Copenhagen University Hospital - Amager and Hvidovre, Denmark
The Danish HNPCC Register

REGION

A Danish model for provider mediated contact in families with Lynch syndrome

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The Danish HNPCC Register

Aims

- Propose a model for provider mediated contact
- Present experience with provider mediated contact
- Discuss in plenum – if and how to implement the model

Proposed model for provider mediated contact in families with Lynch syndrome

1. Identify first-degree relatives at risk during genetic counseling
2. Recommend index person to inform the relatives
3. Agree with the index person on a timeframe to convey the information
4. Ask the HNPCC Register to:
   a) mail a follow-up letter directly to the at-risk relatives ≥25 years of age and
   b) register relatives <25 years of age on a reminder list for a future letter

Background for the model

- 30 years of real-life experience in Denmark
- National data
- Attitudes towards unsolicited letters have been studied
- Uptake of genetic testing can be stratified by +/- letter from the HNPCC Register

Attitudes towards letters from the HNPCC Register

Familial Cancer (2019) 18:43–51
https://doi.org/10.1007/s10689-018-0083-5

ORIGINAL ARTICLE

Unsolicited information letters to increase awareness of Lynch syndrome and familial colorectal cancer: reactions and attitudes

Helle Vendel Petersen[1] · Birgitte Lidegaard Frederiksen[1] · Charlotte Kvist Lautrup[2] · Lars Joachim Lindberg[1] · Steen Ladelund[1] · Mef Nilbert[1,3]

Petersen et al. Familial Cancer 2019

Materials

708 receivers of an unsolicited information letter

Results

- 40% preferred to be informed by a close relative
- 66% preferred to be informed by letter rather than by a distant relative
- 3% preferred not to be informed

- 66% wanted their children to be informed by letter (at age 18 years)

Uptake of genetic testing stratified by +/- letter from the HNPCC Register

cancers

MDPI

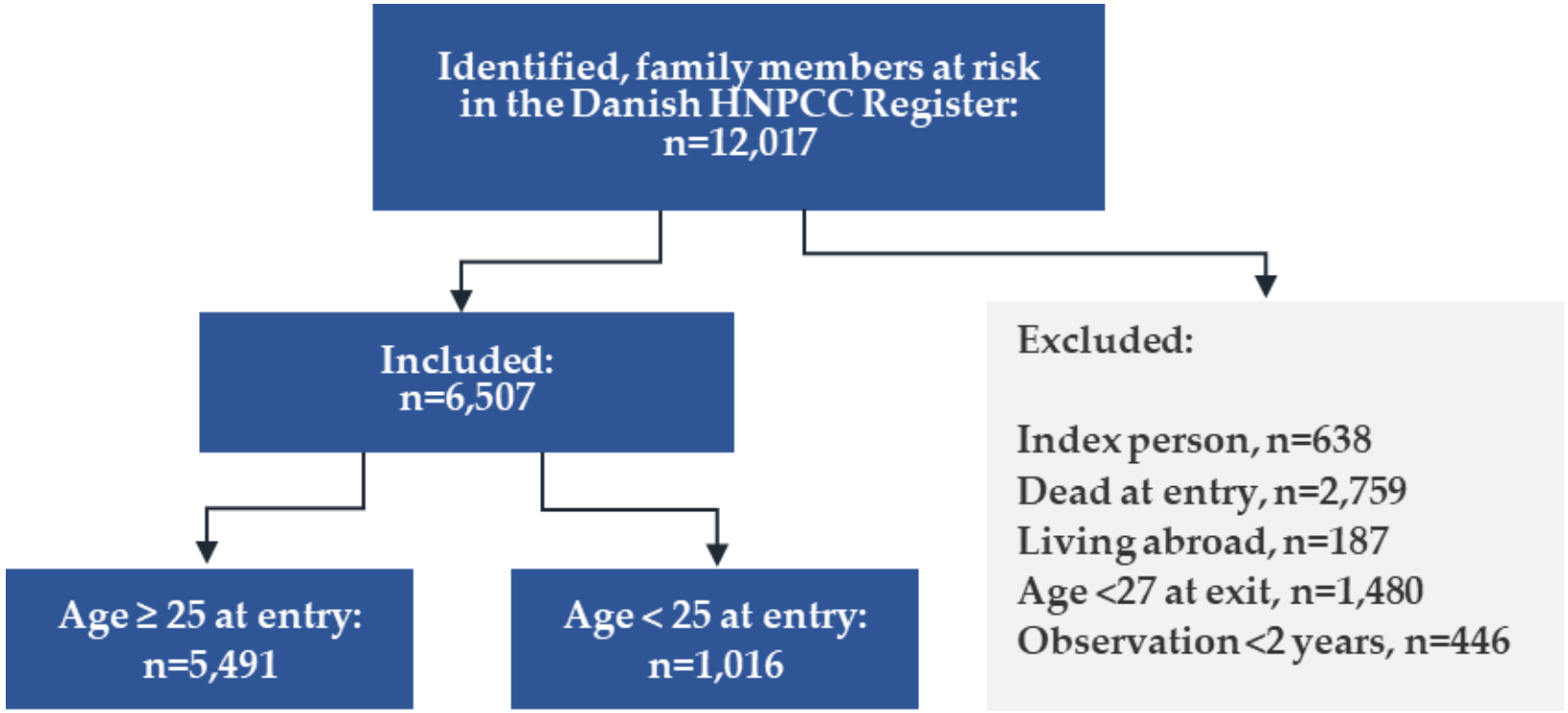
Article

National Experiences from 30 Years of Provider-Mediated Cascade Testing in Lynch Syndrome Families—The Danish Model

Lars Joachim Lindberg [1,2,*], Karin A. W. Wadt [2,3], Christina Therkildsen [1,†] and Helle Vendel Petersen [4,5,†]

Lindberg et al. Cancers 2024

Materials


Identified, family members at risk in the Danish HNPCC Register: n=12,017
Included: n=6,507
Excluded:
Index person, n=638
Dead at entry, n=2,759
Living abroad, n=187
Age <27 at exit, n=1,480
Observation <2 years, n=446
Age ≥ 25 at entry: n=5,491
Age < 25 at entry: n=1,016

Results

Among family members at risk and ≥25 years of age at first diagnosis of Lynch syndrome in the family:

- 1873 (34%) were informed via letter from the HNPCC Register (provider mediated)
- 3618 (66%) were informed otherwise or not informed (family mediated)

Overall result

Uptake of genetic testing was:

54% after family-mediated contact

65% after provider-mediated contact

Odds rate for being tested after a letter from the HNPCC Register was

1.8 (95% CI 1.6–2.1) compared to family mediated contact

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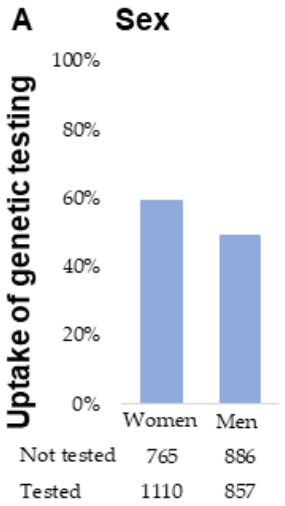

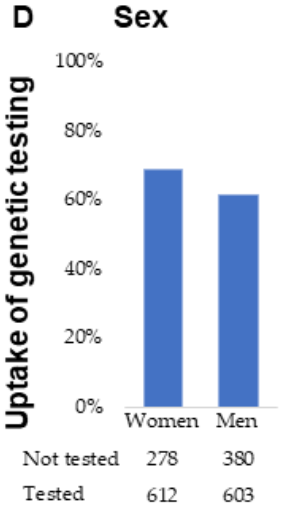

Family-mediated contact Provider-mediated contact

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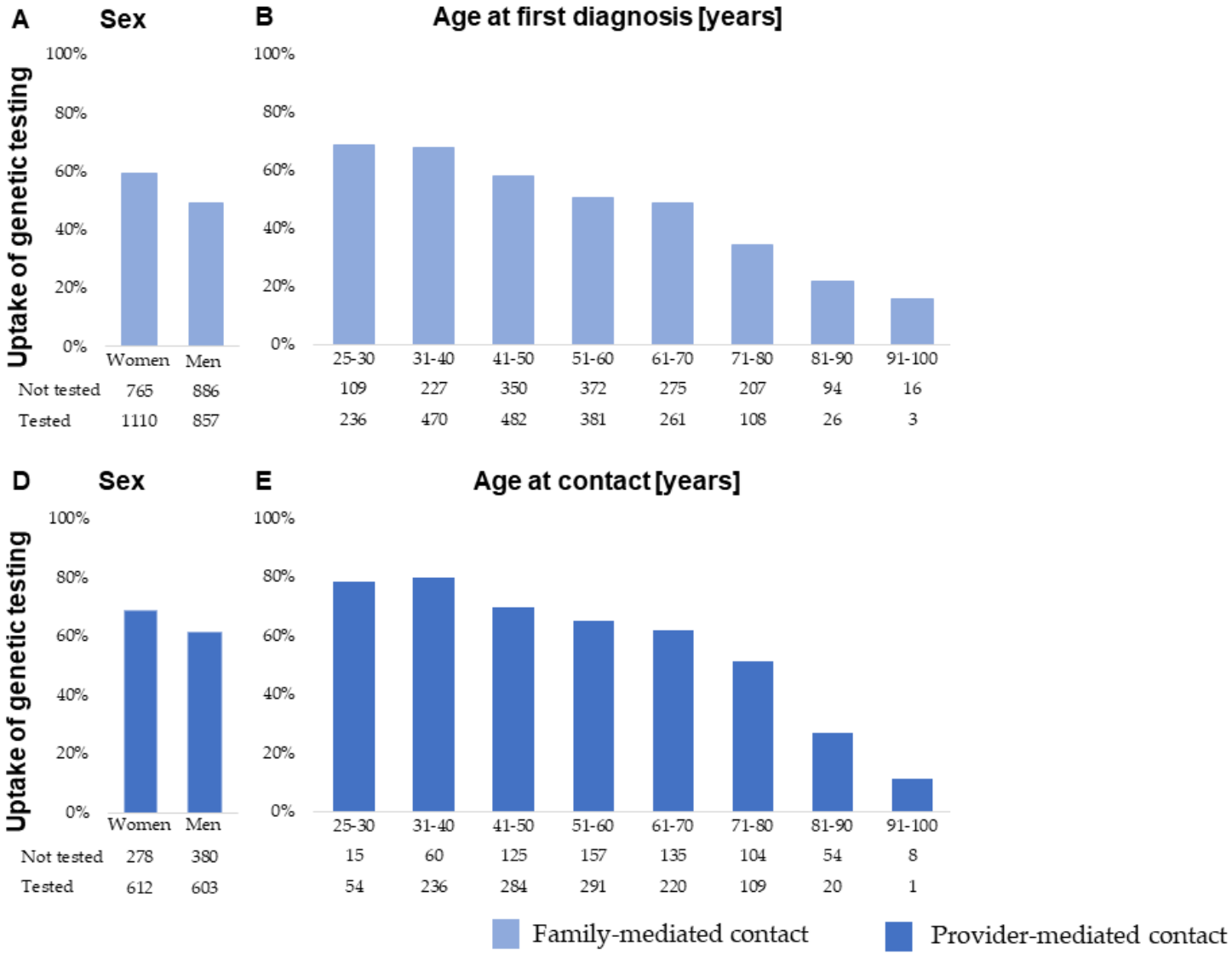

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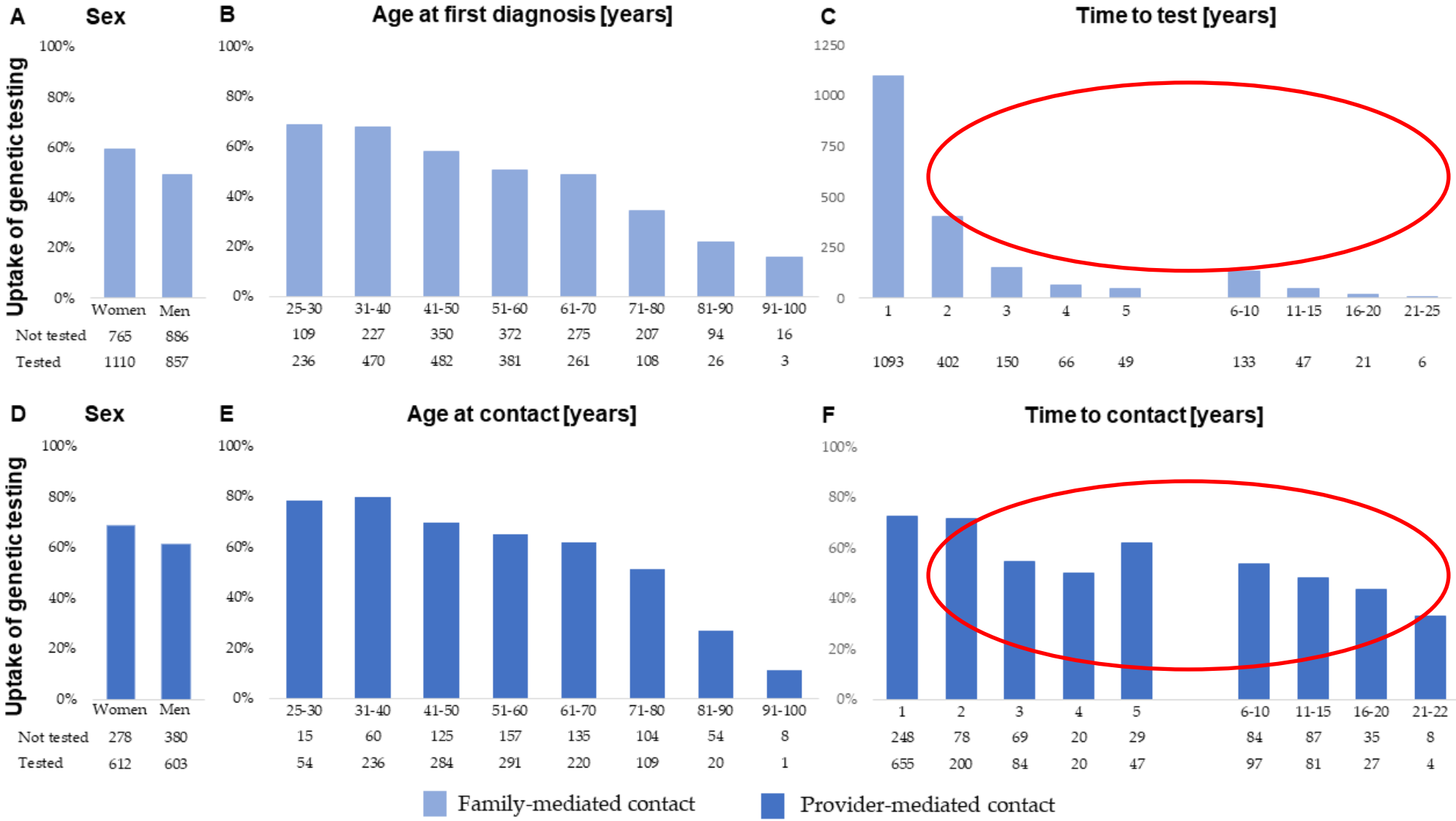

Discussion in plenum

1. Do you want to implement the proposed model for provider-mediated contact?

2. Barriers?

Proposed model for provider mediated contact in families with Lynch syndrome

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Danish legislation

Direct provider-mediated contact is legal after individual judgement by a MD if:

- The condition is serious
- Early diagnosis can prevent the condition or improve the prognosis
- It is possible to test if the individual has the condition

It is not legal to disclose who in the family has the condition