



WEO

The voice of world
endoscopy

Fight CRC: Integrating Stakeholders with Research Initiatives in Early-onset Colorectal Cancer

Caitlin Murphy PhD MPH, UTHealth School of Public Health

Jennifer Kolb MD MS, Greater Los Angeles VA/UCLA



Our goals for today

Who is Fight CRC?

What are the global trends in early-onset colorectal cancer?

How is Fight CRC addressing early-onset colorectal cancer?

- Understanding barriers to diagnostic work-up
- Reducing delays in diagnosis
- Developing tools to identify novel risk factors



Who is Fight CRC?

Patient Support

Build community of stakeholders, including patients, survivors, and caregivers

Connect stakeholders with policy and research efforts

Policy

Develop a strategic action plan for colorectal cancer

Advocate for federal and state policies that increase access to screening

Increase funding for colorectal cancer research

Research

Identify and establish research priorities

Fund pilot projects and fellowships

Convene Early-Age Onset Workgroup

Train research advocates



Research Advocacy Training and Support (RATS) Program

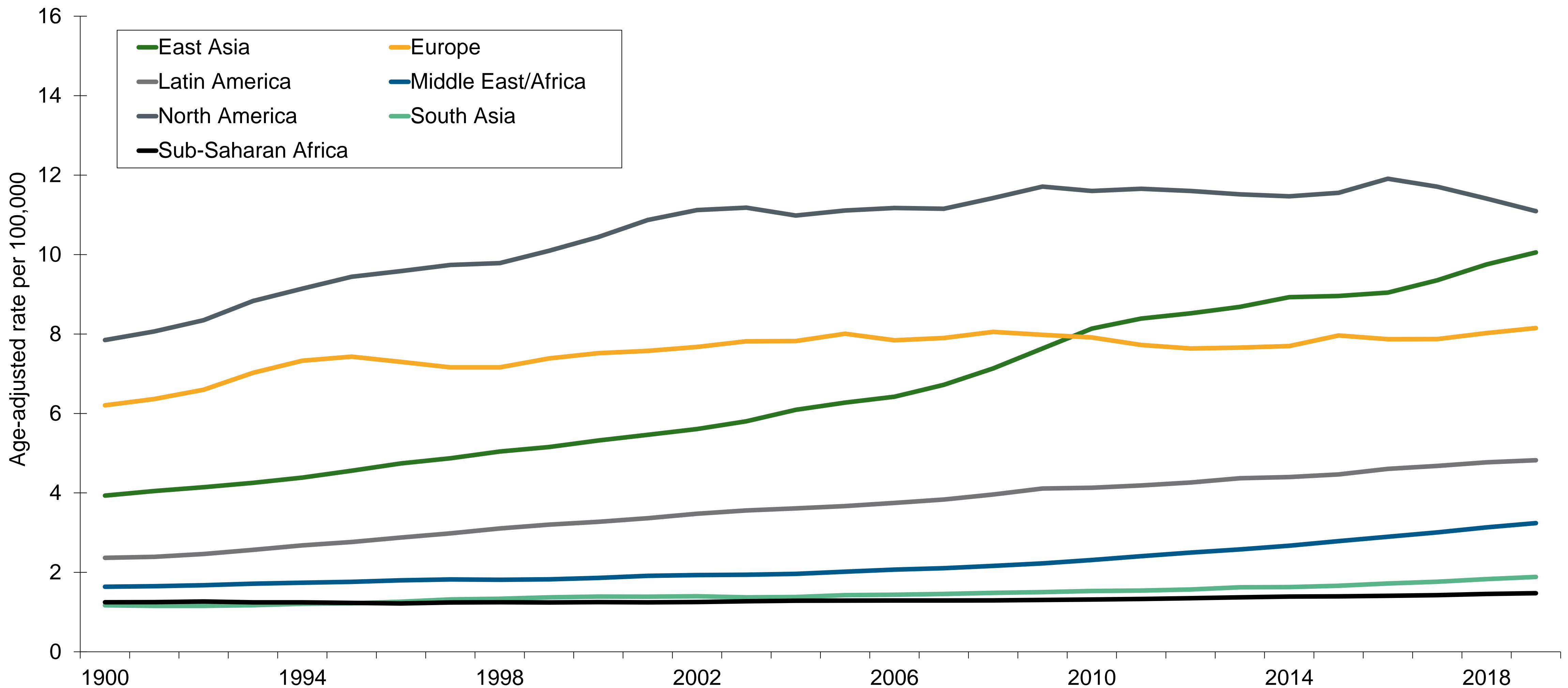
- Empowers patient advocates to effectively participate in the research process
- Opportunity for stakeholder engagement with patients on research initiatives
- Bridge to community partners and other stakeholders in the community – patients, survivors, and caregivers



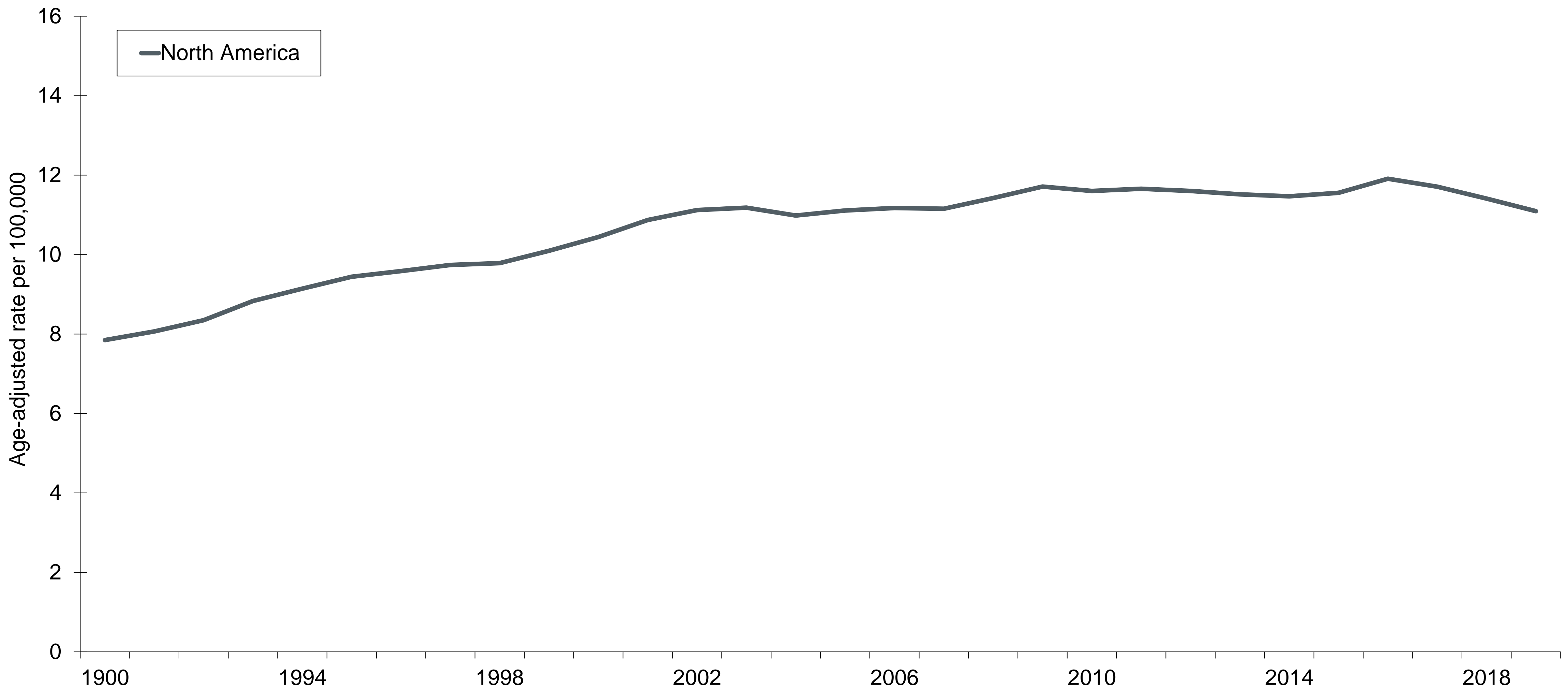
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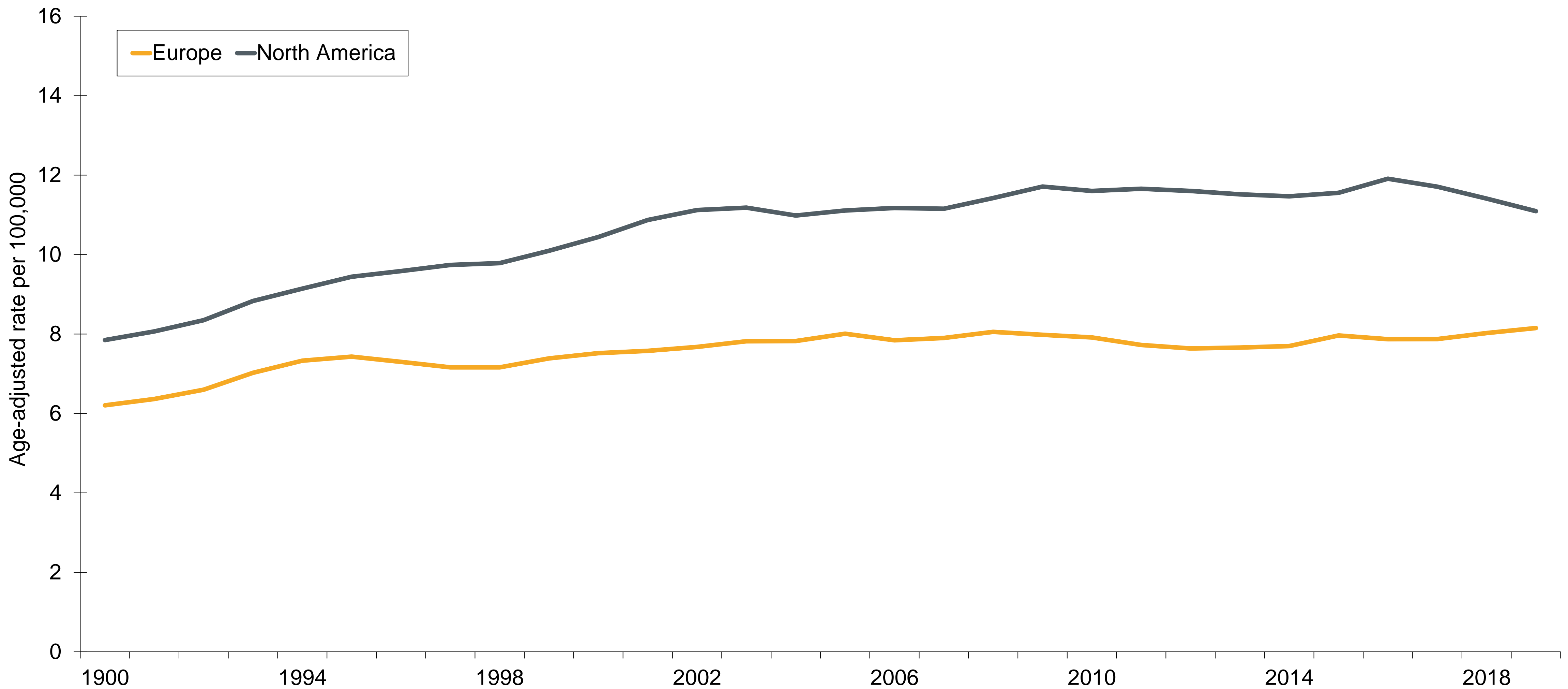
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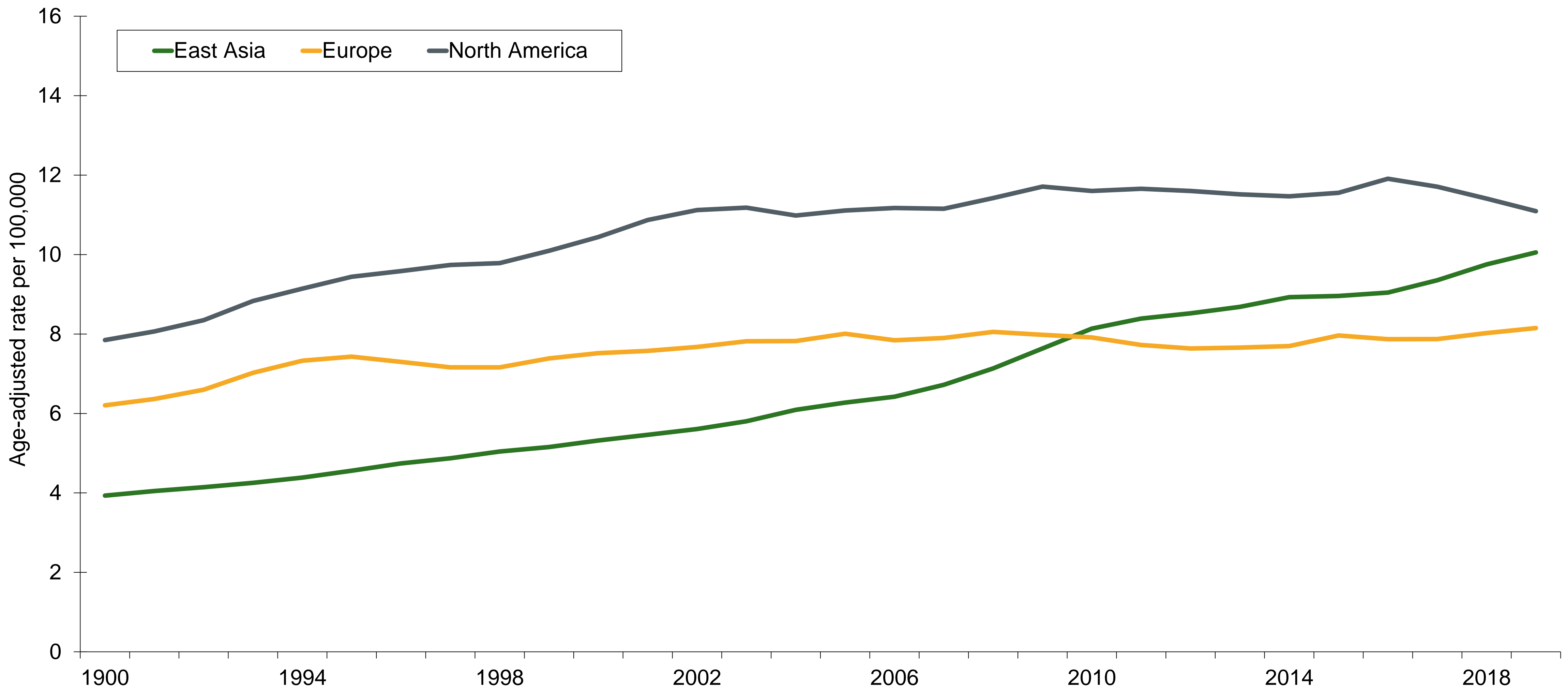
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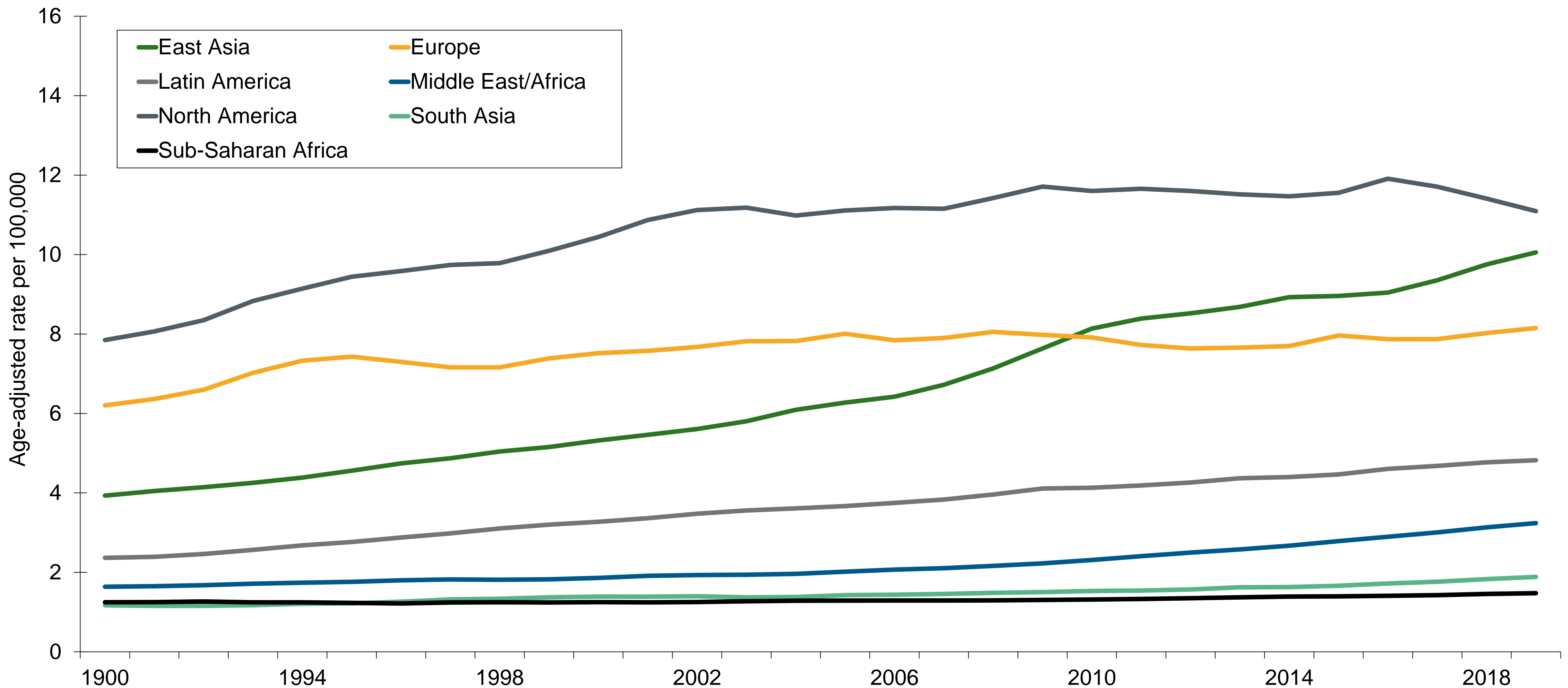
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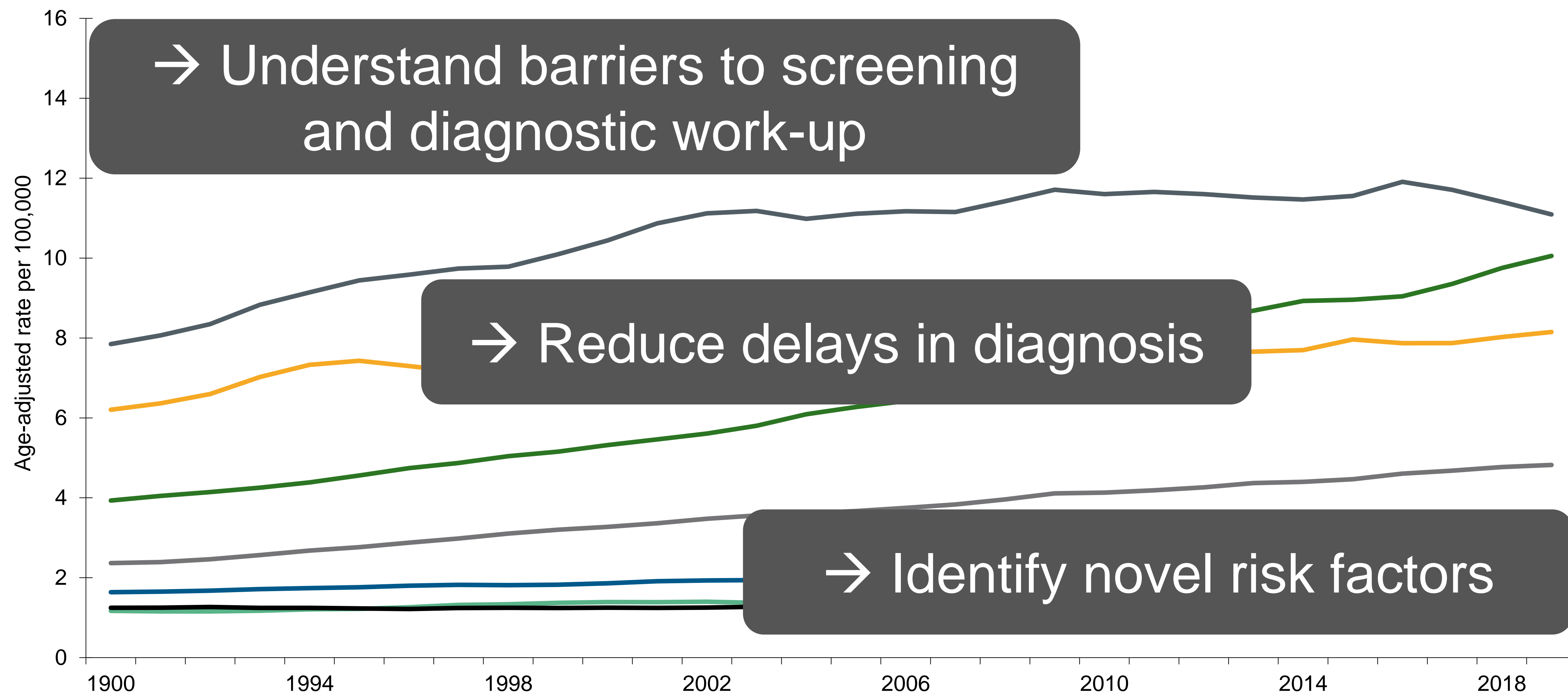
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What are the global trends in early-onset colorectal cancer?



Understanding barriers to diagnostic work-up: cost and insurance

I had great insurance through my job and a strong family history. Still my insurance denied the procedure, so I waited. 2 years later the colonoscopy was covered but *it was too late- I had cancer.*

We are not taught how to use insurance, the politics of how to get approvals or referrals for certain tests so that they will be paid for. A lot of times things are missed because nobody tells us how to use it. Denials can take a long time to appeal.

I was in my 30s and did not want to *spend my money on seeing doctors and insurance*; I wanted to buy beer instead. Then I got diagnosed with stage II colon cancer and lynch syndrome.



Understanding barriers to diagnostic work-up: provider suspicion

I was having bleeding, feeling full, and wasn't going to the bathroom normally. My doctor didn't think we needed to do testing. Then when I saw my OB I finally *felt like she heard me*.

...thought it was a kidney stone for so long.

I had to show my doctor a *picture* of what I saw in the toilet to convince him to order testing.

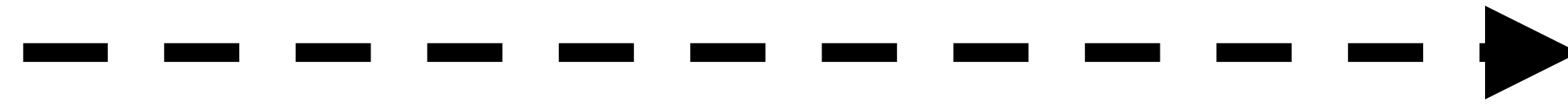
My mom had symptoms for 2 years and her doctor just kept telling her it was hemorrhoids and IBS. Getting a *second opinion from a new doctor* was the only thing that helped. I wish she would have *advocated for herself more*.



Reducing delays in diagnosis by evaluating symptoms and risk

Symptoms

Abdominal pain
Hematochezia, Melena
Weight loss
Fatigue
Diarrhea, Constipation
Iron deficiency anemia



Diagnosis

- Longer time for age <50 (217 vs. 29.5 days)
- Median time for rectal bleeding: 180 days
- Misdiagnosis?

Obstruction
Perforation
Late-stage disease



Developing tools to identify novel risk factors

**Demographic
characteristics**

**History of colorectal
cancer**

**Medical history, including
chronic conditions,
family history of cancer,
and reproductive health**

Medication use

**Physical activity and
diet**

Social habits



CRC History

When was your colorectal cancer diagnosed?

Where was your colorectal cancer located?

What symptoms did you experience that led to your cancer diagnosis? Select all that apply.

What type(s) of surgery did you have for your colorectal cancer? Select all that apply.

Have you received or are you planning to receive radiation therapy to treat your colorectal cancer?

Have you received or are planning to receive chemotherapy to treat your colorectal cancer?

Had you ever had a colorectal cancer screening test before your recent diagnosis? (not including a diagnostic colonoscopy performed after/due to symptoms of colorectal cancer)

Family history

First Degree Relatives

- ☒ Mother
- ☐ Father
- ☐ Sister
- ☐ Brother

Second Degree Relatives

- ☐ Aunt
- ☐ Uncle
- ☐ Grandfather
- ☐ Grandmother
- ☐ Grandson
- ☐ Granddaughter
- ☐ Niece
- ☐ Nephew

Is your mother currently alive?

- ☒ Yes
- ☐ No
- ☐ I don't know

reset

How old is your mother currently?

Was your mother ever diagnosed with cancer?

- ☒ Yes
- ☐ No
- ☐ I don't know

reset

What cancer diagnosis did your mother receive?

- ☐ Breast
- ☐ Ovary
- ☐ Endometrium
- ☐ Cervix
- ☐ Lymphoma
- ☒ CRC
- ☐ Lung
- ☐ Prostate
- ☐ Pancreas
- ☐ Thyroid
- ☐ Other

How old was your mother when she was diagnosed with cancer?



CRC History

When was your colorectal cancer diagnosed?

05-08-2022

Today

M-D-Y

Where was your colorectal cancer located?

☒ Colon

☐ Rectum

What symptoms did you experience that led to your colorectal cancer diagnosis? Select all that apply.

☒ Blood in stool

☐ Change in bowel habits

☐ Bowel obstruction

☐ Bowel perforation

☐ Anemia

☐ Weight loss

☐ Pain - pelvic

☐ Pain - abdominal

☐ No symptoms - colorectal cancer was found during routine screening (i.e. fecal occult blood test, sigmoidoscopy or colonoscopy)

☐ Other

☐ I don't know

What type(s) of surgery did you have for your colorectal cancer? Select all that apply.

☐ Partial colectomy (only the portion of the colon or rectum containing the tumor was removed)

☐ Subtotal colectomy (removal of the entire colon but the rectum was not removed)

☐ Total colectomy (all of the colon, including the rectum, was removed)

☐ Surgery is planned

☐ Surgery is not planned

☐ Other

☐ I don't know

Have you received or are you planning to receive radiation therapy to treat your colorectal cancer?

☐ Yes

☒ No

Have you received or are planning to receive chemotherapy to treat your colorectal cancer?

☒ Yes

☐ No

Had you ever had a colorectal cancer screening test prior to your recent diagnosis? (not including a diagnostic exam performed after/due to symptoms of colorectal cancer)

☐ Yes

☒ No

Family history

Have you ever drank alcohol?

☒ Yes

☐ No

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About how old were you when you first started drinking, not counting small tastes or sips of alcohol?

21

< 4 times a month

Once a week

2-3 days per week

4-7 days per week

Never

In the last 12 months, how often did you have at least one alcoholic drink in a day?

☐

☒

☐

☐

☐

☐

reset

Between the ages of 20-29, how often did you have at least one alcoholic drink in a day?

☐

☐

☒

☐

☐

☐

reset

Between the ages of 30-39, how often did you have at least one alcoholic drink in a day?

☐

☐

☒

☐

☐

☐

reset

Between the ages of 40-49, how often did you have at least one alcoholic drink in a day?

☐

☐

☒

☐

☐

☐

reset

Were you exposed to smoke from other people's cigarettes or tobacco products in settings such as home, work, bars, restaurants, bowling alleys, bingo halls, and friends homes during....

Yes

No

I don't know

...Childhood (0-12 years)

☐

☒

☐

reset

...Teendom (13-19 years)

☐

☒

☐

reset

...your 20's

☐

☒

☐

reset

...your 30's

☐

☐

☒

☐

reset

Dietary Intake

Vitamins

Medications

During the year before your colorectal cancer diagnosis, how often did you eat eggs?

2-3 times per month

▼

When you did eat eggs, how many eggs per day?

2

▼

During the year before your colorectal cancer diagnosis, how often did you eat a cold breakfast?

3-4 times per week

▼

When you did eat cereal, how many servings per day?

1

▼

When you ate cereal, what type of cereal did you typically eat?

☐ "Total" brand cereal

☒ Other brand of cereal

During the year before your colorectal cancer diagnosis, how often did you eat oatmeal?

Never

▼

During the year before your colorectal cancer diagnosis, how often did you drink orange juice?

Once a month

▼

When you did drink orange juice, how many glasses did you drink in a day?

1

▼

When you drank orange juice, it was typically:

I don't know

▼

During the year before your colorectal cancer diagnosis, how often did you drink regular milk, soy milk, chcoloate milk or cocoa?

Never

▼

During the year before your colorectal cancer diagnosis, how often did you drink Sega, Slimfast or Ensure?

Never

▼

During the year before your colorectal cancer diagnosis, how often did you eat breakfast bars, granola bars or meal replacement bars (such as Power Bar)?

2-3 times per month

▼

When you did eat breakfast bars, how many bars did you eat in a day?

1

▼

During the year before your colorectal cancer diagnosis, how often did you eat breads, rolls or English muffins?

Never

▼

	Never	In the past	Currently	I don't know
Vitamin B9 (Folic Acid)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamin B12 (Cyanocobalamin)	<input checked="" type="radio"/>	<input type="radio"/>		
Vitamin C (Ascorbic Acid)	<input type="radio"/>	<input type="radio"/>		
Vitamin D	<input type="radio"/>	<input type="radio"/>		
Vitamin E	<input checked="" type="radio"/>	<input type="radio"/>		
Vitamin K (Phytomenadione)	<input checked="" type="radio"/>	<input type="radio"/>		
B-Complex	<input checked="" type="radio"/>	<input type="radio"/>		
Beta Carotene	<input checked="" type="radio"/>	<input type="radio"/>		
Minerals	<input checked="" type="radio"/>	<input type="radio"/>		
Calcium or Dolomite (Tums included)	<input checked="" type="radio"/>	<input type="radio"/>		
Chromium	<input checked="" type="radio"/>	<input type="radio"/>		

reset

	Never	In the past	Currently
Oral steroids (e.g. prednisone)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Thyroid medications (e.g. Synthroid®, Levoxyl®)	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Antidepressants	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Raloxifene	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tamoxifen	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>

How old were you when you started taking oral steroids?

45

How long altogether have you taken oral steroids?

☐ Less than 1 year

☒ 1-5 years

☐ 6-10 years

☐ Greater than 10 years

☐ I don't know

When using oral steroids, how many days per week would you take the medication?

☐ 1 - 3 days per week

☐ 4 - 6 days per week

☒ 7 days per week

☐ I don't know

How old were you when you started taking thyroid medication?

35

How long altogether have you taken thyroid medication?

☐ Less than 1 year

☐ 1-5 years

☒ 6-10 years

☐ Greater than 10 years

☐ I don't know

Opportunities for Fight CRC – WEO collaboration

Identify opportunities for research collaborations, integrating stakeholder perspective

Fight CRC will co-host “4th Annual Early-Age Onset Colorectal Cancer Symposium” on June 23 (virtual from Spain)

Early-Age Onset Workgroup



Acknowledgements

Fight CRC

Early-Age Onset Workgroup

- Common Data Elements Workgroup
- Signs and Symptoms Workgroup
- Genetics and Family History Advisory Council



