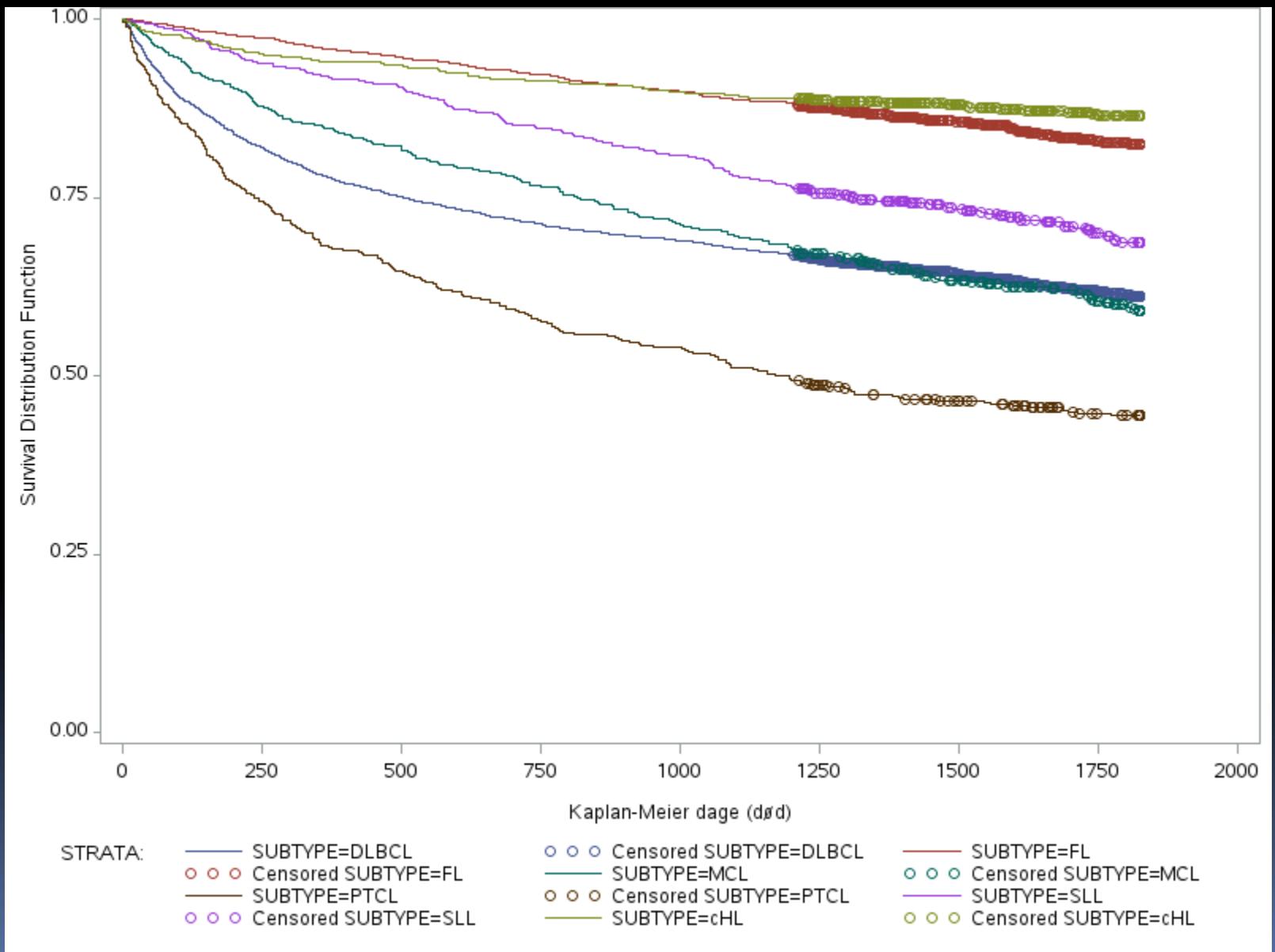
Indikatorer 2021

- Indikator 1a. Dækningsgrad
 - Indikator 1b. Datakomplethed behandlingskema
 - Indikator 1c. Datakomplethed relapsskema
 - Indikator 3a. Mortalitet 180 dage hos pt i behandling og w&w
 - Indikator 3b. Mortalitet 180 dage hos patienter i aktiv behandling
 - Indikator 4. CR eller PR efter 1. linje
 - Indikator 7. Estimeret 3-års overlevelse
 - Indikator 8. Estimeret 5-års overlevelse
 - Indikator 9. Tid fra diagnostisk prøvetagningsdato til 1. behl. dato
 - Indikator 11. Patienter inkluderet i klinisk behandlingsprotokol.
 - Indikator 12. Andel patienter med sikker prognostisk indeks
 - Indikator 15. Andel patienter, der modtager AntiCD20 behandling (1L)
 - Indikator 16. Andel patienter med DLBCL incl. High-grade lymfom, med CNS-IP 4-6, som modtager CNS profylakse.
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Indikatorer CLL

- Indikator 1a. Dækningsgrad
- Indikator 1b. Datakomplethed behandlingskemaer
- Indikator 1c. Datakomplethed relapsskema
- Indikator 3. 180 dages mortalitet (for pt i behl)
- Indikator 7. Estimeret 3-års overlevelse
- Indikator 8. Estimeret 5-års overlevelse
- Indikator 9. Estimeret 10-års overlevelse
- Indikator 10. Udført gendiagnostisk specialundersøgelse (TP53, del17p)
- Indikator 11. Patienter inkluderet i klinisk behandlingsprotokol

Overlevelse 2012-18



Planlagte justeringer

- Indikator 16 udgår
- Ny indikator for patienter behl med cellulær terapi
- Registrering af 3.+ linje behandling
- MDT diskuteres
- Laboratorie værdier fra centralt register
- Yderligere justeringer afventer ny indtastningsplatform