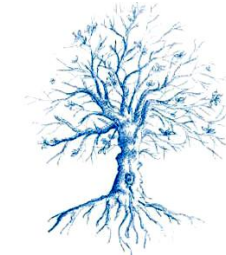


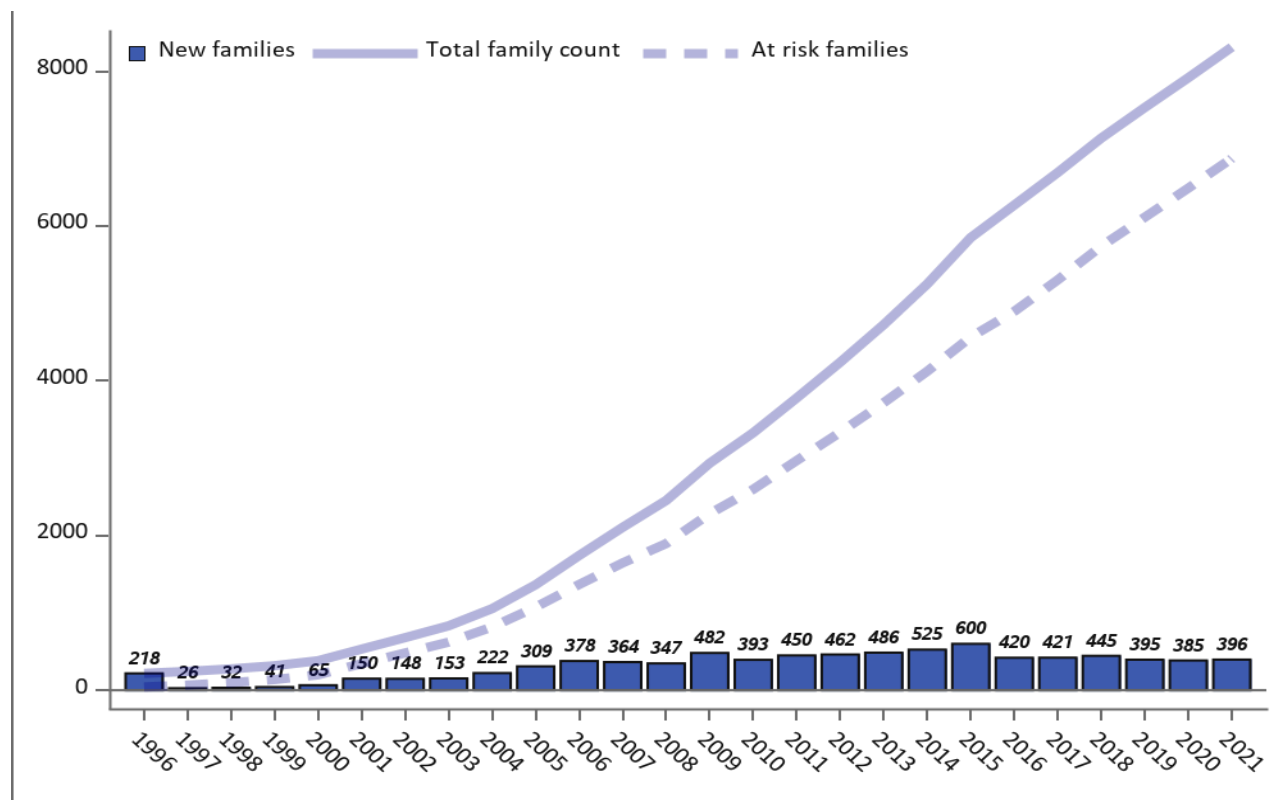


HNPCC Symposium 2022

Extra-colonic cancers in Lynch syndrome – clinical management



New families per year and in total



N= 8,313 in total
N= 6,875 at-risk
Not HNPCC

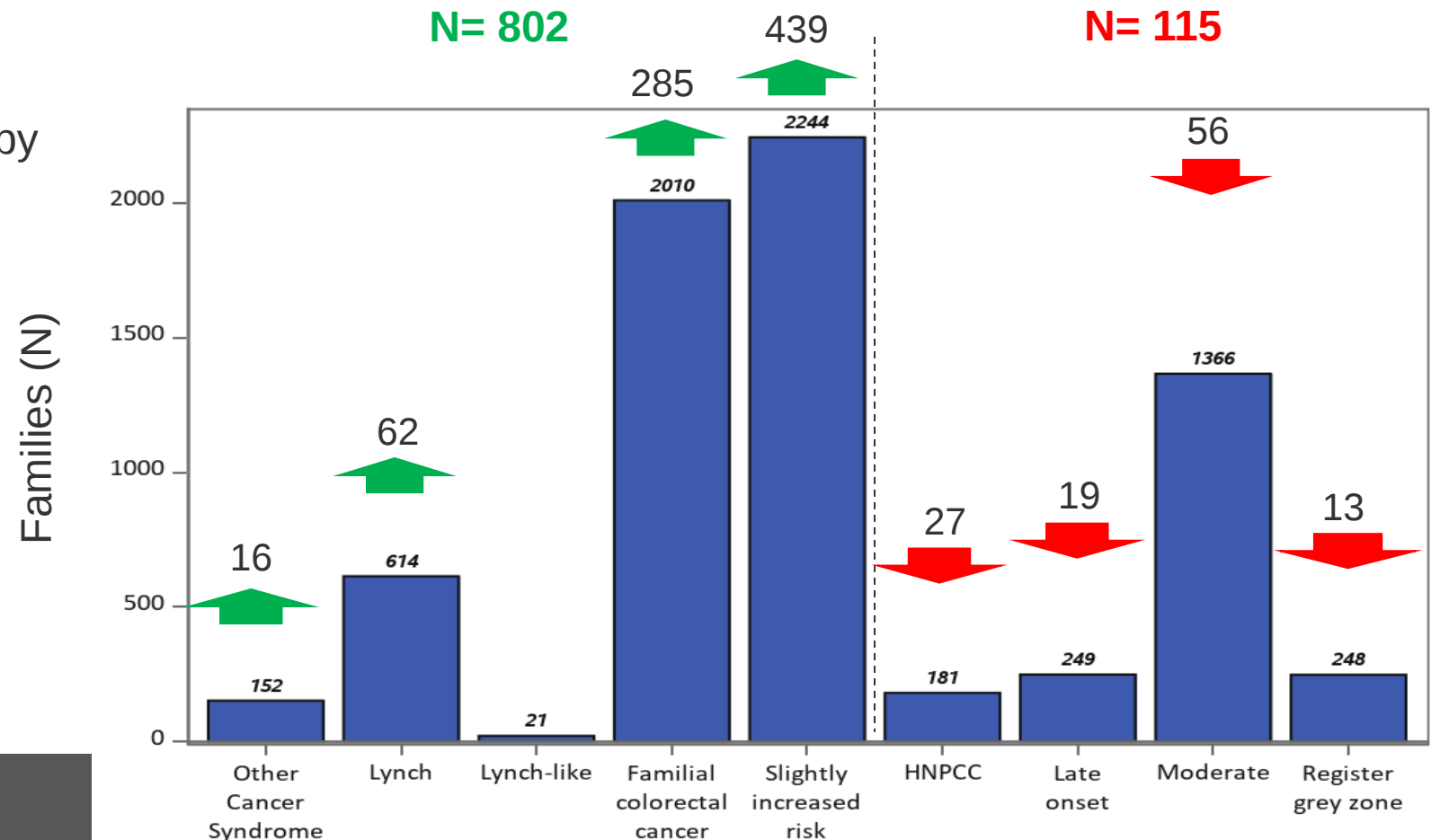


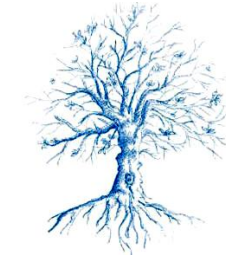
Re-evaluations

- 2,044 families are still not re-evaluated
- Probably not attending surveillance colonoscopy

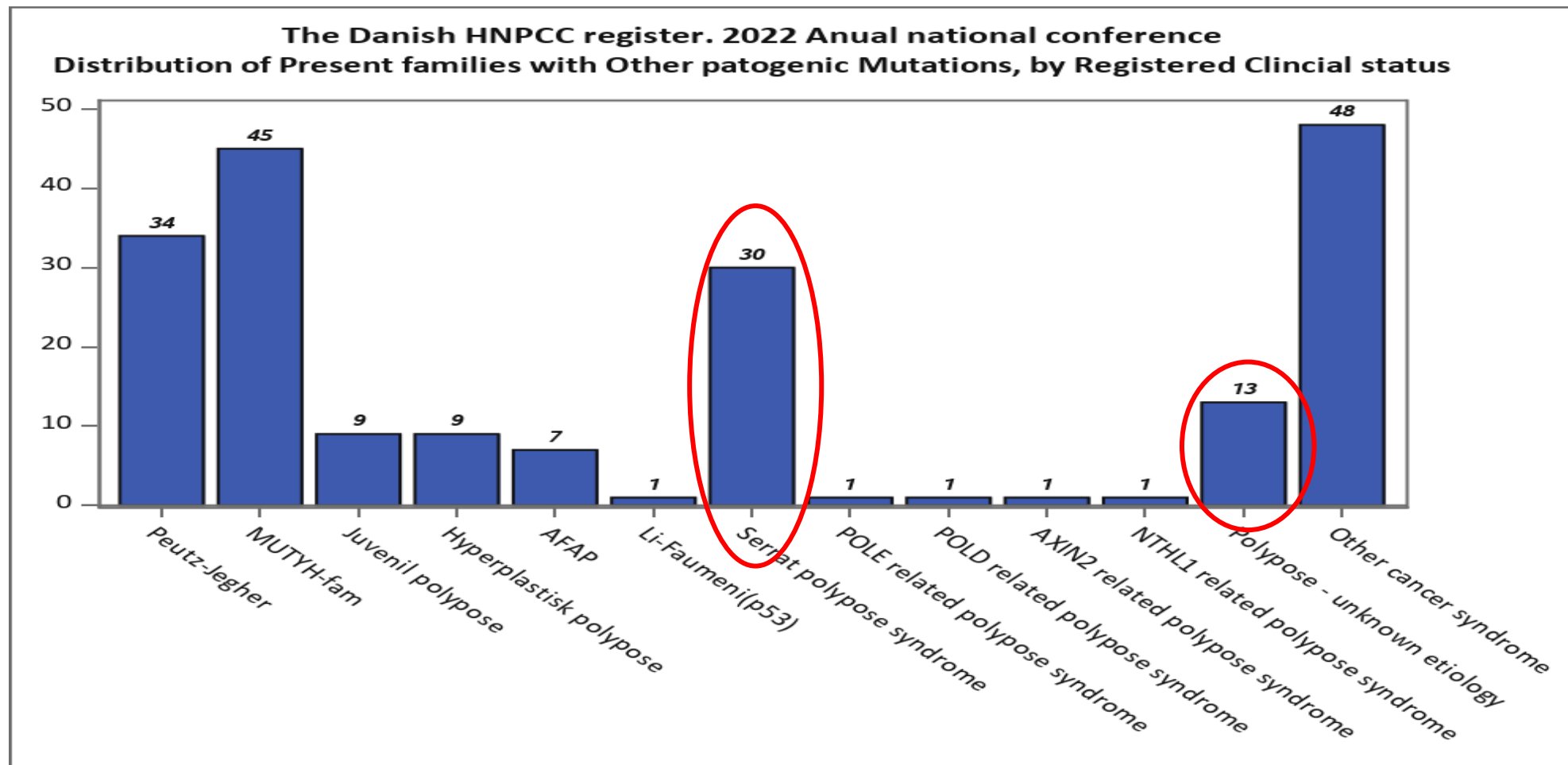
New classification system

Old classification system





Other colorectal cancer syndromes



New guidelines for Lynch syndrome

Lynch syndrome					Familial colorectal cancer (FCC)	Slightly increased risk of CRC
Pathogen variant in	<i>MLH1</i>	<i>MSH2</i>	<i>MSH6</i>	<i>PMS2</i>	Ej påvist patogen variant	
Cancer risk	48% (women) 57% (men)	47% (women) 51% (men)	20% (women) 18% (men)	10% (both sexes)	15-30 %	10-15%
Surveillance program	Colonoscopy every 2 nd year Life long				Colonoscopy every 5 th year Life long	1 colonoscopy at 50 years or First contact >50 years FIT screening thereafter
Age at surveillance initiation	25 year	25 year	30 year	35 year	10 years before youngest affected Earliest at 25 years and latest at 50 years	50 years or at first contact No colonoscopy for people >75 years
Surgery	Subtotal colectomy or proctocolectomy considered when CRC		Subtotal colectomy, proctocolectomy or segmental resection considered when CRC		Like other CRC patients	
Oncology	Adjuvant 5-FU suppl. with oxaliplatin for CRC stage III Immunotherapy should be considered for disseminated CRC				Like other CRC patients	
Lifestyle	Avoid smoking and obesity. Physical activity is recommended.					

InfoBioMed updates

Regarding reports after

- Colonoscopic surveillance
- Gynaecologic surveillance

InfoBioMed v2.1.15.26

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]**
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Surveillance**

Patient information

Civil no

First name

Last name

Treatment

Date of examination

Indication

Symptom

Extent of colonoscopy

Bowel prep.

Examination type

Results

Code

Result

Location path

Path procedure

Tissue sent

Cancers

Code

Cancer

Bemærkninger

+

InfoBioMed updates

Type cpr.nr. and get

- patient's name

InfoBioMed v2.1.15.26

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]**
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Surveillance**

Patient information

Civil no

First name

Last name

Treatment

Date of examination

Indication

Symptom

Extent of colonoscopy

Bowel prep.

Examination type

Results

Code	Result
	Location path
	Path procedure
	Tissue sent

Cancers

Code	Cancer

Bemærkninger

InfoBioMed updates

Type cpr.nr. and get

- patient's name
- +/- known HNPCC

InfoBioMed v2.1.15.26

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
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- Surveillance [F7]**
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Surveillance**

Patient information

Civil no 111111-1111

First name

Last name

Vinduesklip

Treatment

Date of examination

Indication

Information

Denne patient er ikke kendt i HNPCC-registeret. Hvis patienten tilhører en HNPCC-familie, er du velkommen til at kontakte HNPCC-registeret på: hnpcc-registret@hvh.regionh.dk

OK

Res

Co

Result

Location path

Path procedure

Tissue sent

Add Result Delete Result

Cancers

Code

Cancer

Add Cancer Delete Cancer

Bemærkninger

InfoBioMed updates

Type cpr.nr. and get

- patient's name
- +/- known HNPCC

Send report and get

- surveillance program

InfoBioMed v2.1.15.26

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]**
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]**
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Surveillance**

Patient information

Civil no [REDACTED]
First name **Test**
Last name **Testesen**

Treatment

Date of examination **13-10-2022**
Indication **Screening**

Information

XML filen blev korrekt leveret til HNPCC serveren!
Patienten tilhører en familie med status Lynch
Anbefalet kontrolprogram er: Lynch

OK

Res

Co

1

Result **Normal**
Location path
Path procedure
Tissue sent

Cancers

Code
Cancer

Add Result **Delete Result**
Add Cancer **Delete Cancer**

Bemærkninger

InfoBioMed updates

Type cpr.nr. and get

- patient's name
- +/- known HNPCC

Send report and get

- surveillance program
- reevaluation recommendation

InfoBioMed v2.1.15.26

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]**
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Surveillance**

Patient information

Civil no [REDACTED]
First name **Testperson**
Last name **Testfamilie**

Treatment

Date of examination **13-10-2022**
Indication **Screening**
Symptom **None**

Information

XML filen blev korrekt leveret til HNPCC serveren!
Patienten tilhører en familie, som er klassificeret efter de gamle retningslinjer og bør henvises til fornyet genetisk udredning

OK

Location path
Path procedure
Tissue sent

Cancers

Code
Cancer

Add Result Delete Result
Add Cancer Delete Cancer

Bemærkninger

InfoBioMed updates

Type cpr.nr. and get

- patient's name
- +/- known HNPCC

Send report and get

- surveillance program
- reevaluation recommendation
- gyn surveillance stopped

InfoBioMed v2.1.16.27

Login Logout

MAIN MENU

- Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Endometrie surveillance**

Patient information

CPR-nr. [REDACTED]
 Fornavn **Test**
 Efternavn **Testesen**

Undersøgelse

Undersøgelsesdato **13-10-2022**
 Indikation **0 Screening**
 Symptom **0 Ingen**
 Menstruation **0 Normal**

Information

XML filen blev korrekt leveret til HNPCC serveren!
 Patienten tilhører ikke en familie, der er anbefalet gynækologisk surveillance. Hvis det er en fejl, er du velkommen til at kontakte HNPCC-registret på: hnpcc-registret@hvh.regionh.dk

OK

UL af ovarier

Resultat **0 Normal**
 Suppl. Diagnostik **0 Ingen**

Bemærkninger

Væv til histologi

InfoBioMed updates

Type cpr.nr. and get

- patient's name
- +/- known HNPCC

Send report and get

- surveillance program
- reevaluation recommendation
- gyn surveillance stopped
- warning for male gyn pt

InfoBioMed v2.1.17.28

Login Logout

MAIN MENU

- ✓ Welcome [F4]
- Family [F5]
- Individual [F6]
- Surveillance [F7]
- Endometrie surveillance [F8]

FUNCTIONS

- New patient [Ctrl+Ins]
- New examination [Shift+Ins]
- Send XML [Ctrl+S]
- Print list [Ctrl+P]
- Print user report history
- Help [F1]
- Exit [Ctrl+X]

Welcome **Endometrie surveillance**

Patient information

CPR-nr. [REDACTED]
Fornavn Fynbo
Efternavn Test

Undersøgelse

Undersøgelsesdato 13-10-2022
Indikation 0 Screening
Symptom 0 Ingen
Menstruation 5 Amenoré

Information

XML filen blev korrekt leveret til HNPCC serveren!
Patienten er juridisk en mand. Har han feminine genitalia interna, eller er der fejl i cpr. nr.?
Patienten tilhører en familie med status Lynch
Anbefalet kontrolprogram er: Lynch

OK

UL af ovarier

Resultat 9 Ikke undersøgt
Suppl. Diagnostik 0 Ingen

Bemærkninger

Væv til histologi

How to do rese

- Apply the **Scienti**

Lone Sunde
Inge Bernstein
Lars Henrik Jensen
Karin Wadt
Zohreh Ketabi
Louise Klarskov
Henrik Okkels
Christina Therkildsen

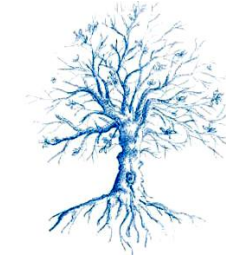
- By mailing the **ap**
- **HVH-HNPCC-Forskning@regionh.dk**

Opdateret 30.7.2018, vers. 2.3.

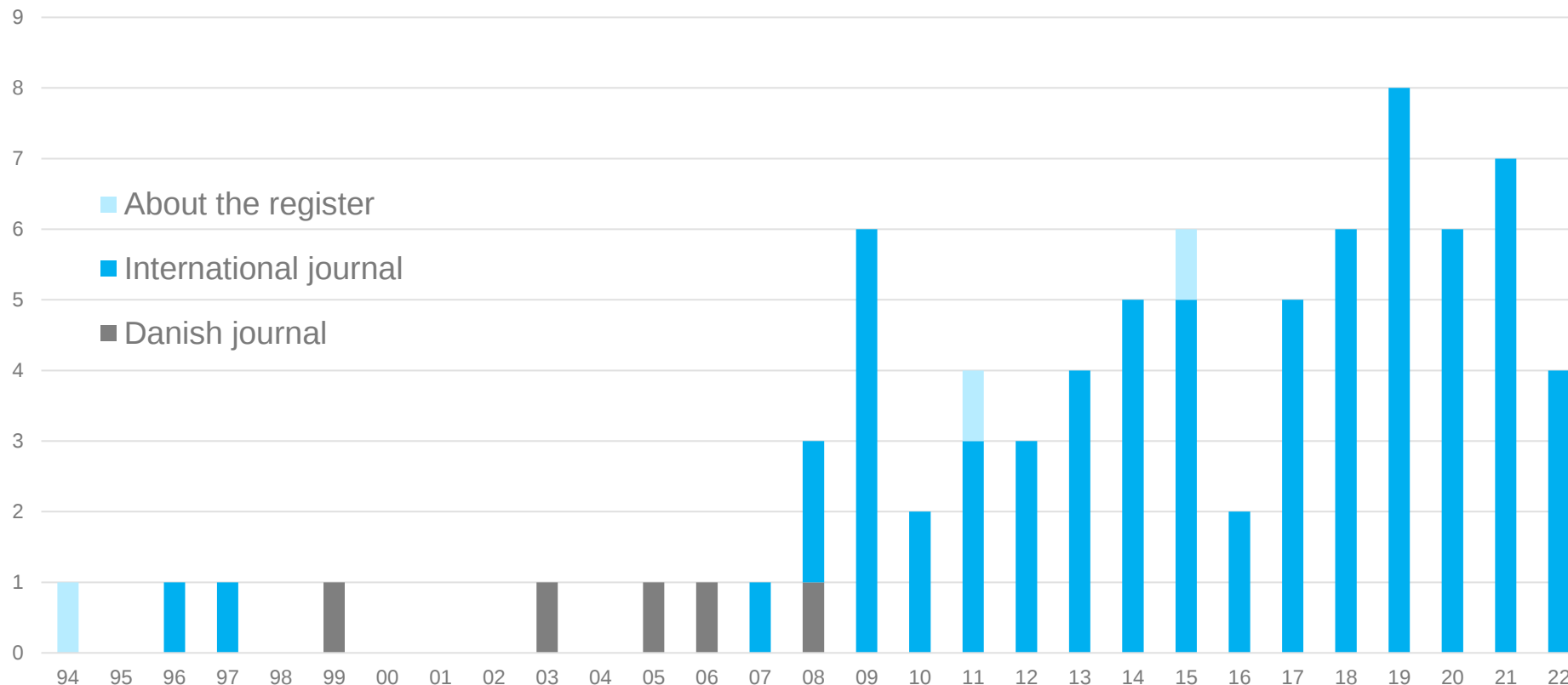
Ansøgningsskema vedr. forskningsdata fra HNPCC-registret	
Ansøgningen udfyldes og sendes elektronisk til HNPCC-registret bilagt korrigeret protokol.	
Projektets titel skal indgå i filnavnet.	
E-mail: hvh-hnpcc-forskning@regionh.dk	
Ansøgningsnummer: (udføres af HNPCC-registret) Klik her for at angive tekst.	
Projekttitel: Klik her for at angive tekst.	
Ansøger:	
Navn:	Klik her for at angive tekst.
Stilling:	Klik her for at angive tekst.
Ansættelsessted:	Klik her for at angive tekst.
Navn, adresse, postnummer og by	
Telefon:	Klik her for at angive tekst.
E-mail:	Klik her for at angive tekst.
Kontaktperson, hvis denne ikke er ansøger: (navn, stilling, ansættelsessted, tlf., e-mail)	
Klik her for at angive tekst.	
Projektdeltagere (navn, afd./institution) - alle skal medtages:	
Klik her for at angive tekst.	
Afdeling/institution som projektet primært udgår fra:	
Klik her for at angive tekst.	
Start- og slutdato for projektet:	
Startdato:	Klik her for at angive tekst.
Slutdato:	Klik her for at angive tekst.

Opdateret 30.7.2018, vers. 2.3.

Direkte kontakt til registrerede individer:	
Planlægges direkte kontakt til registrerede individer i HNPCC-registret?	
Ja: ☐ Nej: ☐	
Hvis ja, beskriv her eller henvis til protokol: Klik her for at angive tekst.	
Oplysninger vedrørende ønskede data:	
1. Tidsperiode for dataudtræk:	Klik her for at angive tekst.
2. Studiepopulation:	Klik her for at angive tekst.
3. Evt. yderligere specificering af population	Klik her for at angive tekst.
4. Variable der ønskes fra HNPCC-registret ¹ (kan også beskrives i protokol)	Klik her for at angive tekst.
5. Ønsket dataformat: CSV (Excel-kompatibelt), XML, SAS, andet)	Klik her for at angive tekst.
Andre oplysninger: Klik her for at angive tekst.	
¹Kun overordnede kategorier/variabelnavne for udtræk skal angives, da præcisering sker efter godkendelse af ansøgning i samarbejde med registret.	
Vil data blive behandlet af andre end de anførte projektdeltagere i indeværende ansøgning?	
Ja: ☐ Nej: ☐	
Hvis ja angiv navn og tilhørende organisation/institution:	



Publications using data from The Danish HNPCC Register



hvh-hnpcc-forskning@regionh.dk

