

NCU bestyrelsesmøde 19. februar 2018 kl. 10.30 – 16.00

Mødested: Kræftens Bekæmpelse, Strandboulevarden 49, København

Ordstyrer: Leif Vestergaard Pedersen, adm. direktør, formand

DAGSORDEN

Dagsorden og referat

1. Godkendelse af dagsorden
2. Godkendelse af referat af mødet 17. november 2017

Sager til beslutning

3. Godkendelse af NCU regnskab 2017, herunder statusoversigt vedrørende strategiske projekter
v/ Dofri Pétursson, revisor, Ernst & Young ehf, Island
4. Godkendelse af NCU budget 2018
v/ Michael Henneberg Pedersen, økonomichef, Kræftens Bekæmpelse
5. NCUs forskningssekretariats overflytning fra Kreftforeningen, Norge til Kræftens Bekæmpelse, Danmark
v/ Leif Vestergaard Pedersen, adm. direktør, Kræftens Bekæmpelse

Erfaringsudveksling og drøftelse

6. Kliniske forsøg i Norden (kl. 11.30)
v/ Kjeld Schmiegelow, professor, Institut for Klinisk Medicin, Rigshospitalet
7. Clinical studies in the Nordic countries – Ethical approval
v/ Ole Alexander Opdalshei, Kreftforeningen, Norge
8. Pakkeforløb i de nordiske lande (kl. 13.00)
v/ Jes Søgaard, cheføkonom og Ina Willaing Tapager, specialkonsulent, Kræftens Bekæmpelse
9. NCU forskningskomites opfordring til forøgelse af NCUs forskningspulje
v/ Michael Henneberg Pedersen, økonomichef, Kræftens Bekæmpelse

10. Forslag til projektforslag/ansøgning om ” Cancer omkostninger i de nordiske lande”
v/ Sakari Karjalainen, generalsekretær, Den Finske Kræftforening
og Paulus Torkki, Associate Professor at the Department of Public Health of
University of Helsinki.
11. Orientering fra ECL
v/ Sakari Karjalainen, generalsekretær, Den Finske Kræftforening
12. Orientering om NCD high level møde – mundtligt
v/ Ole Alexander Opdalshei, vicegeneralsekretær, Kreftforeningen
13. UICC World Cancer Congress 2018 – mundtligt
 - UICC activity: Collaborative initiatives for the WCC 2018 Regional Meetings
v/ Sakari Karjalainen
 - Process for nominations of candidates to UICC Board
v/ Elizabeth Hjorth
14. Orientering fra kræftforeningerne – mundtligt
15. Kommende NCU møder

Eventuelt

NCU's bestyrelsesmøde 19. februar 2018

Punkt 2

Godkendelse af referat af NCU møde den 22. november 2017

Sagsfremstilling (Resume)

Referat af NCU møde den 22. november 2017 i Reykjavik er udarbejdet og udsendt til NCU medlemmerne med opfordring til at fremsende kommentarer.

Endeligt referat er fremsendt til NCU medlemmerne den 12. december 2017.

./. Bilag 1: Referat af NCU møde den 22. november 2017

Indstilling (Rekommandation)

Formanden indstiller at referatet godkendes

Reykjavík den 11 december 2017

NCU:s styrelsemöte i Reykjavík den 17 november 2017

Slutligt referat

Mötesordförande: Ragnheiður Haraldsdóttir

Mötesplats: Skógarhlíð 8, 105 Reykjavík.

Mötestid: Kl.: 09:00 - 16:00. Kaffe: 10:00-10:30; Lunch kl.: 12:00-13:00.

Inledning

1. Mötets öppnande.

NCU:s ordförande förklarade mötet öppnad och därefter höll följande personer inledande tal: Leifur Bárðarson, ställföreträdande Medicinaldirektör, Laufey Tryggvadóttir, direktör för Isländska Cancerregistret, och Guðfinna Halla Þorvaldsdóttir, direktör för Isländska Cancer Föreningen.

2. Godkännande av dagordningen.

Dagordningen blev godkänd med några ändringar av ärendenas ordningsföljd.

3. Slutligt godkännande av referatet från senaste möte.

Referatet från mötet i Stavanger den 29 augusti 2017 blev godkänd.

Beslutsfrågor

4. Förslag till NCU 3-års plan i perioden 2018–2020.

Danska delegationen redogjorde för hur man har lagt upp plan för NCU verksamhet under perioden 2018–2020. De övriga länderna instämde i Danmarks synpunkter.

Beslut

Att styrelsen godkänner rammarna för NCU 3-års plan 2018–2020 och ställer sig bakom genomförandet av konkreta aktiviteter omfattande 1–3 tema under 2018–2019.

5. Rapport om evaluering av NCU:s bidrag till forskningen.

Frågan om evaluering av NCU:s forskningsinitiativ har diskuterats under de senaste möten och strax inför mötet i Stavanger den 29 augusti skickade norska Kreftforeningen ut ett frågeschema och frågade om i vilken utsträckning nämnda projektmedel hade haft betydelse för projekternas framgång. Vid mötet i Reykjavík redovisades sedan resultatet av denna undersökning samt översikt över enskilda projekt och litteraturlista. Det rådde enighet om att den föreliggande rapporten utgör bra underlag för fortsatt diskussion om evaluering av NCU:s bidrag till forskningen.

Beslut

Att styrelsen ställer sig enig i att fortsätta diskussionen om denna fråga vid kommande möte i Köpenhamn i februari 2018.

6. Strategiska projekt, betalningar och översikt. UICC/IARC kandidater.

Ordförandeskapet genomgick strategiska projektens betalningar och översikt samt lista över UICC/IARC kandidater till 2017 IARC Sommarskola. Sekretariatet har inte betalt räkningarna förrän man har varit säker på att ha tillräckligt underlag för sitt beslut om utbetalning.

Beslut

Att styrelsen instämmer i ordförandeskapets hantering av saken.

7. Vetenskapskommitténs förslag till fördelning av forskningsanslag för 2018.

Ordföranden för NCU:s Vetenskapliga Kommitté, Þórunn Rafnar, redogjorde för de projektansökningarna som inkommit för programperioden 2018 och det förslag som kommittén hade enats om. Av 42 forskningsprojekt som sökt forskningsbidrag föreslog man att 19 skulle tilldelas medel. Kommittén baserar sin bedömning på vetenskaplig kvalitet, forskarnas kompetens, nordisk synergieffekt, och relevans för NCU:s strategi.

Komiteen besluttede sig for flere donationer i størrelsesordenen 30-40 tusinde Euro for at kunne støtte flere projekter da forskningsmidlerne ikke rækker til fuld finansiering af støtteværdige projekter. Komiteen påpegede at forskningspuljen burde gøres større da den har været uændret gennem mange år.

Beslut

Att styrelsen godkänner Vetenskapskommitténs förslag för året 2018.

Information och diskussion

8. ”Nordic Trial Alliance – an initiative for increased clinical research in the Nordic countries”.

Norge inledde och det framgick att vad gäller kliniska studier då ligger man i flesta av de nordiska länderna lite efter. I länder som Finland och Norge har forskning på området även minskat avsevärt de senare åren. Underlaget för forskningen är på grund av litet invånarantal också begränsad. Sjukhusen har inte heller prioriterat kliniska studier i sin verksamhet. Det kan inte undvikas att identifiera problemen och stödja kraftigt olika initiativ. Men det rådde enighet om att det vore viktigt som första steg framåt att sammanställa en promemoria om kliniska studier och därmed skapa förutsättningar för fortsatt diskussion om saken. Det underströks dessutom att NCU borde hålla kontakt med specialister inom barnonkologi i Norden. Vidare presenterade Ole Alexander en PowerPoint presentation med överskriften ”NORDIC RESEARCH INITIATIVES-CAN NCU TAKE A MORE ACTIVE ROLE”. Det rådde enighet om att länderna borde uppmärksammas på detta arbete.

Konklusion

Att styrelsen arbetar vidare med saken.

9. NCU forskningsinitiativ.

NCU har senaste 1–2 åren träffat representanter från CRUK- Cancer Research UK och NordForsk samt blivit kontaktad av EORTC (European Organisation for Research and Treatment of Cancer). Dessa organisationer har alla uttryckt önskan om samarbete och har dessutom varit i kontakt enskilda medlemmar av NCU. Det verkar dock först och främst vara önskemål om att få NCU att delta i att finansiera projekt och aktiviteter som dessa organisationer står för eller planerar den närmaste tiden.

Konklusion

Att styrelsen är öppen för konkreta förslag, som de vederbörlande organisationerna eventuellt förelägger NCU bestyrelsen i syfte att etablera eventuellt framtida samarbete på området.

10. Cancer kostnader i de nordiska länderna – ett nytt projekt initiativ.

Finska delegationen redogjorde för cancerkostnaderna i de nordiska länderna med anledning av artikel som nyligen publicerats i Acta Oncologica och meningsutbyte som ägt rum den senaste tiden. Det anses viktigt att utreda närmare cancersituationen i hela Norden och särskilt skillnaderna mellan länderna och inom länderna. Av denna anledning bereds nu ett nytt strategiskt projekt initiativ på området och man räknar med att projektförslag kommer att föreligga i början av nästa år. Det borde således kunna behandlas på styrelsens nästa möte i februari.

Konklusion

Att styrelsen ställer sig bakom att arbetet med projektförslaget fortsätter och att den Finska Cancerföreningen utarbetar projektförslag /ansökan som kan föreläggas NCU styrelsen som ett möjligt strategiskt projekt.

11. Rapport om Islands ordförandeskap i NCU i perioden 2015 – 2017.

Ordföranden Ragnheiður Haraldsdóttir redogjorde för sin rapport om Islands ordförandeskap i NCU under perioden 2015–2017.

Konklusion

Att styrelsen tar informationen för kännedom.

12. Nationella rapporter.

I **Danmark** startade i år Knæk Cancer-programmet i TV 2 den 22 oktober med visning av kända och nya programmer. Fokusen är på information om cancer och insamling av pengar till forskning, prevention, behandling och patientstöd. Veckan kulminerade den 28 oktober i den stora insamlingsshow "Knæk Cancer Live". I år har der været offentlig uppmärksamhet på donation på 50 000 DKR från Bandidos, og der har været forskellige synspunkter om, hvorvidt dessa pengar kan mottas. Emnet drøftes i Kræftens bekæmpelses bestyrelse den 23. November 2017. Kræftens Bekæmpelse orienterer NCU om endelig beslutning om donationen fra Bandidos på næste NCU møde.

På **Färöarna** har sjukkassorna samlat in pengar och dessa kan användas för att stödja cancer- och hjärtpatienter. Man sänder allt fler patienter till utlandet. Sjukkassorna hjälper också patienter som letar efter behandling utomlands. De senaste åren har patienter på Färöarna i växande utsträckning sökt sig sjukvård i Island. Ögonen har varit på män med prostatacancer som nu är vanligaste cancerformen för karlar i våra länder.

i **Sverige** samlade man i år in rekordsumman 84 miljoner kronor under Cancerfondens Rosa bandet-kampanj i oktober (81 miljoner förra året). För att uppmärksamma att ingen ska behöva möta cancer ensam har alla i år kunnat engagera sig genom att skänka en tanke på Cancerfondens webbplats. Några utvalda personer som berörs av cancer har burit interaktiva rosa band som glittrat i olika mönster varje gång någon skänkt en tanke. Cancerfondens forskningsnämnd har under november beslutat om rekordutdelning på 454 milj. kronor som går till 502 forskningsprojekt. De största anslagen är på 2,25 miljoner i 3 år.

Kreftforeningen i **Norge** driver nu Global Kampanj mot antibiotikaresistens och riktar sin uppmärksamhet på vilka konsekvenserna blir för cancerpatienterna i framtiden. Folk frågar hur behandlar man cancer om antibiotikan inte verkar längre? Cancerforskningen anses värdefull och bröstcancerföreningen är i centrum, men på sistone har prostataföreningen kommit fram i rampljuset. Under novembermånad har massmedia

lyft fram män och cancer. Norska Kreftforeningen har gått ut med video med budskapet att varje dag förlorar vi tre män i prostatacancer. Vi behöver mer forskning säger alla, och var och en kan hjälpa. Stött Blå Bandens-aktionen!

Finland har bra hälso- och sjukvård som baserar sig på offentliga tjänster som alla boende i landet är berättigade till. Ansvaret för att ordna tjänsterna ligger hos kommuner och samkommuner. Dessa kan producera tjänsterna själva eller tillsammans med en annan kommun. Kommunen kan även köpa tjänsterna av ett privat företag eller en privat organisation. Cancersjukhus kompletterar den offentliga vården i Finland och behandlar även patienter på uppdrag av kommuner och arbetsgivare. Cancervården har omorganisrats de senaste åren och samtidigt har tagits fram ambitiösa utvecklingsplaner. Grupper av prostatacancerpatienter finns utanför den offentliga Finska Cancerföreningen och står för insamling av pengar till deras verksamhet. Antalet reguljära donatorer ökar inom alla cancerområden och forskningen har fått större prioritet.

I **Island** är det inte bara ”turbulence” i politiken utan också inom cancerområdet. Under de senaste tre åren har Isländska Cancerföreningen haft 4 direktörer och 3 presidenter. Förslag till nationell cancerhandlingsplan har tagits fram. Det är dock oklart om och när den kommer att föreläggas Althinget. Isländska Cancerföreningens ekonomi står stark och det ger möjligheter att vidareutveckla verksamheten. Förhandlingar om nytt kontrakt med Hälsodepartementet förväntas inledas snart.

Avslutande frågor

13. Övriga frågor.

Danmark på vägnar av de andra länderna tackade Island för sin insats under de senaste tre åren. Det avgående ordförandeskapet uttryckte sin uppskattnings över ländernas positiva samarbetsanda och sa att danskarnas förberedelser klart tyder på att de kommer att bli väl förberedda att överta ledningen.

14. Kommande möten.

Nästa möte blir i Köpenhamn den 19 februari och därefter träffas styrelsen den 9 maj och den 8 oktober 2018.

DELTAGARLISTA

Danmark

Leif Vestergaard Pedersen
Hans Henrik Storm
Elizabeth Hjorth

Finland

Sakari Karjalainen
Carita Åkerblom
Helena Hilkko

Island

Ragnheiður Haraldsdóttir (ordf.)
Valgerður Sigurðardóttir
Guðfinna Halla Þorvaldsdóttir
Ingimar Einarsson

Norge

Anne Lise Rye
Ole Alexander Opdalshei

Sverige

Susanna Wärn

Färöarna

Durita Tausen

NCU's bestyrelsesmøde 19. februar 2018

Punkt 3

Godkendelse af NCU regnskab 2017, herunder statusoversigt vedrørende strategiske projekter

v/ Dofri Pétursson, revisor, Ernst & Young ehf, Island

Sagsfremstilling (Resume)

Dofri Pétursson vil præsentere NCU regnskab for 2017. Herunder også statusoversigt over de strategiske projekter.

./. Bilag 1: Financial Statements 2017

Bilag 2: Strategic projects overview in May 2017

Indstilling (Rekommandation)

Formanden indstiller, at bestyrelsen godkender NCU regnskabet for 2017.

Nordic Cancer Union

Financial Statements 2017

Nordic Cancer Union
Skógarhlíð 8
105 Reykjavík

Iceland

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Report on Review of Financial Statements

To the Board of Nordic Cancer Union

We have reviewed the accompanying financial statements of Nordic Cancer Union that comprise the endorsement and statement by the board of directors, statement of financial position as at December 31, 2017, the income statement and a summary of significant accounting policies and other explanatory information.

Board's responsibility

The Board is responsible for the preparation and fair presentation of these financial statements in accordance with general accepted accounting practice and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditors' responsibility

Our responsibility is to express a conclusion on the accompanying financial statements. We conducted our review in accordance with International Standard on Review Engagements (ISRE) 2400, Engagements to Review Historical Financial Statements. ISRE 2400 requires us to conclude whether anything has come to our attention that causes us to believe that the financial statements, taken as a whole, are not prepared in all material respects in accordance with the applicable financial reporting framework. This Standard also requires us to comply with relevant ethical requirements.

A review of financial statements in accordance with ISRE 2400 is a limited assurance engagement. The practitioner performs procedures, primarily consisting of making inquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing. Accordingly, we do not express an audit opinion on these financial statements.

Conclusion

Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not give a true and fair view of the financial position of Nordic Cancer Union as at December 31, 2017 and its financial performance for the year then ended, in accordance with the general accepted accounting practice.

Reykjavík, 16 January 2018

Ernst & Young ehf.



Rögnvaldur Dófri Pétursson
State Authorized Public Accountant

Endorsement and Statement by the Board

The Financial Statements for Nordic Cancer Union are prepared in accordance with general accepted accounting practice.

The board consider the accounting policies used to be appropriate, such that the Financial Statements gives a true and fair view of the Income Statement for the year 2017 and the Balance Sheet at 31 December 2017.

We hereby submit the Financial Statement for the year 2017 to the Board of Nordic Cancer Union for approval.

Reykjavík, 16 January 2018


Ragnheiður Haraldsdóttir
Chairman

Income statement 2017

All amounts in EURO

	Notes	Actual 2017	Budget 2017	Actual 2016
Income				
Income from NCU members		918.810	918.810	1.077.863
Interest from bank accounts		0	0	306
Nordic Summer School repaid		3.677	0	2.263
		<u>922.487</u>	<u>918.810</u>	<u>1.080.432</u>
Activity				
Research		750.000	750.000	750.000
Strategic projects	4	<u>131.650</u>	<u>250.000</u>	<u>101.900</u>
		<u>881.650</u>	<u>1.000.000</u>	<u>851.900</u>
		Result before other cost	40.837	(81.190) 228.532
Other cost				
Secretariat function	5	65.000	65.000	65.000
Travel cost	6	7.217	15.000	10.782
Other cost	7	<u>8.395</u>	<u>12.000</u>	<u>5.697</u>
		<u>80.612</u>	<u>92.000</u>	<u>81.479</u>
		Result for the year	<u>(39.775)</u>	<u>(173.190)</u> <u>147.053</u>

Balance Sheet 31 December 2017

All amounts in EURO

Assets

	Notes	2017	2016
Current Assets			
Short-term receivables	8	46.150	301.802
Cash and cash equivalents		198.059	853.580
Total Current Assets		<u>244.209</u>	<u>1.155.382</u>
		Total Assets	<u>244.209</u>
			<u>1.155.382</u>

Equity and Liabilities

Equity

Equity at year beginning	3	226.190	79.137
Result from operation	3	(39.775)	147.053
Total equity		<u>186.415</u>	<u>226.190</u>

Liabilities

Current Liabilities

Research	9	0	750.000
Other current liabilities		<u>57.794</u>	<u>179.192</u>
Total Current Liabilities		<u>57.794</u>	<u>929.192</u>
Total Liabilities		<u>57.794</u>	<u>929.192</u>

Total Equity and Liabilities	<u>244.209</u>	<u>1.155.382</u>
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Notes to the Financial Statements 2017

All amounts in EURO

1. General information

The Nordic Cancer Union is a collaborative body for cancer societies in the Nordic countries. The registered office is now at Skógarhlíð 8, 104 Reykjavík, Iceland.

2. Summary of accounting policies

Basis of preparation and statement of compliance

The Financial Statements are prepared in accordance with general accepted accounting practice. The Financial Statements have been prepared on a going concern basis and under the historical cost convention. The Financial Statements are presented in EURO, except when otherwise indicated.

Use of estimates and judgements

The preparation of the Financial Statements requires management to make judgements, estimates and assumptions that affect the reported amounts of revenues, expenses, assets and liabilities, and the disclosure of contingent liabilities, at the end of the reporting period. Use of available information and application of judgement are inherent in the formation of estimates. Actual results in the future could differ from such estimates and the differences may be material to the Interim Financial Statements.

Foreign currency translation

Foreign currency transactions

Transactions in foreign currencies are initially recorded at the exchange rate ruling at the date of the transaction. Monetary assets and liabilities denominated in foreign currencies are retranslated at the exchange rate ruling at the balance sheet date. Gains and losses resulting from the translation of foreign currency transactions are taken to the income statement.

Accounts receivables

Accounts receivables are initially recognised at the transaction price. They are subsequently measured at amortised cost using the effective interest method, less provision for impairment. A provision for impairment of trade receivables is established when there is objective evidence that the association will not be able to collect all amounts due according to the original terms of the receivables. The directors assessment is that no provision is needed at year end.

Cash and cash equivalents

Cash and cash equivalents includes cash on hand, demand deposits and other short-term highly liquid investments with original maturities of three months or less. Bank overdrafts, if any are shown within borrowings in current liabilities on the balance sheet.

Notes to the Financial Statements 2017

All amounts in EURO

Trade payables and other payables

Trade payables and other payables are recognised initially at the transaction price or fair value. These financial liabilities are normally non-interest bearing. Trade payables are normally settled within 2 months, and other payables within 12 months.

Income

Income from NCU members is contribution from NCU members.

Interest income on bank accounts is recognised when earned.

3. Equity

Changes in equity are specified as follows:

	Retained earnings	Total
Equity at 1/1	226.190	226.190
Profit (loss)	(39.775)	(39.775)
Equity at 31/12	<u>186.415</u>	<u>186.415</u>

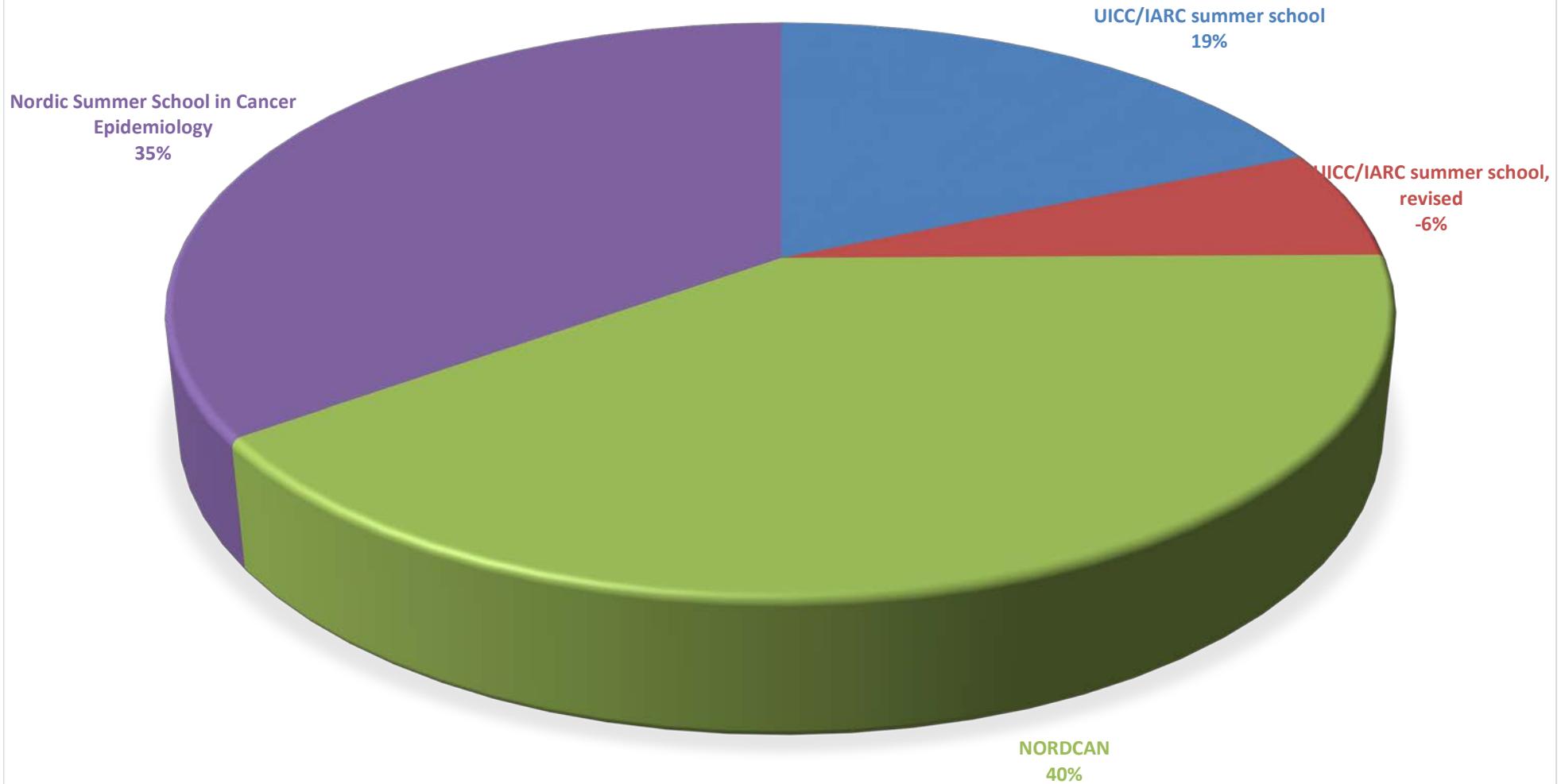
Specifications

<i>All amounts in EURO</i>	<i>Actual 2017</i>	<i>Actual 2016</i>
Income from NCU members		
Members fee	918.810	1.077.863
	<u>918.810</u>	<u>1.077.863</u>
Nordic Summer School repaid		
Nordic Summar School repaid	3.677	2.263
	<u>3.677</u>	<u>2.263</u>
4. Strategic projects		
Secratariet for Nordic Network NECT	50.000	50.000
UICC/IARC summer School	16.400	16.400
UICC/IARC summer School, revised 2015	(16.400)	0
NORDCAN	35.500	35.500
Nordic Summer School in Cancer-Epidemiology	46.150	0
	<u>131.650</u>	<u>101.900</u>
Research		
Grants	750.000	750.000
	<u>750.000</u>	<u>750.000</u>
5. Secretariat function		
Professional service	21.989	22.655
Commission Norge	32.500	32.500
Other office and administration cost	10.511	9.845
	<u>65.000</u>	<u>65.000</u>
6. Travel cost		
Travel cost Iceland	3.821	4.990
Travel cost Faroe Island	3.396	5.792
	<u>7.217</u>	<u>10.782</u>
7. Other cost		
IT-expenses	883	855
Travel expenses	2.947	0
Conference fee and related cost	3.888	4.648
Other office and administration cost	677	194
	<u>8.395</u>	<u>5.697</u>
8. Short-term receivables		
Prepaid financial support	46.150	0
Members fee	0	301.802
	<u>46.150</u>	<u>301.802</u>

Specifications

<i>All amounts in EURO</i>	Actual 2017	Actual 2016
9. Other current liabilities		
Secratariat for Nordic NECT	50.000	98.000
NORDCAN	0	35.500
UICC/IARC summer school	0	16.400
Krabbameinsfélag Íslands	4.088	19.573
Krabbameinsfelagid Faroe Islands	3.396	5.836
IE radgjöf og greining	0	3.883
Ernst & Young ehf.	<u>310</u>	<u>0</u>
	<u><u>57.794</u></u>	<u><u>179.192</u></u>

AREA OF ACTIVITY



Strategic projects overview

Project overview - Agreed by the Board of NCU, in May 2017, All amounts in EURO

Confirmed financial support	Notes	Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019
		2015	2016	2017	2018	2019	
Secretariat for Nordic NECT	1	148.000	48.000	50.000	50.000		
UICC/IARC summer school	2	49.200	16.400	16.400	16.400		
UICC/IARC summer school, revised	2a	-16.400			-16.400		
NORDCAN	3	106.500		35.500	35.500	35.500	
Nordic Summer School in Cancer Epidemiology	4	92.300			46.150	46.150	
Total confirmed support		379.600	64.400	101.900	131.650	81.650	0
Actual payments		Total support	Actual payments 2015	Actual payments 2016	Actual payments 2017	Actual payments 2018	Actual payments 2019
		2015	2016	2017	2018	2019	
Secretariat for Nordic NECT	1	148.000			98.000		
UICC/IARC summer school	2 & 2a	32.800	13.227	14.137	-3.677		
NORDCAN	3	106.500			71.000		
Nordic Summer School in Cancer Epidemiology	4	92.300			92.300		
Total actual payments		379.600	13.227	14.137	257.623	0	0

Notes:

1. Confirmed on a Board Meeting in Helsingør in September 2015
2. Confirmed on a Board Meeting in Reykjavik 22 May 2015
- 2a Revised support for 2016, on a Board Meeting in Stockholm 17 February 2017
3. Confirmed on a Board Meeting in Oslo 19 February 2016
4. Confirmed on a Board Meeting in Copenhagen 25 November 2016

Unpaid confirmed financial support	Notes	Total support	Planned in 2015	Planned in 2016	Planned in 2017	Planned in 2018	Planned in 2019
		2015	2016	2017	2018	2019	
Secretariat for Nordic NECT	1	148.000			50.000		
UICC/IARC summer school	2 & 2a	32.800					
NORDCAN	3	106.500			35.500		
Nordic Summer School in Cancer Epidemiology	4	92.300					
Total confirmed support		379.600	0	0	50.000	35.500	0

NCU's bestyrelsesmøde 19. februar 2018

Punkt 4

Godkendelse af NCU budget 2018

v/ Michael Henneberg Pedersen, økonomichef, Kræftens Bekæmpelse

Sagsfremstilling (Resume)

Michael Henneberg Pedersen vil præsentere NCU budget 2018. Der er udarbejdet to budgetforslag.

Budgetforslag 1

Det ene budgetforslag tager udgangspunkt i NCU budget 2017, hvor der i lighed med 2017 budgetteres med et underskud på 173.190 EUR, hvorved egenkapitalen nedskrives fra 186.415 EUR til 13.225 EUR.

Budgetforslag 2

Det andet budgetforslag baseres på, at indbetalingen fra NCU medlemmerne stiger, således at det forventede resultat for 2018 vil være nul og egenkapitalen blive bibeholdt med niveau som i 2017 på 186.415 EUR.

Dette vil betyde en stigning i medlemmernes samlede kontingent på i alt 173.190,00 EUR.

Nedenstående vises budgetforslag 1 ift. budgetforslag 2, samt udvikling for årene 2016 til 2017:

Land	%	Budgetforslag 1	Stigning	Budgetforslag 2	Budget 2016	Budget
					2017	2017
Danmark	28	257.266,80	48.493,20	305.760,00	301.802	257.267
Færøerne	0,20	1.837,62	346,38	2.184,00	2.157	1.838
Finland	15	137.821,50	25.978,50	163.800,00	161.679	137.822
Norge	27,8	255.429,18	48.146,82	303.576,00	299.645	255.428
Sverige	28	257.266,80	48.493,20	305.760,00	301.802	257.267
Island	1	9.188,10	1.731,90	10.920,00	10.779	9.188
I alt	100	918.810,00	173.190,00	1.092.000,00	1.077,863	918.810

- ./. Bilag 1: Budgetforslag 1 vedr. forventet underskud i lighed med budget 2017 med fordeling
Bilag 2: Budgetforslag 2 uden underskud ved forhøjelse af indtægt fra medlemslandene med fordeling

Indstilling (Rekommandation)

Formanden indstiller, at bestyrelsen godkender et af de præsenterede budgetforslag.

NCU's bestyrelsesmøde 19. februar 2018

Punkt 4 - Bilag 1

Budgetforslag 1

Budgetforslag 1 vedr. forventet underskud i lighed med budget 2017 med fordeling af kontingent

Budget 2018

EUR

	Budget	Actual	Budget
	2018	2017	2017
Income			
Income from NCU members	918.810,00	918.810,00	918.810,00
Interest from bank accounts	0,00	0,00	0,00
Nordic Summer School repaid	0,00	3.677,00	0,00
	918.810,00	922.487,00	918.810,00
Activity			
Research	750.000,00	750.000,00	750.000,00
Strategic projects	250.000,00	131.650,00	250.000,00
	1.000.000,00	881.650,00	1.000.000,00
Result before other cost	-81.190,00	40.837,00	-81.190,00
Other cost			
Secretariat function	65.000,00	65.000,00	65.000,00
Travel cost Faroe Island and Island	15.000,00	7.217,00	15.000,00
Other cost	12.000,00	8.395,00	12.000,00
	92.000,00	80.612,00	92.000,00
Result for the year	-173.190,00	-39.775,00	-173.190,00
	2.018,00	2017	
Equity			
Equity at year beginning	186.415,00	226.190,00	
Result from operation/budget 2018	-173.190,00	-39.775,00	
	13.225,00	186.415,00	

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Fordeling af medlemslandenes kontingent ved budgetforslag 1 2018:

Allocation in %		Payment
Denmark	28	257.266,80
Faroe Islands	0,20	1.837,62
Finland	15	137.821,50
Norway	27,8	255.429,18
Sweden	28	257.266,80
Iceland	1	9.188,10
Income	100	918.810,00

NCU's bestyrelsesmøde 19. februar 2018
Punkt 4 - Bilag 2
Budgetforslag 2

Sagsfremstilling (Resume)

Budgetforslag 2 uden underskud ved forhøjelse af indtægt fra medlemslandene med fordeling

Budget 2018
EUR

	Budget	Actual	Budget
	2018	2017	2017
Income			
Income from NCU members	1.092.000,00	918.810,00	918.810,00
Interest from bank accounts	0,00	0,00	0,00
Nordic Summer School repaid	0,00	3.677,00	0,00
	<u>1.092.000,00</u>	<u>922.487,00</u>	<u>918.810,00</u>
Activity			
Research	750.000,00	750.000,00	750.000,00
Strategic projects	250.000,00	131.650,00	250.000,00
	<u>1.000.000,00</u>	<u>881.650,00</u>	<u>1.000.000,00</u>
Result before other cost	92.000,00	40.837,00	-81.190,00
Other cost			
Secretariat function	65.000,00	65.000,00	65.000,00
Travel cost Faroe Island and Island	15.000,00	7.217,00	15.000,00
Other cost	12.000,00	8.395,00	12.000,00
	<u>92.000,00</u>	<u>80.612,00</u>	<u>92.000,00</u>
Result for the year	<u>0,00</u>	<u>-39.775,00</u>	<u>-173.190,00</u>
	2.018,00	2017	
Equity			
Equity at year beginning	186.415,00	226.190,00	
Result from operation/budget 2018	0,00	-39.775,00	
	<u>186.415,00</u>	<u>186.415,00</u>	

NCU's bestyrelsesmøde 19. februar 2018

Fordeling af medlemslandenes kontingent ved budgetforslag 2 2018:

Allocation	%	EUR
Denmark	28	305.760,00
Faroe Islands	0,20	2.184,00
Finland	15	163.800,00
Norway	27,8	303.576,00
Sweden	28	305.760,00
Iceland	1	10.920,00
Income	100	1.092.000,00

Difference pr. country	EUR
Denmark	48.493,20
Faroe Islands	346,38
Finland	25.978,50
Norway	48.146,82
Sweden	48.493,20
Iceland	1.731,90
Difference	173.190,00

Kontingentet fra medlemslandene er reguleret med 173.190 EUR sammenlignet med 2017 budget og budgetforslag 1 for 2018.

NCU's bestyrelsesmøde 19. februar 2018

Punkt 5

NCUs forskningssekretariats overflytning fra Kreftforeningen, Norge til Kræftens Bekæmpelse, Danmark

v/ Leif Vestergaard Pedersen, adm. direktør, Kræftens Bekæmpelse

Sagsfremstilling (Resume)

Af § 5 i NCUs statutter fremgår:

"The chairmanship of the NCU is responsible for the Union's secretariat function during the mandate period in relation to general matters and the scientific committee. The responsibility for the NCU secretariats function may be transferred to another member country than that of the NCU chairman by a specific agreement, which has to be accepted by the majority member countries. Similarly, the responsibility of the secretariat of advisory committees, including the scientific committee, may by a specific agreement for a period of time be transferred to another member organisation than that of the NCU chairman".

Kreftforeningen, Norge har været ansvarlig for NCUs forskningssekretariat i 12 år. Kreftforeningen ønsker at videreføre NCUs forskningssekretariat til Kræftens Bekæmpelse, som har overtaget formandskabet for NCU for perioden 1. januar 2018 – 31. december 2020.

Kreftforeningen og Kræftens Bekæmpelse har den 24. januar 2018 holdt møde om praktiske forhold og rutiner knyttet til overdragelse af NCU forskningssekretariatet.

Indstilling (Rekommandation)

Formanden indstiller, at NCU bestyrelsen beslutter, at NCUs forskningssekretariat ligeledes overflyttes til Kræftens Bekæmpelse fra 1. januar 2018

NCU's bestyrelsesmøde 19. februar 2018

Punkt 6

Kliniske forsøg i Norden

v/ Kjeld Schmiegelow, professor, Institut for Klinisk Medicin, Rigshospitalet

Sagsfremstilling (Resume)

Medlemmer af NCU bestyrelsen har tidligere rejst spørgsmålet om muligheder for et øget samarbejde i Norden om kliniske forsøg.

Til belysning af spørgsmålet er professor Kjeld Schmiegelow, Institut for Klinisk Medicin, Rigshospitalet, Danmark inviteret til at give en præsentation, hvor han beskriver erfaringer af både positiv og negativ karakter fra mange års deltagelse i fælles nordiske kliniske studier.

I præsentationen vil blandt andet være fokus på hvilke forhold, der er nødvendige forudsætninger for at fælles nordiske kliniske studier

- fungerer – organisatorisk, økonomisk og manpowermæssigt
- munder ud i resultater, der efterfølgende kan implementeres i kræftbehandlingen rundt om i de enkelte lande.

Indstilling (Rekommandation)

Formanden indstiller at præsentationen drøftes.

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Punkt 7

Clinical studies in the Nordic countries – Ethical approval

v/ Ole Alexander Opdalshei, Kreftforeningen, Norge

Sagsfremstilling (Resume)

NCU has on several occasion stressed the importance of Nordic clinical trials. In today's area of personalized medicines it is reason to believe that common clinical studies in the Nordic countries will be even more important in the years to come.

NCU can – and do – play different roles when it comes to increase the number of studies and patients in the Nordic countries that are recruited to clinical trials. We do finance clinical studies both through our regular founding mechanism and through strategic commitment (e.g. Nordic Nect). And we can also work on the political level advocating for clinical studies through pointing at barriers and solutions.

From our experiences and relationships with clinicians and researchers we understand that the process of ethical approval is a well known barrier for implementation of clinical studies in the Nordic countries. To carry out a clinical study in the Nordic countries today you need clinical approval from each of the participant countries. And the process of obtaining an ethical approval is different in each of the countries (both regarding application scheme and sought documentation). The result is that obtaining an ethical approval is both time- and resource demanding.

To reduce this problem we suggest that NCU – on behalf of each cancer society in the Nordic countries – issue a statement where we ask for a system for mutual recognition of ethical approval in the Nordic countries. Stating that if a clinical study receives a clinical approval in one of the Nordic countries this should be accepted in the other countries. The Nordic countries share very similar moral values, cultures and health care and legal systems, which means that they have an excellent opportunity for mutual recognition of ethical approval.

This will be in accordance with the recommendations in the report written by Bo Könberg on "The Future of Nordic Co-Operation on Health". In this report, it is stated: "...The countries must remove practical, legal and ethical obstacles to common use of date for research..." and "...A model for mutual recognition of ethical reviews of Nordic research projects will be introduced..." .

So far – to our knowledge – there has not been done any work to introduce such a model. There is our hope – and belief – that a common statement from the Secretary Generals in the Nordic cancer leagues can be a push towards implementing such a model.

A draft for such a statement is attached.

If the General Secretaries of the Nordic cancer societies support this initiative, we will follow up the decision towards The Nordic Council, Ministries of Health in each country, and media.

./. Bilag 1: Call for mutual recognition of ethical approval in the Nordic countries

Indstilling (Rekommandation)

Kreftforeningen, Norge recommends, that

- the subject is discussed
- decision is taken regarding possible support to the initaitive
- Kreftforeningen is asked to follow up the decision within guidelines decided by the NCU Board

Call for mutual recognition of ethical approval in the Nordic countries

The Nordic Countries as an arena for clinical research

It is well established that the potential for further collaboration regarding clinical trials in the Nordic countries has a huge potential. Each of the Nordic countries has on a global scale a small population, but the total number of inhabitants in the Nordic countries are 26 million people. This together with the facts that we have a strong public health care systems, good quality registers, and high quality researchers makes the Nordic countries an excellent arena for clinical research.

From a patient perspective, access to clinical trials is important for several reasons. It gives better care for cancer patients today, and better treatment for tomorrow's patient.

Mutual recognition of ethical approval

Our experience based on contact and feedback from clinicians and researchers shows us that today's system where there is a need to obtain ethical approval in each country is time- and resource demanding. Therefore a barrier for clinical trials. The Nordic countries share very similar moral values, cultures and health care and legal systems. This gives us a unique opportunity.

On this background, the Secretary Generals in the cancer leagues calls for mutual recognition of ethical approval in the Nordic countries. If a clinical study receives a clinical approval in one of the Nordic countries this should be accepted in the other Nordic countries.

This call is in line with the conclusion in the report written by Bo Könberg on "The Future of Nordic Co-Operation on Health".

On behalf of the General Secretaries in the following organizations

<name of cancer society is supporting the call>

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Punkt 8

Pakkeforløb i de nordiske lande

v/ Jes Søgaard, cheføkonom og Ina Willaing Tapager, specialkonsulent, Kræftens Bekæmpelse

Sagsfremstilling (Resume)

Til fremme af og koordinering af nordisk forskning om kræftpakker i de nordiske lande søges NCU om,

- At forskning om "kræftpakker" forstået som standardiserede pakkeforløb for kræft vedr. dækningsgrad og funktionalitet, tidlig diagnosticering, lighed i behandling, patientoplevet kvalitet, effekt på prognose samt organisering og kvalitetsforbedring bliver anerkendt som NCU strategisk projekt
- 500.000 DKK over to år til forskningsinitiering via et netværkssamarbejde

Baggrund

I Danmark introduceredes standardiserede pakkeforløb for kræft (kræftpakker) for ti år siden, i Norge og Sverige for 3-4 år siden, og i Finland og Island planlægges introduktion af lignende kræftpakker (Finland i 2020). Kræftpakker er standardiserede vårdprogrammer og vårdforløb for diagnostik og behandling af kræftsygdomme. Pakkeforløbene skal sikre ensartet høj kvalitet og sammenhæng i udredning og behandling uden unødig ventetid til gavn for patienternes prognose og livskvalitet.

Kræftpakkerne har i Danmark – og til tider i Norge og Sverige – været genstand for både forskning og evaluering, men samlet set har den kliniske og epidemiologiske forskningsinteresse været ret begrænset i Norden. Forskningen i kræftudredning i pakkeforløb i Danmark og Storbritannien har haft stor værdi for den løbende optimering af sundhedsvæsenets kræftindsats, men den øvrige kliniske, epidemiologiske og organisatoriske forskning har været begrænset.

Et nordisk samarbejde om forskning i kræftpakkeforløb kan stimulere til mere forskning og viden om, hvordan pakkeforløbene udfolder sig regionalt og nationalt i de nordiske lande, hvilke tilsigtede – og måske utilsigtede – virkninger, pakkeforløbene har samt muligheder for faglige, organisatoriske og teknologiske forbedringer. Vi kan lære af hinanden, og vi kan inspirere hinanden.

Den særlige mulighed for nordisk samarbejde og komparative studier og erfarringsopsamling på tværs af landegrænser giver vigtig basis for gensidig inspiration og deling af idéer og læring, der kan bruges til at fremme arbejdet med at sikre bedste praksis i forløbet fra misstanke om kræft til behandling, efterbehandling og tilbagevenden til livet.

Regionale Cancercentrum i Samverkan under Sveriges Kommuner och Landsting i Sverige har taget initiativ til opstartsmøder i Danmark, Norge og Sverige om forskning i kræftpakkeforløb. Der har været- afholdt møder i hhv. Stockholm, Oslo og København med et støt stigende

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antal deltagere. Til sidste møde i København i november 2017 deltog 65 forskere (forstået i bredeste forstand) (deltageroversigt vedlagt). Møderne viser stor interesse og potentiale for samarbejde på tværs af landegrænser. På sidste møde blev det besluttet at invitere forskere fra Finland og Island til at deltage i samarbejdet fremover.

På mødet i København i november 2017 mundede drøftelserne blandt andet ud i følgende bruttoliste til komparative studier:

- Inklusion og gennemførsel af pakkeforløb:
 - Hvor mange kommer i pakkeforløb, hvor mange har kræft, hvor mange diagnostieres ad anden rute?
 - Hvordan er forløbstidsfordelingen for forskellige kræftformer?
 - Hvordan er variationen indenfor og mellem landene?
- Forskning om tidlige symptomer på kræft
- Lighed i behandling:
 - Er pakkeforløb med til at skabe mere lighed i behandling?
 - Sker der forskydninger på tværs af patienttyper (crowding-out effekter)?
- Patientoplevet kvalitet:
 - Undersøge og sammenligne patienterfaringer og evalueringer
 - Samordne/koordinere planlagte patientsurveys (PREMs)
 - Patienternes perspektiv på pakkeforløb/standardiserede vs. individualiserede vårdforløb
 - Supplere med kvalitative studier
- Effekt på prognose:
 - Kan man se en sammenhæng mellem variation i på den ene side inklusion i pakkeforløb og forløbstid og på den anden side observeret stадie ved diagnose og overlevelse?
- Organisering og kvalitetsforbedring af kræftpakkeforløb
 - Patientinvolvering
 - Sundhedsøkonomi (equity, costs og cost-effectiveness)
 - Flow efficiency

Metodemæssigt har der været drøftelser om at bygge på de gode erfaringer i NordCan til at danne en nordisk pakkeforløbskohorte ("data spine"), der kunne ligge til grund for analyserne.

Forslag til fælles nordisk netværkssamarbejde om forskning i kræftpakkeforløb

Blandt deltagerne i møderne er der bred opbakning til at etablere et fællesnordisk strategisk netværkssamarbejde om erfearingsopsamling, evaluering og flerfaglig forskning i kræftpakkeforløb. Netværket skal stimulere pakkeforløbsforskning i de nordiske lande, sikre vidensdeling og -spredning af resultater og skabe fora, hvor forskerne fra de nordiske lande kan mødes og etablere samarbejde, og hvor forskere fra andre lande naturligvis også er velkomne. Netværket har en særlig opgave i at sikre, at forskning i landene organiseres som egentlige komparative eller multi-country studier, hvor det giver mening og komparative fordele.

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Et nordisk samarbejde og komparative studier og erfarringsopsamling på tværs af landegrænser om pakkeforløb giver muligheder for gensidig inspiration og deling af idéer og læring, der kan bruges til at fremme arbejdet med at sikre bedste praksis i forløbet fra mistanke om kræft til behandling, efterbehandling og tilbagevenden til livet.

Organisering

Fra deltagergruppen har følgende seks personer fået i opdrag at skabe et formaliseret netværkssamarbejde for forskning i de nordiske lande om kræftpakker:

- Helena Brandsström, PhD, Samordnare nationella vårdprogram & standardiserade vårdförflopp Regionala cancercentrum i samverkan, Sveriges kommuner och landsting
- Henry Jensen, Ph.d., cand. scient. san., Post doc, Kræftens Bekæmpelses Center for Forskning i Cancerdiagnostik i Praksis (CaP), Aarhus Universitet
- Line Melby, PhD, seniorforsker SINTEF, førsteamannensis NTNU
- Jes Søgaard, cheføkonom, Kræftens Bekæmpelse, professor Syddansk Universitet,
- Ina Tapager, cand.polit., specialkonsulent, Kræftens Bekæmpelse
- Kjell Magne Tveit, MD, PhD, professor Universitetet i Oslo og Strategidirektør Helsedirektoratet, Norge

Netværket foreslås koordineret af en gruppe med mindst to repræsentanter fra hver af de fem nordiske lande, en til forskermøder og forskningskoordinering og en "landereditør" til netværkets hjemmeside.

Der er i første omgang ikke planlagt etablering af et formelt netværkssekretariat. Sekretariatsfunktionen vil gå på runde mellem landene og med den funktion følger også et netværksformandskab. Dog vil der være én bevillingsansvarlig for den to årige forsøgsperiode.

Hjemmeside

Netværket vil etablere en fællesnordisk hjemmeside med information om deltagere (tilknyttede forskere), forskellige aktiviteter som møder, kurser og konferencer i de enkelte nordiske lande, fællesnordiske og internationale, planlagte, igangværende og på sigt afsluttede forskningsprojekter, oplysninger om forskningsfinansiering m.v. Hjemmesiden skal have et fast land som base.

Forskermøder

Netværket vil desuden arrangere et tværgående nordisk forskermøde og bistå med specifikke og ad hoc møder tilknyttet forskellige aspekter af pakkeforløbsforskning. Netværket vil hjælpe forskere med at finde hinanden på tværs af landene, institutioner og

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forskningsområder for at fremme flerfagligt og tværnordisk samarbejde om forskning i kræftpakkeforløb.

Samarbejdsrelationer

Netværket vil samarbejde med ANCR, NCU, nationale kræftforeninger og andre relevante netværk og grupper inden for kræftforskning.

Budget

Til at drive netværket søger vi NCU om et strategisk tilskud ("seed money") på 500.000 DKK til opstart og etablering af netværket og drift i en to årig periode, heraf

- DKK 280.000 til opstartsstøtte til forskningsprojekter, dvs. protokoludarbejdelse og ansøgninger
- DKK 85.000 til hjemmeside
- DKK 135.000 til forskningsmøder

Tentativt budget ses nedenfor. For den to årige periode vil Jes Søgaard være bevillingsansvarlig.

Tentativt budget: "Pakkeforløb i de nordiske lande - opstart af forskningsnetværk" (beløb i DKK)

	År 1	År 2	Total
Opstartsstøtte - forskningsprojekter			
Protokoludarbejdelse, ansøgninger	150.000	130.000	280.000
Hjemmeside			
Layout osv.	25.000	-	25.000
Hosting gebyr	10.000	10.000	20.000
Vedligeholdelse/opdatering	10.000	10.000	20.000
Diverse	10.000	10.000	20.000
<i>Hjemmeside - total</i>	<i>55.000</i>	<i>30.000</i>	<i>85.000</i>
Forskningsmøder			
Samlet fællesnordisk forskningsmøde		60.000	60.000
Mindre samarbejds-/forskningsmøder	25.000	-	25.000
Symposier o.lign.	25.000	25.000	50.000
<i>Forskningsmøder - total</i>	<i>50.000</i>	<i>85.000</i>	<i>135.000</i>
Total	255.000	245.000	500.000

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Statusrapportering og evaluering

Netværksgruppen vil ved den bevillingsansvarlige udarbejde et-årige statusrapporter til NCU. Til den anden statusrapport vil der indgå en evaluering om, hvordan netværkssamarbejdet har fungeret. Succeskriterier er

1. Opstart af kræftpakkeforskning i de nordiske lande og herunder i særlig grad
 - a. Komparative projekter eller multi-lande projekter
 - b. Gensidig orientering og læring samt erfaringsspredning mellem landene
2. En fungerende og informativ hjemmeside for netværket
3. Et samlet fællesnordisk forskningsmøde med bred tilslutning

./. Bilag 1: Deltagerliste til Forskningsmötet SVF 14-15 november 2017

Indstilling (Rekommandation)

Formanden indstiller, at bestyrelsen drøfter forslaget, herunder

- om projektet kan blive et NCU strategisk projekt
- om projektet kan opnå støtte fra NCUs strategiske midler

Namn	Arbetsplats	Land	Epost
Anders Birr	Enhetschef och läkare Diagnostiskt Centrum Helsingborg	Sverige	anders.birr@skane.se
Andreas Hellström	Chalmers tekniska högskola	Sverige	andhel@chalmers.se
Andreas Stensvold	Sykehuset Østfold	Norge	Andreas.Stensvold@so-hf.no
Anita Das	SINTEF/NTNU	Norge	anita.das@sintef.no
Anita Sandmo Lyngøy	Diagnostisk senter, Stavanger universitetssykehus	Norge	aily@sus.no
Anne Sidenius	Syddansk Universitet, Forskningsenheden for Almen Praksis	Danmark	asidenius@health.sdu.dk
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Øyvind Antonsen	Akershus universitetssykehus	NORGE	oant@ahus.no

NCU's bestyrelsesmøde 19. februar 2018

Punkt 9

NCU forskningskomites opfordring til forøgelse af NCUs forskningspulje v/ Michael Henneberg Pedersen, økonomichef, Kræftens Bekæmpelse

Sagsfremstilling (Resume)

Af referatet fra bestyrelsesmødet i Reykjavik den 17. november 2017 fremgår af punkt 5 "Rapport om evaluering af NCUs bidrag til forskningen", at der var enighed om, at den foreliggende rapport udgør et godt grundlag for fortsat diskussion om evaluering af NCU's bidrag til forskningen.

Det blev således besluttet, at bestyrelsen er enige om at fortsætte diskussionen om dette spørgsmål ved det kommende møde i København i februar 2018, herunder forskningskomiteens opfordring til forøgelse af NCUs forskningspulje.

NCU formandskabet foreslår, at en model kunne være følgende:

"NCU medlemmer, der individuelt ønsker at yde bidrag til NCUs forskningspulje udover den årlige faste pulje på 750.000 euro, kan gøre dette ved at oplyse NCU formandskabet om beløbets størrelse for det pågældende kalenderår, således at NCU forskningskomite kan informeres om, at der vil være et ekstra beløb på "X euro" til uddeling, såfremt der er ansøgninger, der kvalitetsmæssigt lever op til at modtage støtte."

Indstilling (Rekommandation)

Formanden indstiller, at bestyrelsen drøfter spørgsmålet om forøgelse af forskningspuljen, herunder det beskrevne forslag til model herfor.

NCU's bestyrelsesmøde 19. februar 2018

Punkt 10

Forslag til projektforslag/ansøgning om ”Cancer omkostninger i de nordiske lande”

v/ Sakari Karjalainen, generalsekretær, Den Finske Kræftforening
og Paulus Torkki, Associate Professor at the Department of Public Health of University of Helsinki.

Sagsfremstilling (Resume)

Total cost of cancer is expected to raise mainly due to increasing number of new cancer cases and introduction of new expensive treatments. According a recent study made in Finland the real cost of cancer increased one percent per year between 2009 - 2014. This was less than had been expected. Furthermore, the real cost per new cancer case decreased slightly. It seems that, at least in Finland, the health care system was able to buffer the effects of drivers which increase or tend to increase costs. As discussed at the NCU Board Meeting on November 17, 2017 in Reykjavik, it would be most useful to find out what is the situation in other Nordic countries and whether there are differences in distribution of costs to direct and indirect costs and, especially, between different categories of direct costs. Also, alongside costs, it would be interesting to follow the development of those outcome measures that are currently available (e.g. mortality, survival and in some countries also patient-reported outcome measures).

Dr Paulus Torkki (FI) and Dr Riikka-Leena Leskelä (FI) from the Nordic Healthcare Group have now prepared the attached proposal of a Nordic benchmark study on total cost of cancer. The proposal is based on discussions the researchers have had with the representatives of the Danish, Icelandic, Norwegian and Swedish Cancer Societies. The proposal is for discussion and feedback at this meeting. The aim is to present it for strategic funding at the next Board Meeting in May 2018.

./. Bilag 1: Cancer cost and outcomes - a proposal for a Nordic benchmark study

Indstilling (Rekommandation)

The Board is supposed to discuss the proposal and give feedback. The Nordic research group is requested to present an amended proposal at the next Meeting of the Board in May 2018.

Cancer cost and outcomes

Results from Finland and proposal for Nordic cooperation

Updated proposal based on preliminary discussions with consortium
members

19.1.2018

Methodology in Finnish research

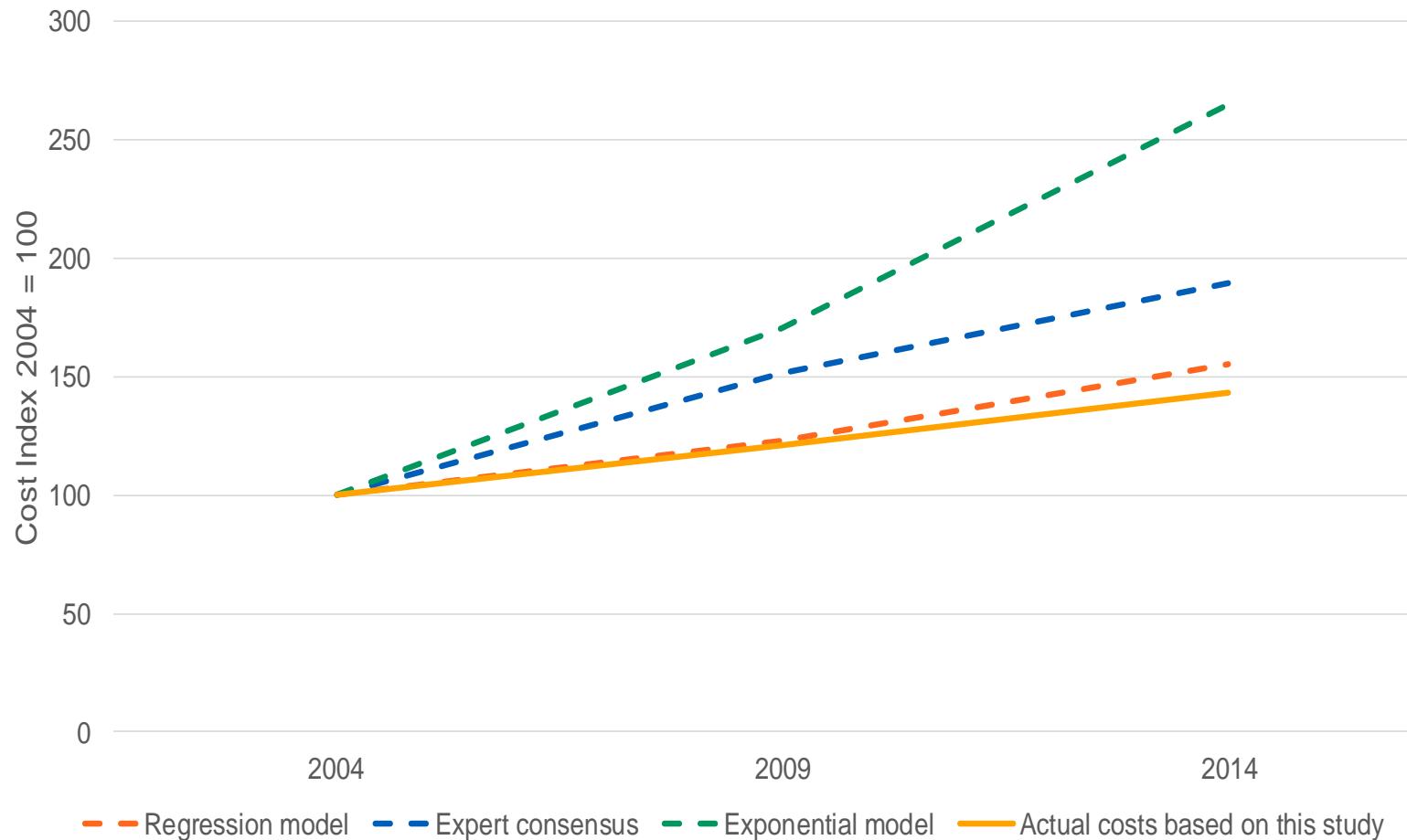
- Statistical data obtained from Finnish Institute for Health and Welfare (THL)
 - Care episodes and inpatient days
 - Outpatient visits
 - Unit costs
 - Includes primary care and secondary care data
- National Social Insurance Institution (KELA):
 - Outpatient medication
 - Rehabilitation
 - Disability pensions
 - Sick leave reimbursements
- Finnish Cancer Registry:
 - Screening data
 - Data on new diagnoses
- Data between 2009 and 2014
 - 2004 results were obtained from Mäklin and Rissanen (2006) report
- Data organized by ICD-10 groups (C00-D48)

Total costs including indirect costs

Data available per cancer site

Cost increase is below estimates in Finland

Source: Torkki et al. 2017, Acta Oncologica



Real costs

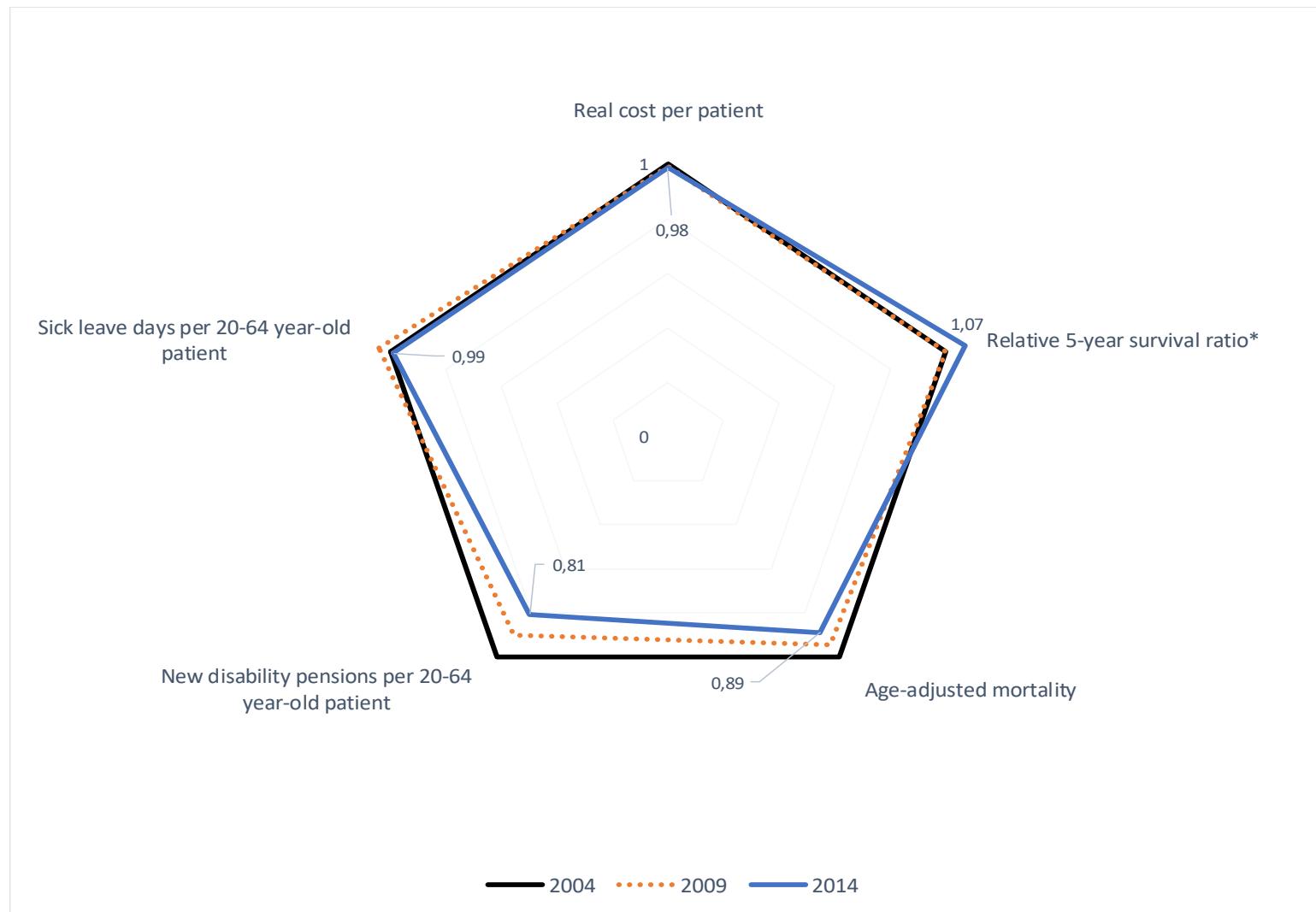


Real cost per new cancer patient



Outcomes have improved

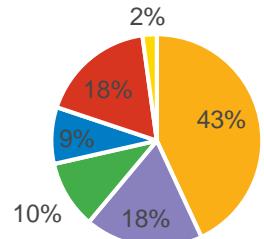
Source: Torkki et al. 2017, Acta Oncologica



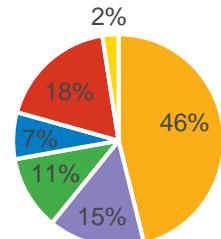
Data enables cancer site specific analysis

Source: Torkki et al. 2017, sent for review

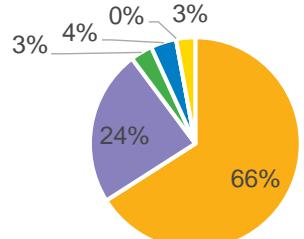
Breast Cancer 2009



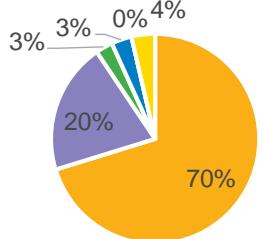
Breast Cancer 2014



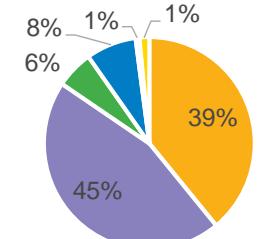
Prostate Cancer 2009



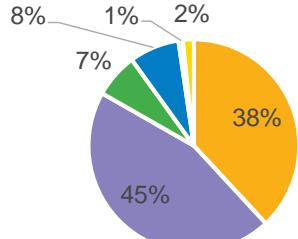
Prostate Cancer 2014



Colorectal Cancer 2009



Colorectal Cancer 2014



Outpatient

Inpatient

Sick leaves

Disability pensions

Screening

Travel costs



Updated proposal of benchmarking study in Nordic Countries

Research motivation and research questions

- The objective of the study is to provide insight into cancer cost and drivers which affect the costs in the Nordic countries
- The results can be used in communication with politicians, authorities, healthcare professionals, patient associations and the general public. The objective is to also produce a scientific article to be published in an international journal.

Research questions:

- What are the trends in cancer costs different cost drivers in the Nordic countries? Are the trends similar? What are the differences?
- What are the trends in register-based outcome measures (mortality, survival)?
- To understand the possible explanations for differences in costs or changes in costs the major cost drivers will be analyzed in more detail:
 - Are the treatment processes (outputs) similar? Are there differences in the number or length of inpatient episodes? What is the roles of primary and secondary care in cancer treatment?
 - How have medication costs developed? Are there differences in the adoption of new medication between the countries?
 - What are the effects of cancer for lost productivity in the form of sick leaves and disability pensions? What are the trends in lost productivity in different countries?

Other interesting issues to consider – even though data may not be available from each country

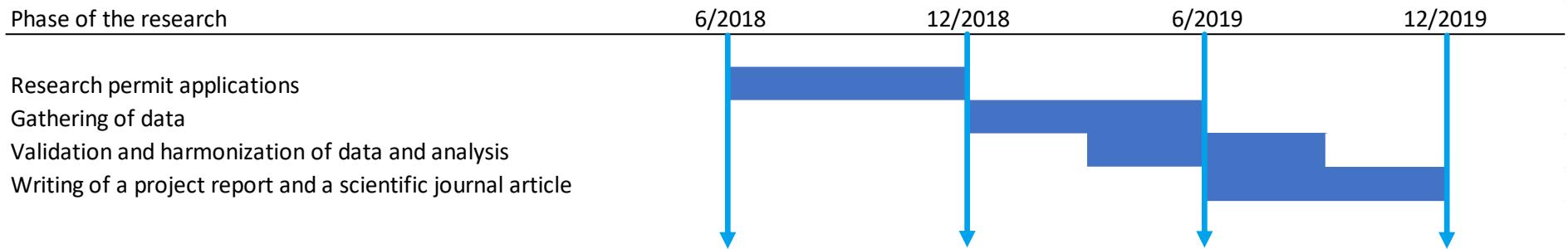
- Role and amount of informal care given by family members
- Patient relevant outcomes (patient-reported outcome measures and patient-reported experience measures) for cancer patients

Project partners and roles

- Consortium: Kræftens Bekæmpelse (Denmark), Kreftforeningen (Norway), Cancerfonden (Sweden), Krabbameinsfélagið (Iceland), Syöpäyhdistys (Finland)
 - Responsible for research permit processes
 - Collection of data from national sources
 - Support coordinator in the processing, harmonization and validation of data
 - Description of cancer care system
 - Interpretation of results, commenting on the project report and journal manuscript
 - Dissemination of results locally
- Coordinator: Nordic Healthcare Group Ltd. (NHG)
 - Adjusts the methodology together with the professionals in Nordic countries depending e.g. availability of data in different countries
 - Provides the research plan and data specifications needed for research permits
 - Provides specifications for the data collection of data by local researchers from local data sources
 - Helps in situations when some data are not available in specified format
 - Validates the data and define possible more detailed data collections depending on the preliminary analysis
 - Combines the data and conducts analysis between countries and by cancer site
 - Writes the project report and the manuscript for a scientific journal

Time table and cost

- Projected time table of the project: 1,5 years
 - Time table may change depending on the research permit process and the data collection



- Estimated costs for the project: 150 000 € - 200 000 €
 - Rough estimate is 30 000 € per country (15 000 € NHG/analysis and reporting + 15 000 € national collaborator/data collection)
 - After preliminary discussions some countries may need more resources for data collection
 - Cost estimate will be revised once the research proposal has been written
 - Main cost is element labor (salaries and related costs).
 - Other costs:
 - data costs (in case registries charge for processing research permits and making data queries)
 - travel costs (e.g. joint meetings of the consortium)

Next Steps

- Country-specific discussions between the coordinator (NHG) and national collaborators have been organized and all parties are interested in continuing the planning of the project:
 - Denmark: Jes Søgaard, Ina Tapager
 - Iceland: Halla Þorvaldsdóttir, Tinna Laufey Asgeirsdóttir,
 - Sweden: Ulrica Sundholm
 - Norway: Ole Alexander Opdalshei, Stine Bergliot Olsen
 - Finland: Sakari Karjalainen
- NHG drafts a research proposal in February for the members of the consortium to comment and edit
- Presentation of research proposal to the NCU board in May 2018

Preliminary data specifications

Final specifications will be decided on jointly

Data category	Data type	Service data	Cost data
Cancer care	Inpatient episodes in secondary /tertiary care	Number of episodes, number of inpatient days, number of patients	Unit cost (either average cost per episode or cost per inpatient day including cost of hospital medication)
	Outpatient visits in secondary / tertiary care	Number of visits, number of patients	Unit cost (average cost per visit including cost of hospital medication)
	Inpatient episodes in primary care / other	Number of episodes, number of inpatient days, number of patients	Unit cost (either average cost per episode or cost per inpatient day)
	Outpatient visits in primary care / other	Number of visits, number of patients	Unit cost (average cost per visit)
	Outpatient medication (medication patients take outside the hospital)		Cost of outpatient medication per diagnosis Cost of outpatient medication of top 20 ATC codes* (per code)
	Rehabilitation (If not included in the episodes and visits above)	Number of patients	Total cost per diagnosis
Screening	Palliative care (If not included in the episodes and visits above)	Number of visits and inpatient episodes (or days) and home care episodes	Unit cost (average cost per visit, average cost per inpatient or home care episode or inpatient day)
		Number of diagnostic tests, number of patients	Unit cost per test
Indirect costs	Disability pensions	Number of patients on disability pension, number of new disability pensions	Disability pension payments
	Sick leaves	Number of sick leave days, number of patients with sick leave	Average cost per sick leave day or sick leave reimbursements paid

- Data will be gathered from 2012 – 2017 (or 2012 – 2016 if 2017 not available)
- Aggregated data only, aggregation level: ICD-10 diagnosis code with 3 signifying digits (C00-D48)
 - Each year reported separately

*ATC (Anatomical Therapeutic Chemical) code specifies the active ingredient of the drug

Other data

Outcome and other data

Data type	Data description
Survival	Relative 5- year relative survival ratio (to be obtained from NORDCAN)
Mortality	Age-adjusted cancer mortality per 100 000 person-years (to be obtained from NORDCAN)
Number of new cancer patients	Number of new cancer patients (to be obtained from NORDCAN)
Number of new working age (20 – 64-year old) cancer patients	Number of new working age (20 – 64-year old) cancer patients
Hospital medication costs	Hospital medication costs per diagnosis Hospital medication costs of top 20 ATC codes (per code)

Optional data

Data type	Data description
Travel costs	Cost of traveling to the hospital for treatment
Cost of informal care	Value of care given by family members or others
Patient-reported outcome measures / Quality of life measures	Measures used systematically and on a national level per cancer site Possible collection of measure scores will be discussed later

Qualitative description of the cancer care system

- For the interpretation of the results it is important to understand the cancer care (and health care) system in each country
- Therefore, all participants are asked to provide a short description of the healthcare system, for example:
 - How is primary care organized? How is secondary/tertiary care organized? (Who produces, how are they financed?)
 - How is cancer care organized? What is the role of primary care? What is the role of secondary/tertiary care?
 - How is palliative and end of life care organized?
 - Which cancers have a screening program?
 - Cancer medication: Who decides what new medication is introduced and how?

NCU's bestyrelsesmøde 19. februar 2018

Punkt 11

Orientering fra ECL

v/ Sakari Karjalainen, generalsekretær, Den Finske Kræftforening

Sagsfremstilling (Resume)

The Association of European Cancer Leagues (ECL) is a non-profit, pan-European umbrella organization of national and regional cancer societies. Located in Brussels, ECL provides a platform for members to collaborate with their international peers, primarily in the areas of cancer prevention, tobacco control, access to medicines and patient support, and creates opportunities to advocate for these issues at the EU level. ECL has 26 member organizations from 23 countries (incl. Cancer Society of Finland, Danish Cancer Society, Faroese Cancer Society and Icelandic Cancer Society).

ECL's VISION is "A Europe free of cancers" and ECL's MISSION is "To advocate for improved cancer control and care in Europe through facilitating collaboration between cancer leagues, and influencing EU and pan-European policies."

In this year, the annual meetings of ECL will take place on November 13 – 16 in Berlin.

Sakari Karjalainen is currently President and Elizabeth Hjorth Board Member of the ECL.

The three attachments demonstrate the nature and some activities of the ECL. Later, Sakari Karjalainen will present other activities of the ECL (namely, Patient Support Working Group and Task Force on Access to Medicines).

./. Bilag 1: About ECL Membership

Bilag 2: ECL About MAC

Bilag 3: ECL Promotion of ECAC

Indstilling (Rekommandation)

For information.

The Association of European Cancer Leagues (ECL) is a non-profit, pan-European umbrella organisation of national and regional cancer societies. Located in Brussels, ECL provides an exclusive platform for members to collaborate with their international peers, primarily in the areas of cancer prevention, tobacco control, access to medicines and patient support, and creates opportunities to advocate for these issues at the EU level.

ECL's VISION: A Europe free of cancers

ECL's MISSION: To advocate for improved cancer control and care in Europe through facilitating collaboration between cancer leagues, and influencing EU and pan-European policies.

CANCER PREVENTION

The cancer burden is projected to increase by 25% by 2030. It has been estimated that almost half of all deaths due to cancer in Europe could be avoided if everyone followed the 12 recommendations of the European Code against Cancer (ECAC).

ECL offers a unique platform for cancer leagues in Europe to exchange best practices, and benchmark cancer prevention strategies implementing the ECAC, by convening technical workshops, and organising study exchange visits for cancer leagues to learn first-hand from their peers.



ACCESS TO MEDICINES

Established in 2016, the ECL Access to Medicines Task Force aims to make cancer medicines available for all cancer patients in Europe by insisting on accessibility, sustainability of healthcare systems and transparency of drug prices.



The Task Force strongly believes in the power of dialogue. We urge all stakeholders to push for improved innovative treatments, advancing both overall survival and the quality of life of cancer patients. Currently, 25 national/regional cancer leagues, representing over 450 million Europeans, have signed the Task Force's Declaration of Intent.

TOBACCO CONTROL

Tobacco is the single most important risk factor for cancer, responsible for over 30% of cancer burden in Europe.



ECL joins efforts with other European and international partners to advocate for e.g. proper implementation of the Framework Convention on Tobacco Control (FCTC), the Tobacco Products Directive, plain packaging, tax policies, tobacco free investment and the fight against illicit trade.

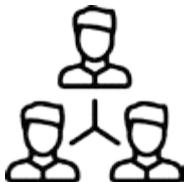
PATIENT SUPPORT

Since 2007 the ECL Patient Support Working Group (PSWG) connects cancer care experts who work together on topics such as access to insurance and financial services, return to work, caregiver support, cancer rehabilitation and palliative care. PSWG members share best practices, develop guidelines and other information sources to raise awareness and improve quality of care, and seek to empower the patient voice in national and European policy-making.



BECOME A MEMBER

GROW YOUR NETWORK



- Join the only platform dedicated exclusively to national and regional cancer societies in Europe, which currently connects 26 members in 23 countries
- Participate in ECL's Working Groups
- Connect with peers in cancer leagues to collaborate on the implementation of the European Code against Cancer
- Support the ECL Access to Medicines Task Force and become a key voice on equal access for cancer patients in Europe
- Contribute to improvement of the quality of life of cancer patients and survivors within the Patient Support Working Group
- Engage with ECL partners such as European CanCer Organisation (ECCO), European Society for Medical Oncology (ESMO), World Health Organization (WHO), International Agency for Research on Cancer (IARC), European Cancer Patient Coalition (ECPC), European Public Health Alliance (EPHA) and others

MAKE YOUR VOICE HEARD

- Contribute to cancer control advocacy in the EU
- Meet with Members of the European Parliament (MEPs), in particular via the MEPs Against Cancer (MAC) interest group, for which ECL provides Secretariat
- Be involved in EU projects dedicated to coordinated intergovernmental action on cancer (e.g. Horizon 2020, EU Joint Actions)
- Contribute to multi-stakeholder platforms coordinated by the European Commission where ECL is a member
- Receive updates on initiatives and meetings at the EU and pan-European level and contribute to policies through stakeholder meetings and consultations



BOOST YOUR IMPACT



- Receive financial support to participate in the following:
- Grants worth €2,000 for lower-income leagues to attend the annual International Fundraising Congress with a priority given to new participants
- Full reimbursement for attendance to selected EU project meetings, such as the workshops related to the European Code Against Cancer
- 50% subsidy for lower-income leagues to attend the ECL Patient Support Working Group and the ECL Access to Medicines Task Force meetings
- Discounts or waivers of fees for international meetings negotiated by the ECL Secretariat & priority access to grants offered by ECL partners (ECCO, ESMO, etc.)
- Have the opportunity to host international meetings, such as the ECL Annual General Assembly, working groups' meetings, and the triennial European Conference on Tobacco or Health (ECToH)

MEMBERSHIP FEES

ECL is funded through an Operating Grant via the EU Health Programme (2014-2020) for 2018-2021 and through membership fees. Membership fees are calculated at 0.1% of the league's income, with a minimum of €1,500 and a maximum capped at €14,500. ECL also receives an unrestricted grant from Garnier.

Apply today by contacting the ECL Secretariat!

ECL@europeancancerleagues.org



Co-funded by
the Health Programme
of the European Union



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www.europeancancerleagues.org



MEPs Against Cancer

MAC Seminar
30 January 2018
EP Members' Salon



Sakari Karjalainen, ECL President

Supported by

Anna Prokupkova
Policy and Project Officer
Association of European Cancer Leagues (ECL)



Co-funded by
the Health Programme
of the European Union

ECL has received funding under an operating grant (number: 785273)
from the Third EU Health Programme (2014-2020).



WHAT IS THE MAC GROUP?

- A forum for MEPs from all political groups which enables them to discuss all aspects of European cancer policy and encourages them to take action in cancer control
- A platform to gather input and exchange views with MEPs, other EU and national officials, experts, researchers, and other relevant stakeholders
- Secretarial support is provided by the ECL



Slide 2

EA1 EuropeanCancerLeagues Advocacy; 5.9.2017

 European Parliament

36 MAC Members



1. Alojz Peterle (EPP, Slovenia) MAC President 	2. Nessa Childers (S&D, Ireland) MAC Vice President 	9. Matt Carthy (GUE/NGL, Ireland) 	10. Deirdre Clune (EPP, Ireland) 
3. Pavel Poc (S&D, Czech Republic) MAC Vice President 	4. Charles Tannock (ECR, United Kingdom) MAC Vice President 	11. Therese Comodini Cachia (EPP, Malta) 	12. Miriam Dalli (S&D, Malta) 
5. Ivo Belet (EPP, Belgium) 	6. Lynn Boylan (GUE/NGL, Ireland) 	13. Jose Inacio Faria (ALDE, Portugal) 	14. Lorenzo Fontana (Non Attached, Italy) 
7. Biljana Borzan (S&D, Croatia) 	8. Cristian Bușoi (EPP, Romania) 	15. Ildis Joanna Geringer de Oedenberg (S&D, Poland) 	16. Nathalie Griesbeck (ALDE, France) 
17. Theresa Griffin (S&D, UK) 	18. Françoise Grossetête (EPP, France) 	25. Miroslav Mikolášik (EPP, Slovakia) 	26. Piernicola Pedicini (EFDD, Italy) 
19. Marian Harkin (ALDE, Ireland) 	20. Brian Hayes (EPP, Ireland) 	27. Sirpa Pietikäinen (EPP, Finland) 	28. Michèle Riviére (Group of the Greens/European Free Alliance, France) 
21. Anneli Jäätteenmäki (ALDE, Finland) 	22. Karin Kadenbach (S&D, Austria) 	29. Christel Schaldemose (S&D, Denmark) 	30. María Lluïsa Rodríguez (GUE/NGL, Spain) 
23. Sean Kelly (EPP, Ireland) 	24. Andrey Kovatchev (EPP, Bulgaria) 	31. Jutta Steinruck (S&D, Germany) 	32. Dubravka Šuica (EPP, Croatia) 
33. Lieve Wierinck (ALDE, Belgium) 	34. Jana Žitnánská (ECR, SK) 	35. Lívia Járóka (EPP, Hungary) 	

17. Theresa Griffin (S&D, UK) 	18. Françoise Grossetête (EPP, France) 	25. Miroslav Mikolášik (EPP, Slovakia) 	26. Piernicola Pedicini (EFDD, Italy) 	33. Tibor Szanyi (S&D, Hungary) 
19. Marian Harkin (ALDE, Ireland) 	20. Brian Hayes (EPP, Ireland) 	27. Sirpa Pietikäinen (EPP, Finland) 	28. Michèle Riviére (Group of the Greens/European Free Alliance, France) 	34. Lieve Wierinck (ALDE, Belgium) 
21. Anneli Jäätteenmäki (ALDE, Finland) 	22. Karin Kadenbach (S&D, Austria) 	29. Christel Schaldemose (S&D, Denmark) 	30. María Lluïsa Rodríguez (GUE/NGL, Spain) 	35. Jana Žitnánská (ECR, SK) 
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2017 Roundtables

- November: Alcohol & Cancer (MEP Borzan)
- November: Disparities in Lung Cancer Treatment (MEP Peterle)
- September: Occupational cancer – Firefighters (MEP Poc)
- June: Sunbed Use: all cost, no benefit (MEP Childers & Tannock)
- February: Alternative Diagnostic Methods (MEP Peterle)



2018 Roundtables



CONFIRMED

- 30 January:** Improving outcomes, driving efficiency in cancer care (MEP Wierinck)
- 27 February:** Cost-effective innovation model for treatment of cancer patients (MEP Peterle, Wierinck)
- 6 March:** Quality of Cancer Care (MEP Clune)
- 16 May:** European Cancer Nursing Day (MEP Harkin)

OTHER PROSPECTED TOPICS

- Tobacco Free Investments
- Obesity & Cancer
- Paediatric Cancers

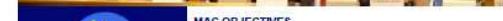


Strategic Goals 2014-2019

MAC aims to:

- **Reduce cancer incidence** by promoting prevention
- **Reduce mortality** by ensuring equitable access to high quality treatment and care
- **Ensure a good quality of life** for cancer patients and survivors.

MAC works together with the European Commission and the Council, and collaborates with relevant organisations to reduce cancer incidence by 15% by the year 2020.



STRATEGIC GOALS 2014-2019

- TO REDUCE CANCER INCIDENCE BY:
 I. PROMOTING PREVENTION
 II. REDUCING MORTALITY BY ENSURING EQUITABLE ACCESS TO HIGH QUALITY TREATMENT AND CARE
 III. ENSURING A GOOD QUALITY OF LIFE FOR CANCER PATIENTS AND SURVIVORS

LATEST MAC MEETINGS

- Sunbeds: all cost, no benefits
 Cancer screening in the EU
 New diagnostic methods
 Lung cancer disparities
 Paediatric Medicines Regulation
 European Code Against Cancer
 Glyphosate & Cancer

MAC OBJECTIVES

The MEPs Against Cancer (MAC) work together in order to improve cancer control and prevention in Europe. In the belief that European cooperation adds value to member state actions. In order to address the challenges faced by the EU, MAC collaborate with the European Commission, the Council and other relevant organisations to reduce cancer incidence by 15% by 2020.

ABOUT MAC MEMBERS

The MAC group was founded in 2009 and remains the only dedicated group to cancer control in the European Parliament. It includes approximately 30 MEPs from all political groups and different EU Member States. The President Mr. Alojz Peterle (SPP, Slovenia), Vice-Presidents Ms. Nessa Childers (S&D, Ireland), Mr. Pavel Poc (S&D, Czech Republic), and Dr. Charles Tannock (ECR, United Kingdom), and other members are committed to taking action in the fight against cancer.

"I think it is crucial for this term to provide more added value in the fight against cancer at the EU level, as well as better co-operation with stakeholders in the Member States. What is of the utmost importance is a concrete preventive policy in order to diminish the inflow of new cancer patients, which has been also the wish of the cancer patients in the EU." Alojz Peterle, MAC President

ECL The MEPs Against Cancer group receives secretarial support from the Association of European Cancer Leagues (ECL), a Brussels-based non-profit organisation who represents national cancer leagues/societies across Europe.

If you would like to become a member of MAC and make a difference in cancer control or receive more information about our initiatives, please visit www.mepagainstcancer.eu or contact us at MAC@europcancileagues.org.

Follow MAC
 @MAC_MEPs
 MEPs Against Cancer



WEBSITE & SOCIAL MEDIA

New website

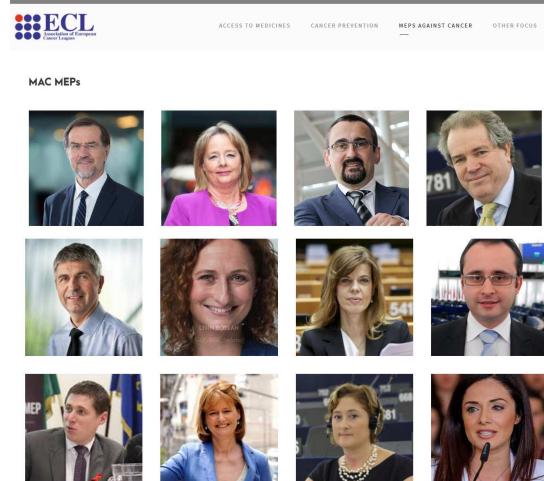
<http://staging.europeancancerleagues.org/meps-against-cancer-mac-meps/>

Twitter 

[@MAC_MEPs](#)

Facebook 

[@MEPsAgainstCancer](#)



THANK YOU!

MAC Seminar

30 January 2018
EP Members' Salon



FOLLOW MEPs Against Cancer

 [@MAC_MEPs](#)

 [@MEPsAgainstCancer](#)

 www.mepsagainstcancer.eu



Co-funded by
the Health Programme
of the European Union

ECL has received funding under an operating grant (number: 747456)
from the Third EU Health Programme (2014-2020)

Primary Cancer Prevention in Europe

The role of European Cancer Leagues



Dr Sakari Karjalainen

ECL President & Secretary General of the Finnish Cancer Society
LPCC conference dedicated to the European Code against Cancer

Coimbra, Portugal

10 November 2017

ECL has received funding under an operating grant (number: 747456) from the Third EU Health Programme (2014-2020).



Co-funded by
the Health Programme
of the European Union

Contents of presentation

- About the European Cancer Leagues
- Cancer Prevention & the European Code against Cancer
- Role of ECL in disseminating the European Code against Cancer
- Examples from national cancer leagues
- Conclusions



Declaration of interest

- ECL has received an Operating Grant from the European Commission under the Third EU Health Programme 2014-2020:

- FPA 2014 (664682)
- SGA 2015 (671365)
- SGA 2016 (709864)
- SGA 2017 (747456)



Co-funded by
the Health Programme
of the European Union

- ECL is also supported by an L'Oréal Garnier through an unrestricted annual educational grant.

3



26 ECL Members in 23 Countries

- ECL's vision is for a Europe Free of Cancers
- Main actions:



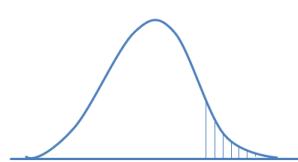
Cancer Prevention



NIH definition: “**action taken to decrease the chance of getting a disease or condition.**” Two main approaches:

High-risk strategies

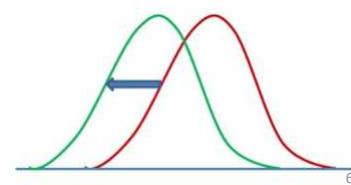
Targeted at certain individuals at most risk

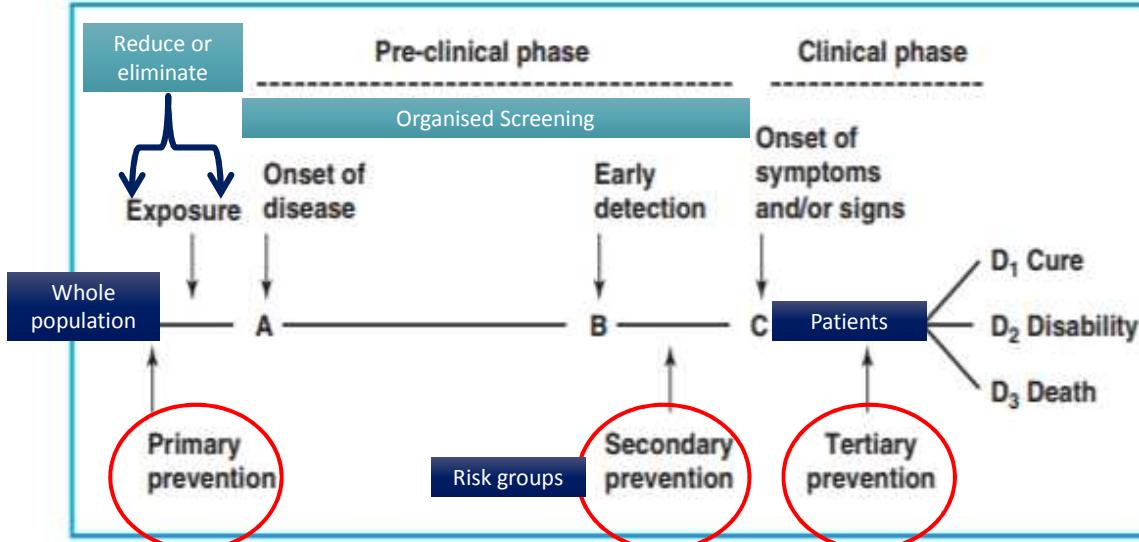


Geoffrey Rose
Sick individuals and sick populations,
International Journal of Epidemiology
(2001)

Population strategies

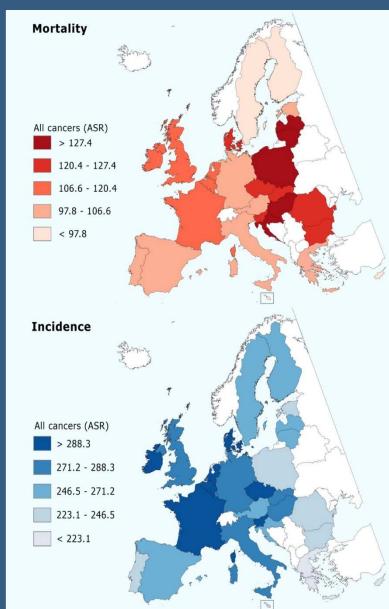
Shift distribution of risk in entire population





Social and Environmental Determinants of Health

7



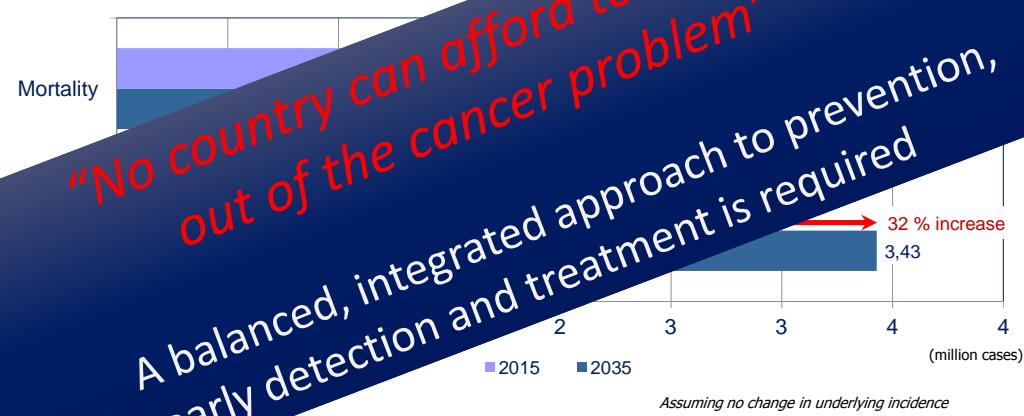
Cancer Burden in the EU

- **2.7 million** people were diagnosed with cancer in the EU28 in 2012
- **About 1 in 4 deaths attributable to cancer.** Second most common cause of death (after cardiovascular disease)
- At least **1/3** (and up to **1/2**) of cancer burden is preventable. Mortality can be further reduced by early detection
- **25% expected increase in EU until 2030** (to 3.3 million new cases each year)

8

Cancer burden in the EU

Forecasted increase in next 20 years

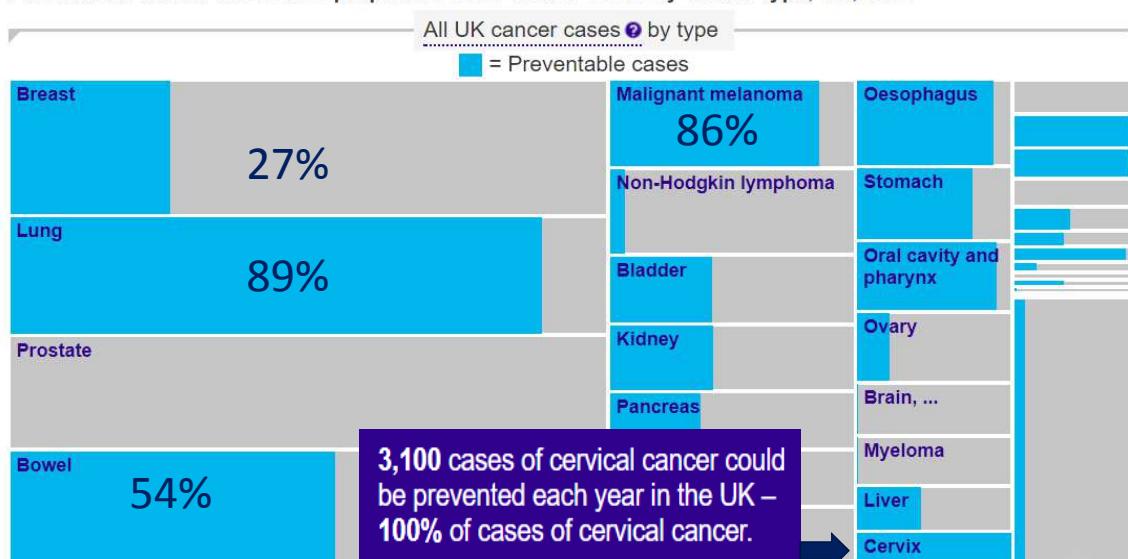


International Agency for Research on Cancer
World Health Organization

Reproduced from Dr C P Wild (IARC) presentation given at ECL annual conference 2017, Copenhagen

GLOBOCAN 2012
ESTIMATED CANCER INCIDENCE, MORTALITY AND PREVALENCE WORLDWIDE IN 2012

Preventable cancer cases as a proportion of all cancer cases by cancer type, UK, 2011



Cancer Research UK : <http://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/preventable-cancers>



~50% of all cancers are preventable: modifiable risk factors

Cause	% cancer	Possible reduction	Evidence example
Smoking	33	75%	Comparison of lung cancer mortality
Overweight/Obesity	20	50%	Bariatric surgery and sustained changes in weight and markers
Diet	5	50%	Folate and colorectal cancer
Physical inactivity	5	85%	Adolescent physical activity
Occupation	5	50%	Asbestos workplace regulation
Virus	5-7	100%	Liver cancer reduction by vaccine
Alcohol	3	50%	Regulation

International Agency for Research on Cancer



Adapted from **Colditz et al.** Applying what we know to accelerate cancer prevention.

Sci Transl Med. 2012 Mar 28;4(127);

Reproduced from presentation by C ESPINA, IARC, July 2017

What is the European Code Against Cancer?



- Inform the public about **actions they can take**, for themselves or their families, **to reduce their risk of cancer**.
- **12 messages** most people can follow without any special skills or advice.
- **The more messages people follow, the lower their risk of cancer will be.**

ECAC update (4th edition)

- Prepared in 2012-13 by cancer specialists & experts in Europe.
- Update of scientific evidence - revisit existing recommendations and potentially adding new ones
- Present each message in a manner that promotes effective public communication
- Focus on general population: EU citizen**

What can I do to reduce my risk of cancer?



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Level I: Code

General public

12 evidence-based recommendations on primary and secondary prevention of cancer


ECL
Association of European
Cancer Leagues

Level II: “Questions and Answers” (Q&A)

General public

Additional information on the recommendations or on cancer prevention topics not covered by the recommendations



Level III: Scientific Justification

Scientists

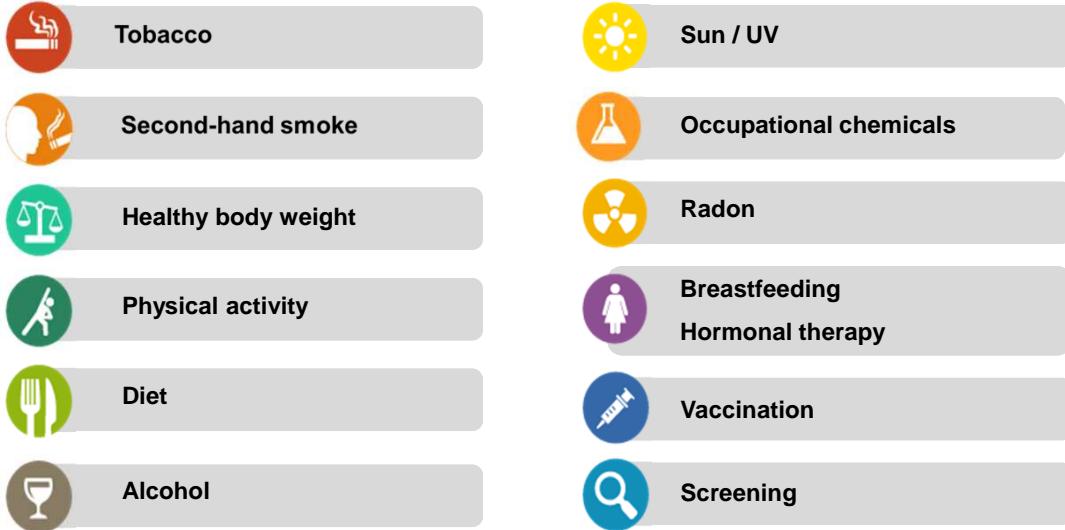
Justification of each recommendation and the scientific statements made in Q&A

Peer-reviewed publications (open access)



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Level I: 12 areas of the European Code Against Cancer



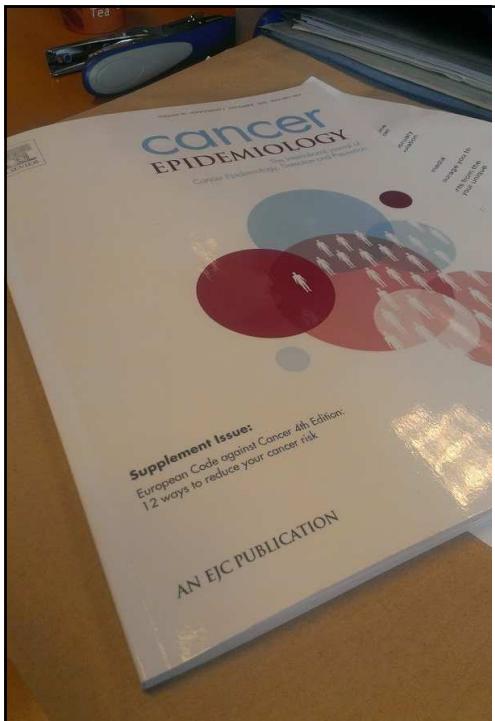
15

The screenshot shows the homepage of the European Code Against Cancer. At the top, there's a navigation bar with links for 'PÁGINA INICIAL', '12 FORMAS', 'SÓBRE O CÂNCER', 'ECLADOS CERTIFICADOS', and 'ACERCA DO CÓDIGO'. Below the navigation is a large banner with the text 'Código Europeu Contra O Câncer' and '12 FORMAS DE REDUZIR O RISCO DE CÂNCER'. To the left of the banner is a sidebar titled 'Perguntas e respostas' with icons for each of the 12 areas: Tobacco, Fume passivo, Peso corporal saudável, Actividade física, Regime alimentar, Álcool, Exposição solar/UVA, Invernos, Radiação, Anorexia, Terapia hormonal, Vacinação e infecções, and Rumores. The main content area features a video thumbnail of two people and the text 'Fazer da sua casa uma casa sem fumo. Apóie regras anti-tabágicos no seu local de trabalho.' Below the video, there's a detailed text section about passive smoking.

Level II: Question & Answers

- Find out more information about each of the 12 messages
- Phrased in FAQ (Frequently Asked Questions) style
- Answers produced by scientific working groups
- Examples:
 - “What can I do to quit smoking?”
 - “What is second-hand smoke?”
 - “How do I reduce my calorie intake to have a healthy body weight?”
- Available in **23 EU languages!**
- <http://cancer-code-europe.iarc.fr/>

16



Level III: Scientific papers supporting the Code



- 12 ways to reduce your cancer risk
- Methodology
- Tobacco and Cancer
- Obesity, Body Fatness and Cancer
- Physical Activity and Cancer
- Diet and Cancer
- Alcohol drinking and Cancer
- Ultraviolet radiation and Cancer
- Environment and Occupation and Cancer
- Ionising and Non-Ionising Radiation and Cancer
- Breastfeeding and Cancer
- Medical exposures including hormonal therapy, other pharmaceuticals, and medical radiation and Cancer
- Infections and vaccinations and Cancer
- Cancer Screening

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ECL's role in disseminating ECAC



Convening



Promotion



Networking



Resource support & assistance

ECL MICROGRANT PROGRAM 2016:
OVERVIEW OF SUPPORTED ACTIONS



The Romanian Cancer Society took advantage of the Microgrant to support two separate initiatives: promotion and dissemination of the European version of the European Code against Cancer worldwide; and support for the annual Sun Smart campaign.

The campaign will be implemented during

The period of May to August

2017. Therefore, the timing of the campaign will be used for the early development and preparation of fresh promotional materials.

The Sun Smart campaign targets 3 specific groups: parents; children;

and teenagers / young adults. Above is an example of one of the target group posters.

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ECL Youth Ambassadors for European Code against Cancer



What? Initiative of ECL to draw on the enthusiasm of **young health advocates** to help disseminate the European Code against Cancer.

Why? Key target group for the Code is **young people** - to establish health-supporting behaviours from an early age. Best way to reach this group is to have **peers promoting the Code**.

Who? Open application from **young people with links to networks, associations, societies, etc.**, who can disseminate the Code locally and provide input to global promotion.

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Countries represented by current Youth Ambassadors



20

National cancer leagues' dissemination of ECAC

Finland

- Dedicated website to cancer prevention, based on European Code against Cancer science
- Available in Finnish, Swedish, and now in English



For a Good Life
Free from Cancer

KNOW THE CANCER RISKS CHECK YOUR BODY

YOU CAN PREVENT CANCER BY LEADING A HEALTHY LIFESTYLE

Random, hereditary, and lifestyle factors play a significant role in the onset of cancer. We are unable to influence random or hereditary factors, but we can influence things by the choices we make. Up to 40% of cancers are preventable through leading a healthy lifestyle.

[READ MORE >](#)

Know the cancer risks

By following the guidelines for a healthy lifestyle provided here, you can reduce the risks of getting cancer and be in better health overall.

TOMATO PRODUCTS **ALCOHOL** **NUTRITION** **WEIGHT MANAGEMENT** **EXERCISE** **SUN** **VIRUSES AND BACTERIA** **WORK AND ENVIRONMENT**

[READ MORE >](#)

Incroyable ! Une méthode efficace qui diminue votre risque de cancer de plus d'un tiers !

Belgium

- Novel campaign advertising “miracle pill” that reduces risk of cancer by at least a third
- Created authentic looking packaging, which has inside the 12 messages of the ECAC
- Promoted at pharmacies, in GPs surgeries and in lifestyle magazines

1. Fumez pas. Ne consommez pas de tabac, sous quelque forme que ce soit.

2. Faites de votre domicile un environnement sans tabac. Soutenez les mesures d'interdiction de fumer



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Prolongitudine®

Vermindert uw kans op kanker met meer dan een derde
Diminue votre risque de cancer de plus d'un tiers
240mg/20mg
Over gebruikt tegen kanker

12 capsules

Prolongitudine®

INCROYABLE !
Une méthode efficace qui diminue votre risque de cancer de plus d'un tiers !

Bien sûr, la pilule miracle existe pas. Mais en suivant au mieux les 12 conseils de cette notice, vous pourrez réduire votre risque de cancer de plus d'un tiers.

Les personnes qui ne consomment pas d'alcool, sont également moins sujettes au cancer.

1. Faire du sport ou de l'activité physique régulièrement.

2. Faire du sport ou de l'activité physique régulièrement.

3. Faire un sport ou de l'activité physique régulièrement.

4. Manger des légumes de saison et de qualité sur votre assiette tous les jours.

5. Boire de l'eau douce.

6. Boire de l'eau douce.

7. Boire de l'eau douce.

8. Boire de l'eau douce.

9. Boire de l'eau douce.

10. Boire de l'eau douce.

11. Boire de l'eau douce.

12. Boire de l'eau douce.

Si vous souhaitez en savoir plus sur la manière de faire face au cancer, veuillez nous écrire à info@prolongitudine.com.

[Télécharger la version .pdf](#)

Based on the messages of the European Code against Cancer

ECL
Association of European Cancer Leagues

Well received by the media and the general public.

Nieuw "wondermiddel" doet risico op kanker met derde dalen

Prolongitudine

Le Code Européen contre le Cancer propose des mesures simples et possibles que tout citoyen peut mettre en œuvre pour limiter la prévalence du cancer. Ces recommandations sont développées par le Comité ECODE et soutenues par le Comité de Développement.

"Méthode miracle" contre le cancer!

Prolongitudine

Le Code Européen contre le Cancer propose des mesures simples et possibles que tout citoyen peut mettre en œuvre pour limiter la prévalence du cancer. Ces recommandations sont développées par le Comité ECODE et soutenues par le Comité de Développement.

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Cancer Focus NORTHERN IRELAND

12 WAYS To Reduce YOUR Cancer Risk

An easy guide to the European Code Against Cancer

ECL
Association of European Cancer Leagues

6 Don't drink alcohol
Alcohol is bad for your body.
Not drinking alcohol is better for you.
If you drink, try to limit your intake.

7 Don't spend too much time in the sun
Spending too long in the sun can damage your skin.
You can protect yourself:
• Staying in the shade during the hottest part of the day
• Putting sun screen on, (using a minimum of 15+ and a 4 or 5 star rating)
• Wearing a long sleeve shirt,
trousers and hat
• Do not burn your skin in the sun
• Do not use sunbeds

Northern Ireland



Rep. of Ireland

Fit for Work & Life Programme

Contents

- Unit 1: What is Health?
- Unit 2: Physical Activity
- Unit 3: Healthy Eating
- Unit 4: Smoking
- Unit 5: Alcohol and Health
- Unit 6: Reduce Your Risk and Early Detection
- Unit 7: Making Changes and Sharing with Your Community



Programme Objectives

At the end of the programme, participants will be able to:

... Describe the concepts underpinning the European Code Against Cancer - including healthy eating, physical activity, being a healthy weight, not smoking, alcohol, being sunsmart and early detection.



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From advice to action

Denmark

European
Code
Against
Cancer

Ambitious
national
goals

How can
we
achieve
the
goals?

What to
do?



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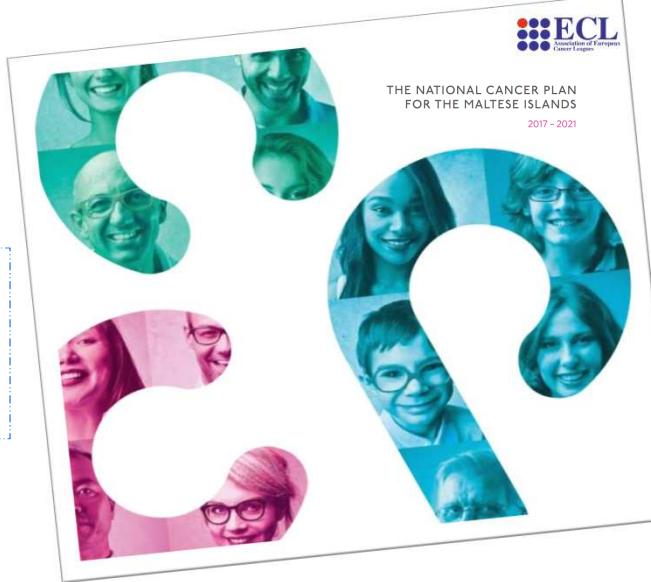
National Cancer Plans

Malta's new National Cancer Plan sets out an integrated and comprehensive plan of action for the next five years (2017 to 2021).

"Cancer prevention, especially when integrated with prevention of chronic diseases, offers the most cost-effective long-term strategy for cancer control "

National Cancer Plan Supports:

- Dissemination of the European Code against Cancer in schools, workplaces, health and community centres;
- Plus, many actions related to each of the 12 messages e.g. vaccination, screening, occupational cancers, etc.



Source:

<https://deputyprimeминистр.gov.mt/en/CMO/Documents/NationalCancerPlan2017.pdf>

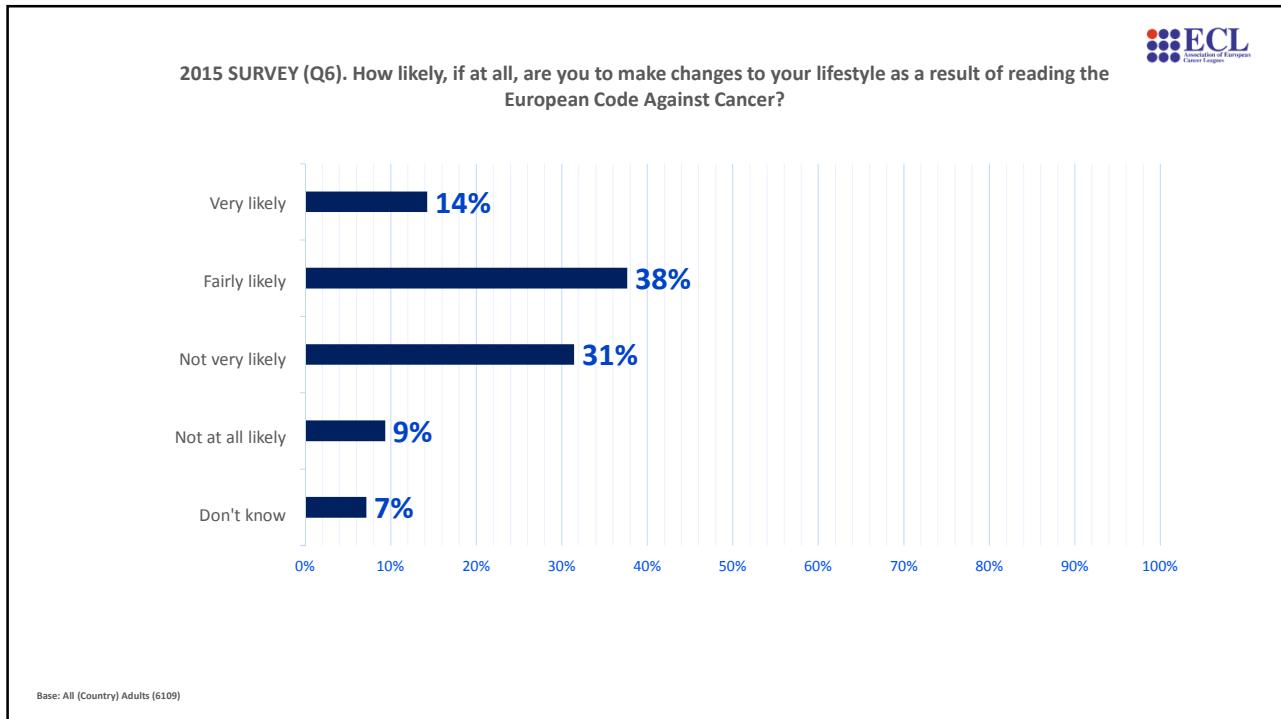
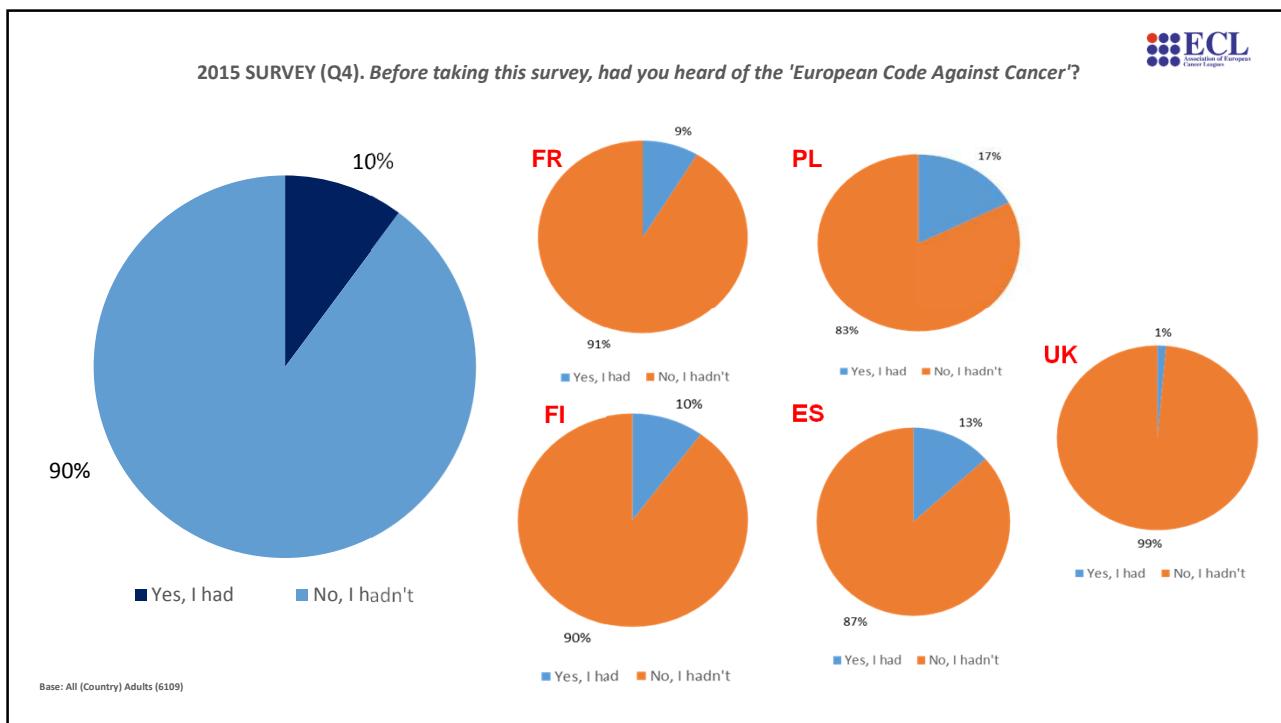
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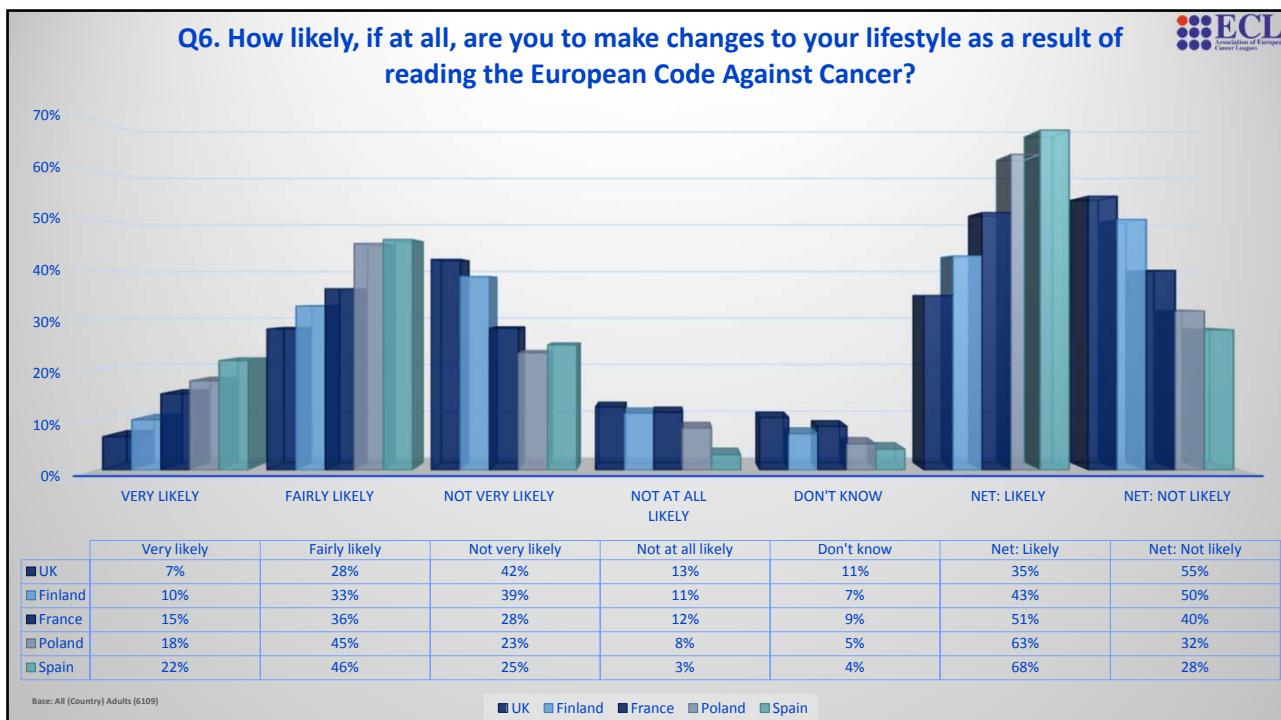


European Code Against Cancer online survey

Conducted by YouGov on behalf of Association of European Cancer Leagues (ECL) – October- November 2015





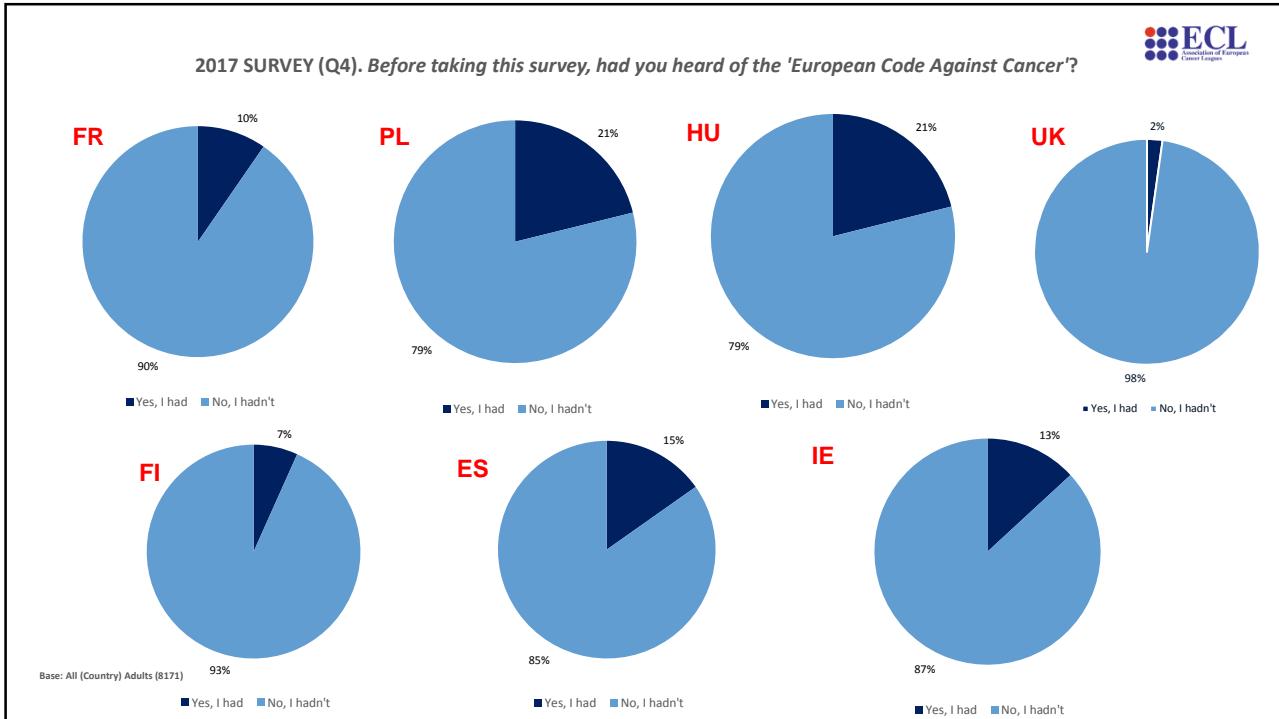
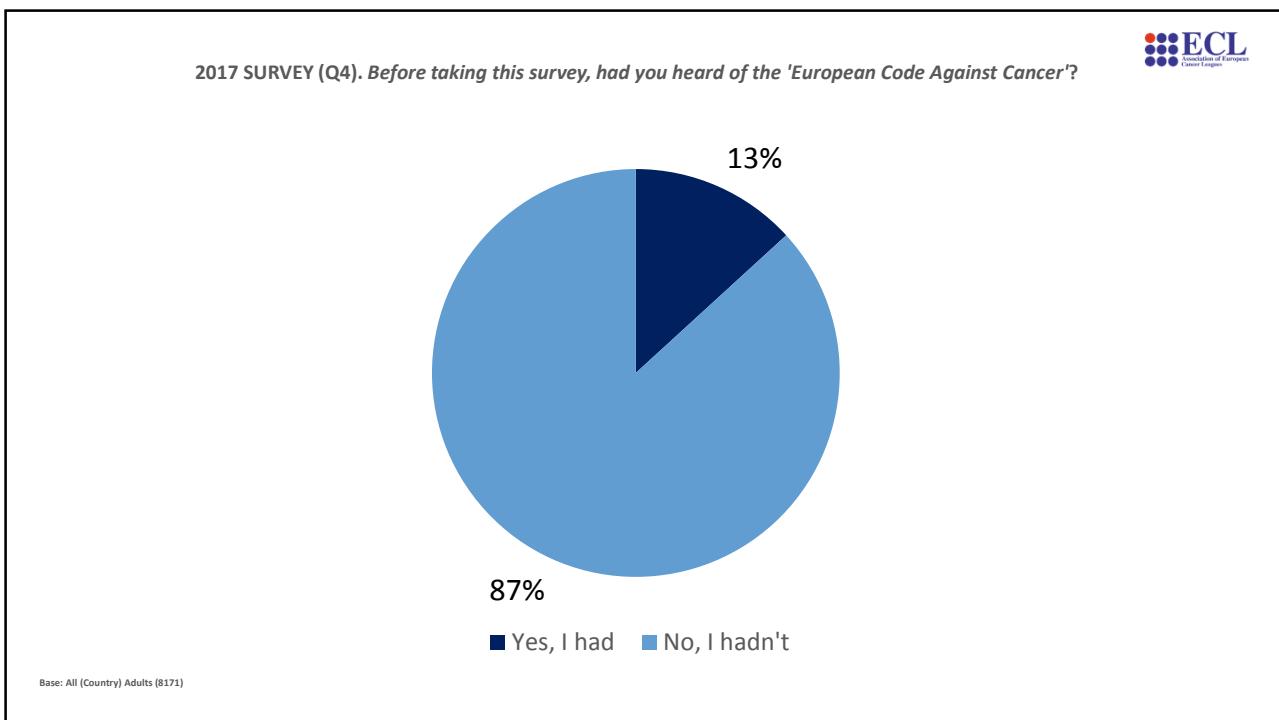


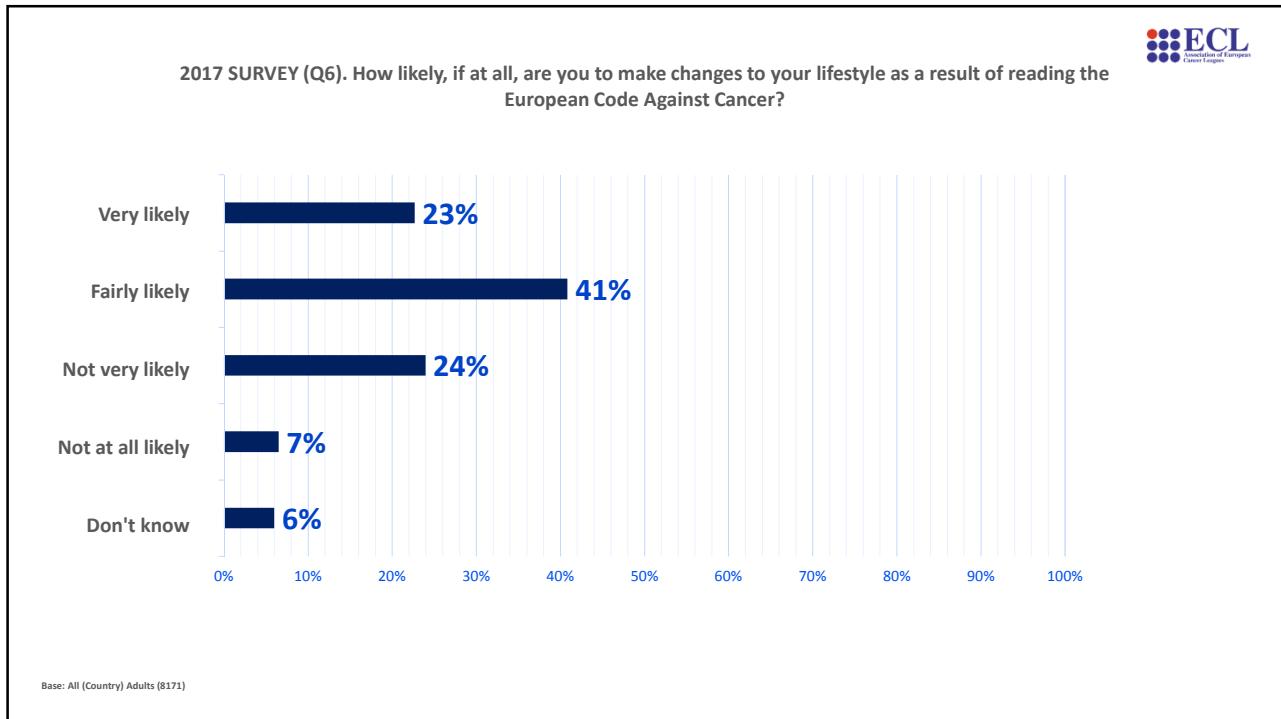
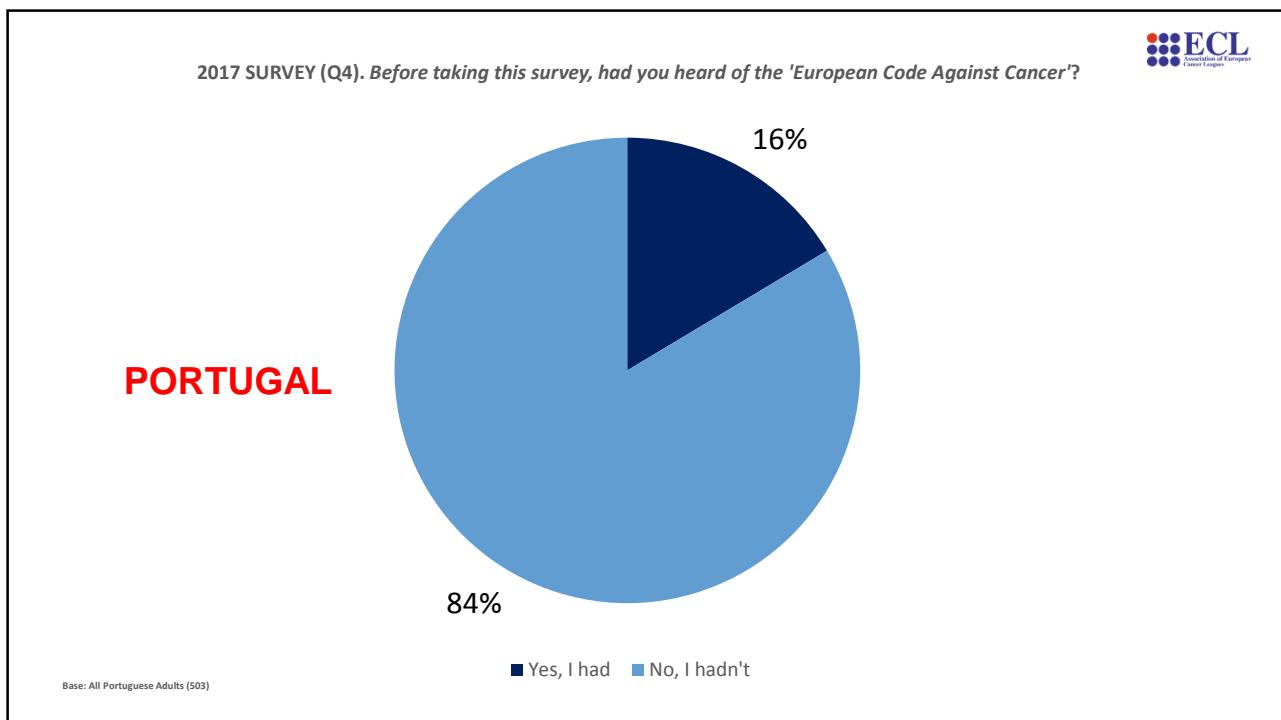
European Code Against Cancer online survey

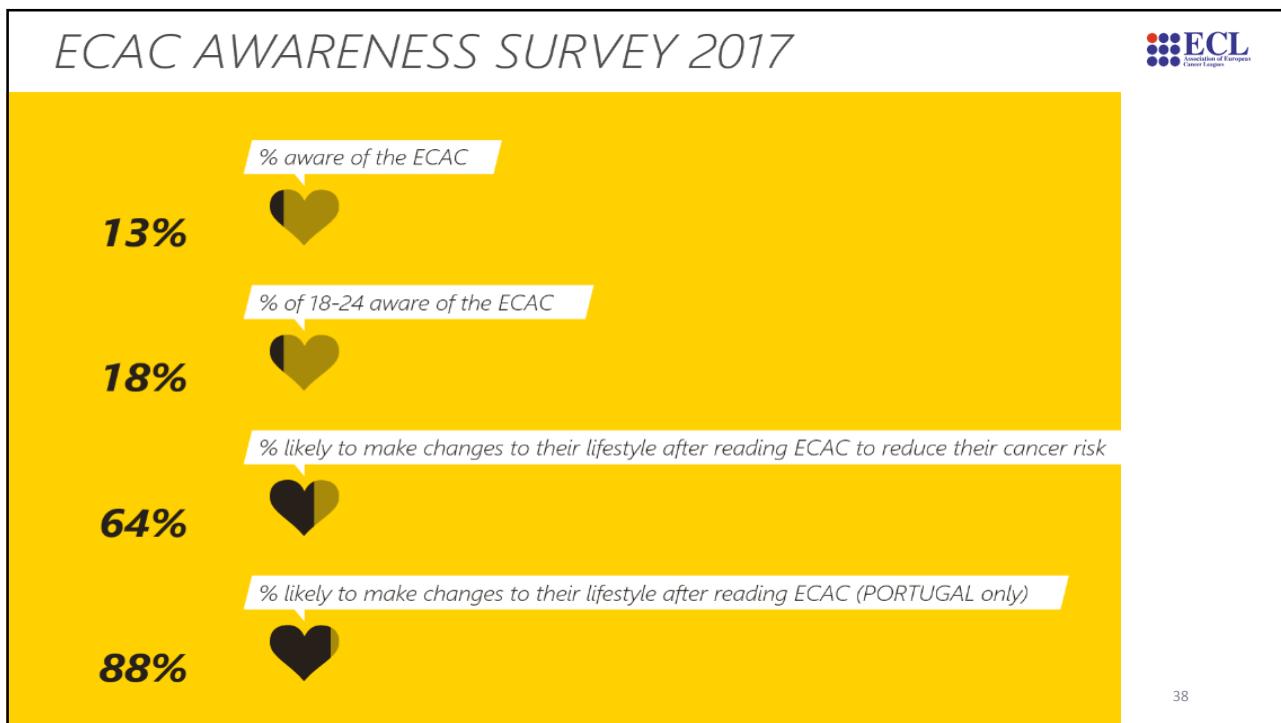
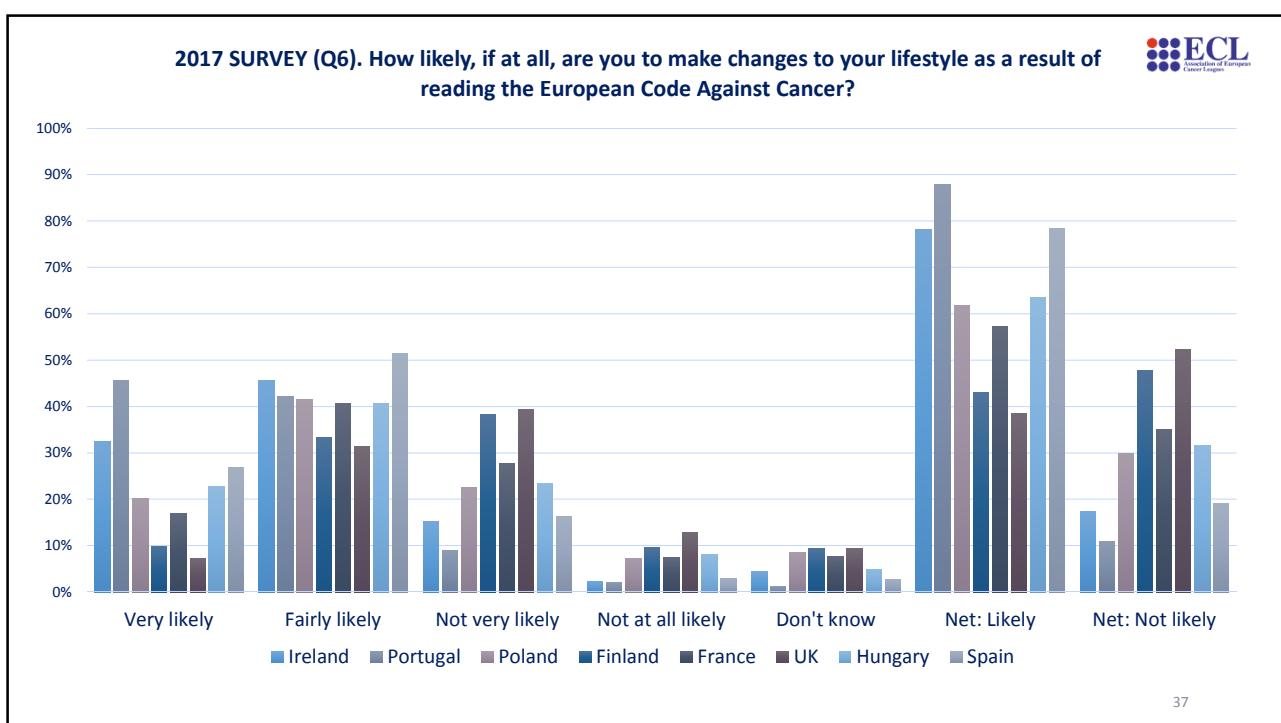
2017 results

Conducted by YouGov on behalf of Association of European Cancer Leagues (ECL)
Fieldwork Dates: 18th - 24th October 2017











Conclusions

- ECAC is an excellent, scientifically sound resource that has been **used and adapted in a wide variety of materials and services, and has had real impact**
- Engaging stakeholders and citizens as promoters is crucial – especially the role of volunteers at national cancer leagues
- Collaborations with other NCD organisations must continue and be extended locally, nationally, and internationally
- After 30 years of promotion, it is timely to engage in a thorough evaluation of the use of ECAC. **Cancer leagues will be central to this process**
- Remember: “footnote” to ECAC is essential for full implementation of messages

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EUROPEAN CODE AGAINST CANCER

12 ways to reduce your cancer risk

FOOTNOTE:

The European Code Against Cancer focuses on actions that individual citizens can take to help prevent cancer.

Successful cancer prevention requires these individual actions to be supported by governmental policies and actions.

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European Code Against Cancer - Acknowledgements

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 Eero Suonio
 Lawrence von Karsa
 Joachim Schüz
 Carolina Espina
 Patricia Villain



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Obrigado!

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www.european cancerleagues.org
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NCU's bestyrelsesmøde 19. februar 2018

Punkt 15

Kommende NCU møder

Sagsfremstilling (Resume)

I 2018 er aftalt følgende datoer for NCU bestyrelsesmøder:

- 9. maj 2018 i København
- 8. oktober 2018 i København