

e-tools and social networks for epidemiology

COLLOQUE INTERNATIONAL

Mardi **21** mai 2013, de 9h à 18h

à LA CITÉ INTERNATIONALE UNIVERSITAIRE, Espace Adenauer, Paris 14^{ème}

JOURNÉE D'ÉCHANGES ENTRE

ACTEURS ACADÉMIQUES ET INDUSTRIELS

SUR L'ÉMERGENCE

DE TECHNOLOGIES INNOVANTES

Studies in the general population

The E3N and E4N cohorts



Françoise Clavel-Chapelon

Inserm, UP-Sud, IGR – France

Etude Epidémiologique auprès des femmes de la MGEN





E3N - CONCEPTUAL FRAMEWORK

Nutrition and hormones as major components of women's health

Nutrition

dietary habits
dietary supplements
alcohol consumption
weight
physical activity

Hormones

hormonal treatments
reproductive factors
endogenous levels



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Major outcomes

cancers
CVDs
asthma
diabetes
fractures
autonomy



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reproductive factors
endogenous levels

Major outcomes

cancers
CVDs
asthma
diabetes
fractures
autonomy

***avoiding recall bias
using epidemiological and biological data***



➤ **Main objective:**

Investigate risk factors for cancer and major diseases in women

➤ **Follow-up of the E3N cohort:**

- ✧ self-administered questionnaires
- ✧ files from the MGEN insurance plan



European Prospective Investigation into Cancer and Nutrition

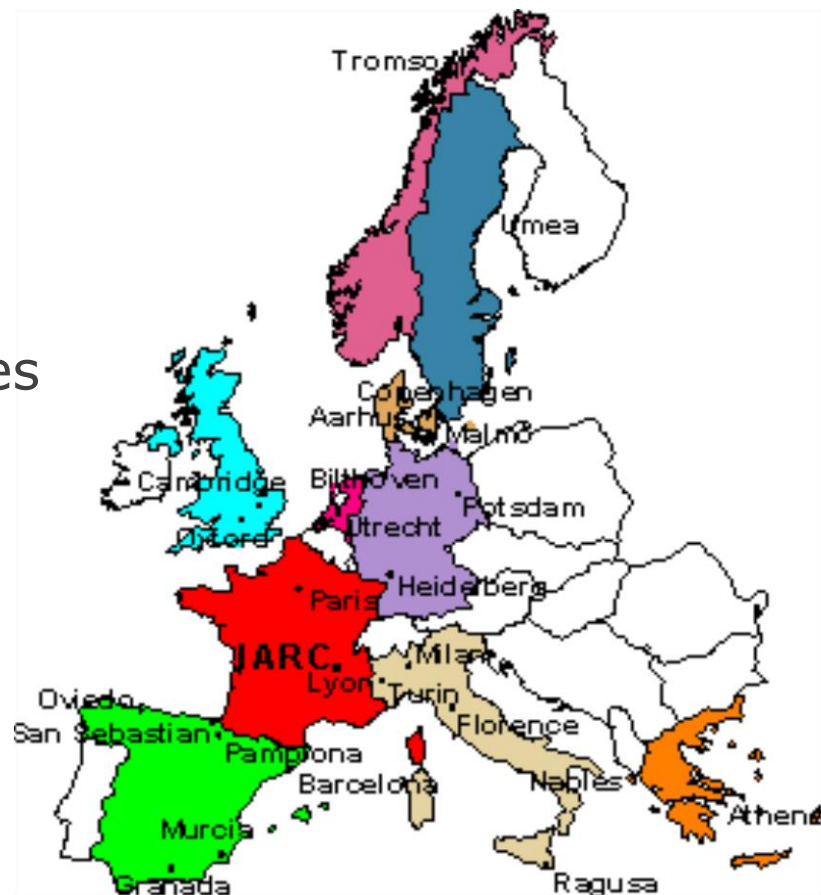
➤ 10 European countries:

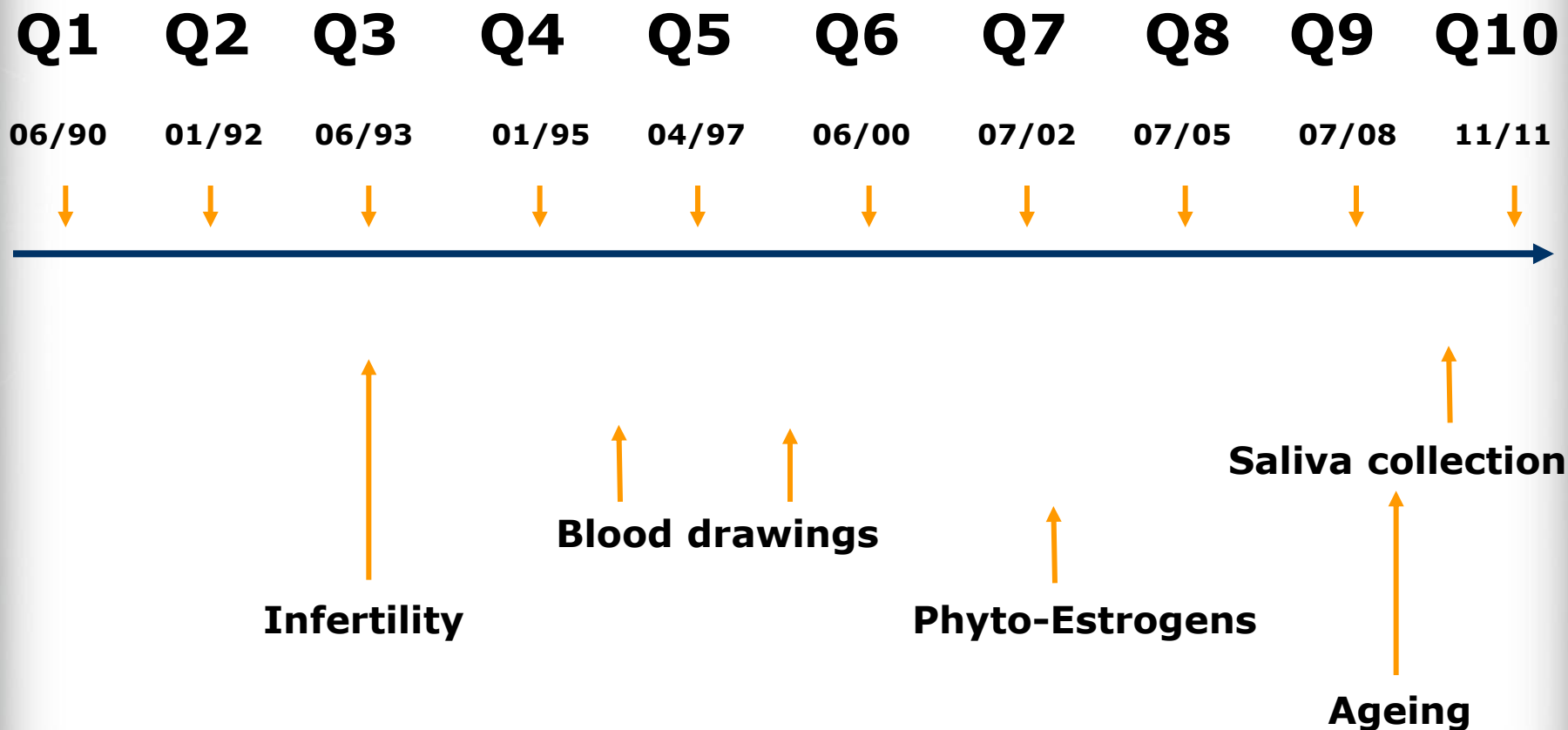
500 000 subjects

400 000 with blood samples

➤ Objective:

Investigate the relationships between diet and chronic diseases, especially cancer





Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10

06/90 01/92 06/93 01/95 04/97 06/00 07/02 07/05 07/08 11/11



ESTROGÈNES SEULS OU ASSOCIÉS À D'AUTRES HORMONES					
PAR VOIE BUCCALE COMMERCIALISÉES ACTUELLEMENT	183	184 CYCLODÈNE 5	185 CYCLODÈNE 5	186 CYCLODÈNE 5	187
188 ESTROFEM	189	190	191	192	193
194	195	196	197	198	199
PAR VOIE PERCUTANÉE (patch ou gel) COMMERCIALISÉES ACTUELLEMENT	200	201	PAR VOIE VAGINALE COMMERCIALISÉES ACTUELLEMENT	202 COLPOTROPINE	203
204	PAR VOIE INJECTABLES COMMERCIALISÉES ACTUELLEMENT	205	206	207	208
209	210	211	212	213	

blood drawings

Phyto-Estrogens

Saliva collection

Ageing

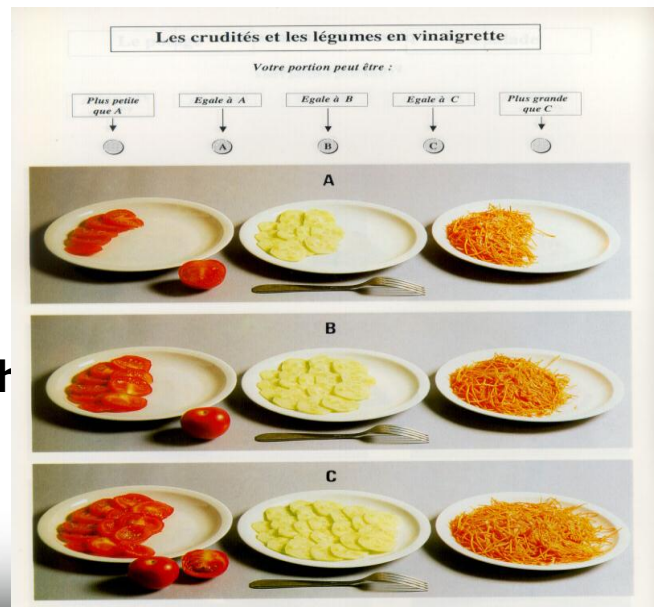


Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10

06/90 01/92 06/93 01/95 04/97 06/00 07/02 07/05 07/08 11/11



Food drawings



Ph

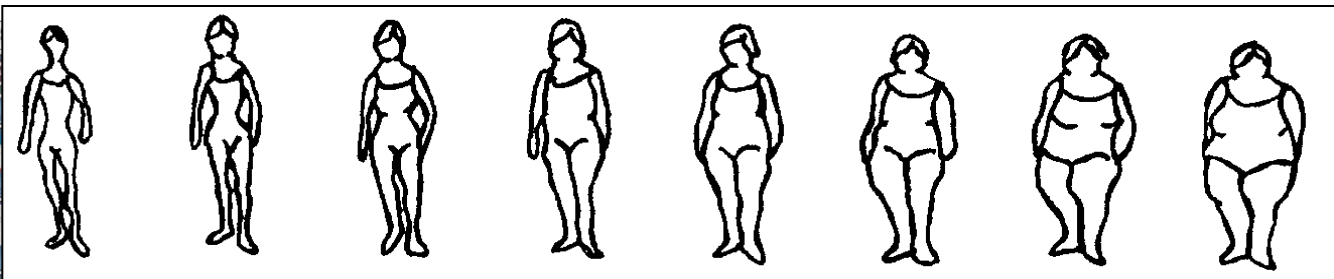
on

Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10

06/90 01/92 06/93 01/95 04/97 06/00 07/02 07/05 07/08 11/11

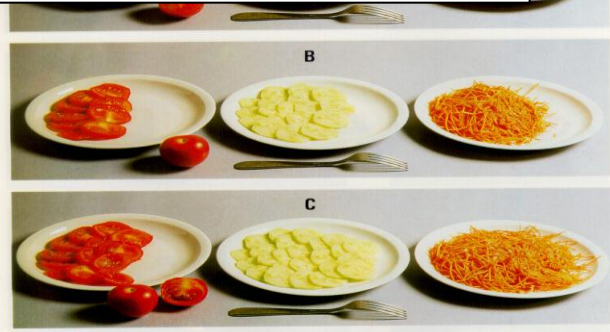


OESTROGÈNES SEULS			
PAR VOIE BUCCALE COMMERCIALISÉES ACTUELLEMENT			
PAR VOIE PERCUTANÉE COMMERCIALISÉES ACTUELLEMENT			
PAR VOIE INJECTABLES COMMERCIALISÉES ACTUELLEMENT			
PAR VOIE VAGINALE COMMERCIALISÉES ACTUELLEMENT			
ESTROGÈNES RETARDÉS			
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ESTROGÈNES RETARDÉS			



10 drawings

Ph



on

Q1 **Q2** **Q3**
 06/90 01/92 06/93

Examens pratiqués depuis 2008 ou votre dernière réponse à un questionnaire E3N

	Cochez si oui	Date du plus récent		Normal	Anormal	Si résultat anormal, précisez ses conclusions	
		Mois	Année				
Frottis	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>		
Mammographie	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>		
Coloscopie	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>		
Hémocult®	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>		

	Cochez si oui	Date du plus récent		Normal	Anormal	Traité	Non traité
		Mois	Année				
Cholestérol Total	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cholestérol LDL	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cholestérol HDL	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Triglycérides	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Glycémie	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tension artérielle	<input type="checkbox"/>			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Avez-vous fait une ostéodensitométrie ? Non Oui

Si oui :

- résultats normaux Mois Année
- diagnostic d'ostéopénie Date premier diagnostic
- diagnostic d'ostéoporose Date premier diagnostic

Q8 **Q9** **Q10**
 07/05 07/08 11/11

NOM ET ADRESSE MEDECINS ou ETABLISSEMENTS D'HOSPITALISATION
 Si vous acceptez que les médecins d'E3N contactent vos médecins, indiquez leurs coordonnées :

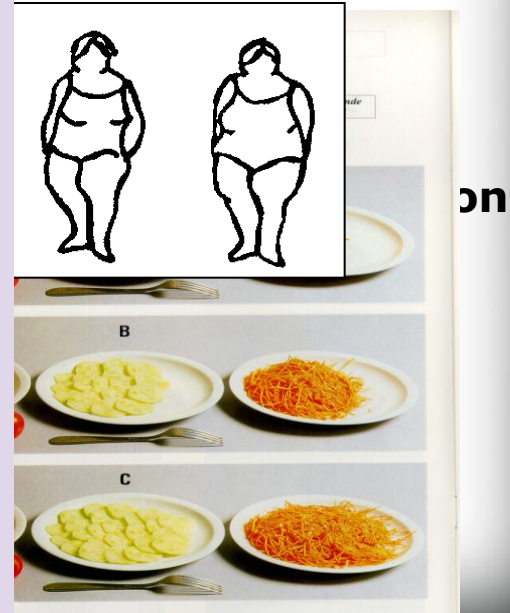
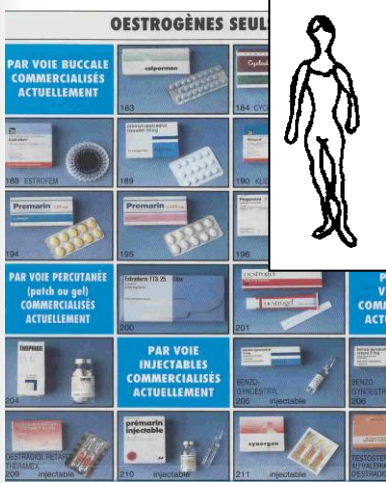
Vos mesures anthropométriques actuelles

Poids kg Taille 1 cm Tour de taille (au plus mince) cm

Tour de taille (au niveau du nombril) cm Tour de hanches (au plus large des hanches/fesses) cm

Tabac
 Avez-vous déjà fumé dans votre vie ?
 Non Oui, et je fume toujours Oui, mais j'ai arrêté Votre âge à l'arrêt

Si, au cours des 20 dernières années, vous avez vécu/travaillé dans une pièce enfumée, indiquez :
 Combien d'heures environ par jour : Combien d'année(s) : Ne sait pas



Active follow-up. A newsletter helps increasing the participation rate.

- Around 80-85% at each questionnaire
- Around 65% have answered all questionnaires



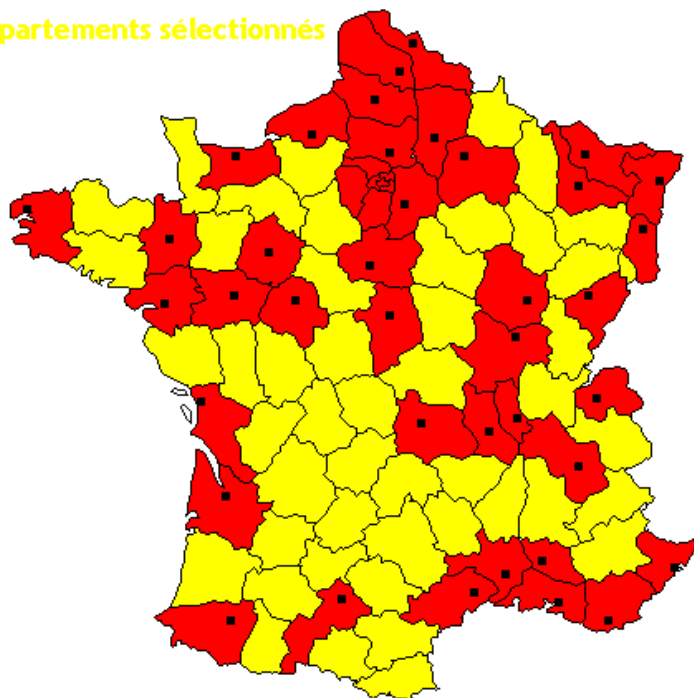
Passive follow-up. Transfer of MGEN information on addresses, hospitalisations, vital status, reimbursed drugs

E3N – PREPARATION OF THE DATA

- Huge volume
- ID numbers are scanned (for reminders to be sent rapidly)
- Questionnaires are optically read
- All answers are video-checked (and corrected) one by one
- Images are saved



46 départements sélectionnés



Blood sample
25 000 women



Saliva sample
47 000 women



E3N - CANCER OUTCOMES

➤ Breast	9 978
➤ Skin	4 996
➤ Colon-Rectum	1 216
➤ Thyroid	801
➤ Ovarian	645
➤ Endometrial	548
➤ Lung	412

All cancers **22 467**



E3N – OTHER OUTCOMES

➤ Diabetes	3 374
➤ Venous thromboembolism	3 206
➤ Stroke	1 477
➤ Myocardial infarction	585
➤ Asthma	6 231
➤ Severe depressive symptoms	6 244



SOME RESULTS

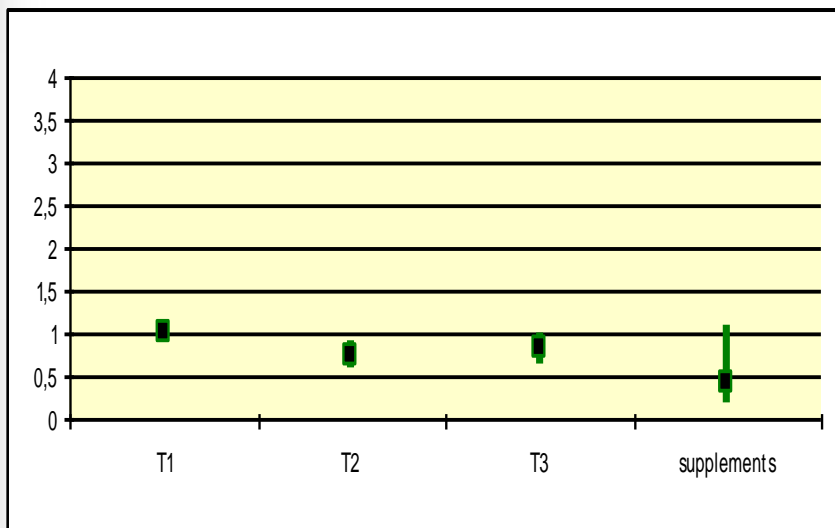
(among more than 400 publications)



Beta-carotene intake and risk of tobacco-related cancers

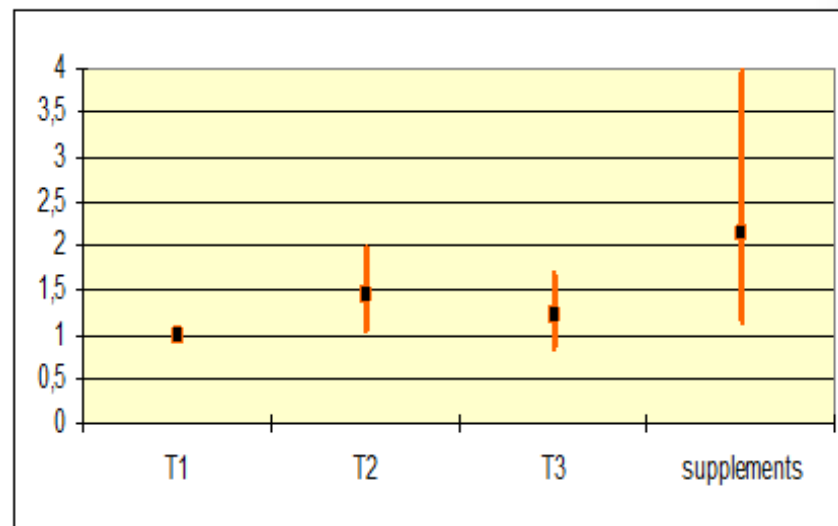
N = 700 cases

Never smoked



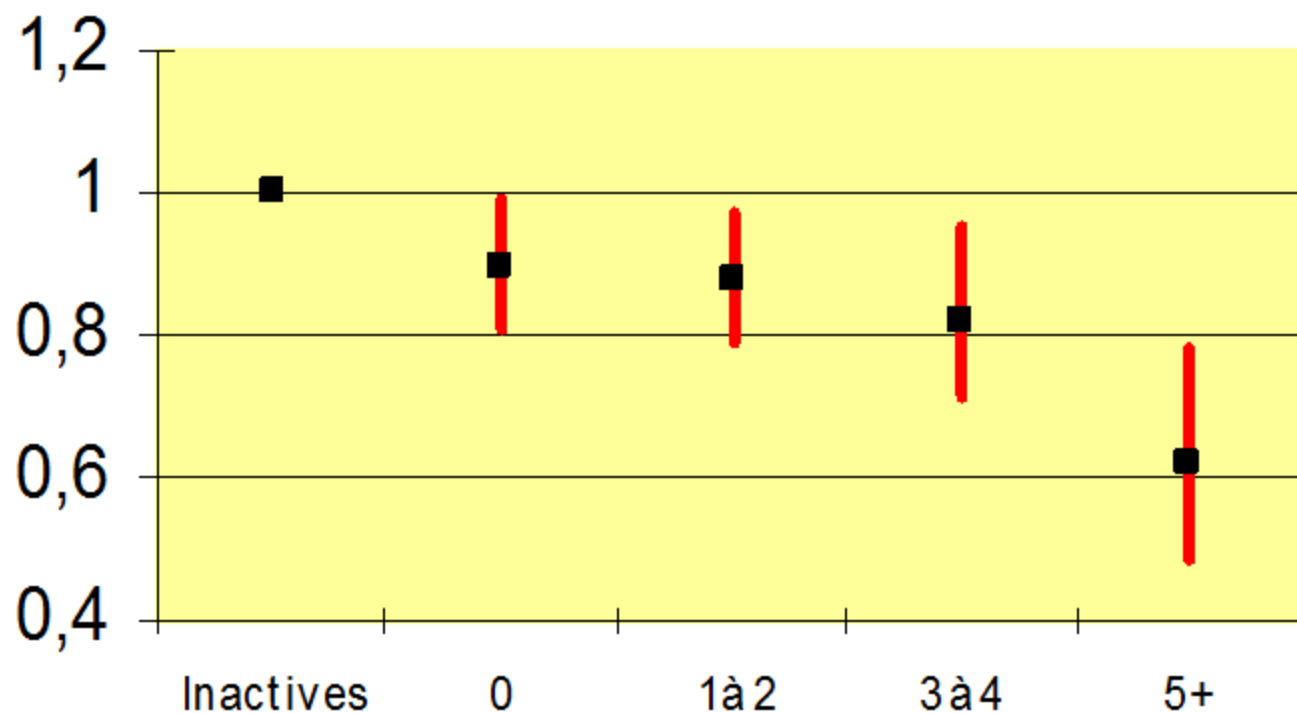
P trend = 0.03

Ever smoked



P trend = 0.09

Intensive physical activity and breast cancer risk

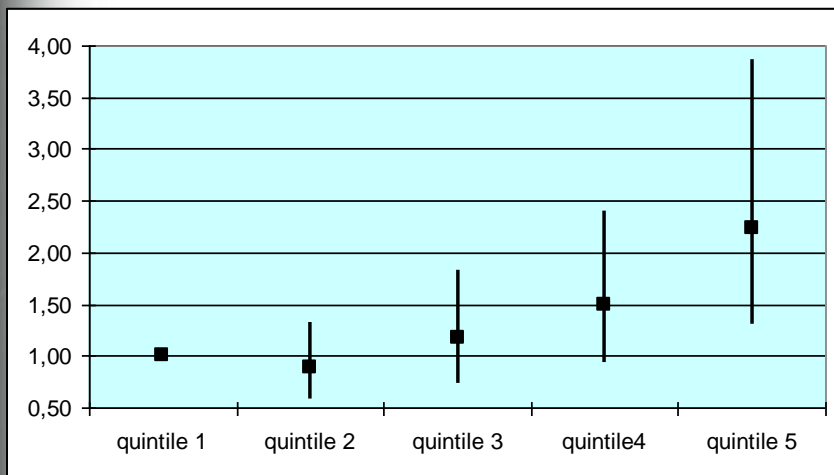


P trend = 0.0001

Tehard et al., CEBP (2006)

Breast cancer risk and biomarkers levels in nested case control studies

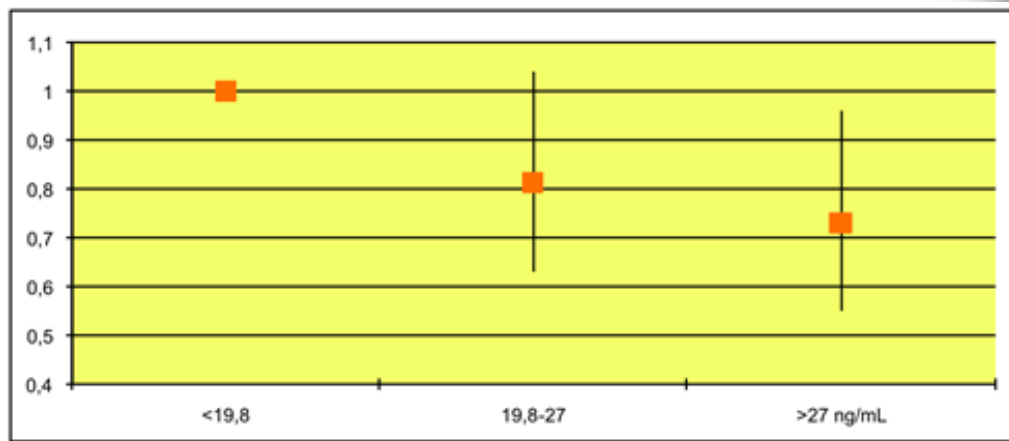
trans 16:1n-7,
trans palmitoleic acid
(n=362 cases – 702 controls)



P trend <0.002

Chajes et al., AJE (2008)

25(OH) vitamin D
(n=636 cases -1272 controls)



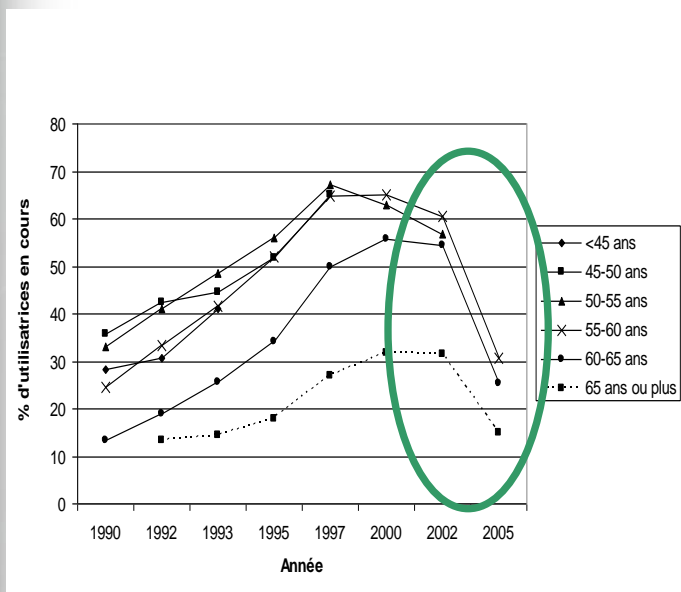
P trend <0.02

Engel et al., CEBP (2010)

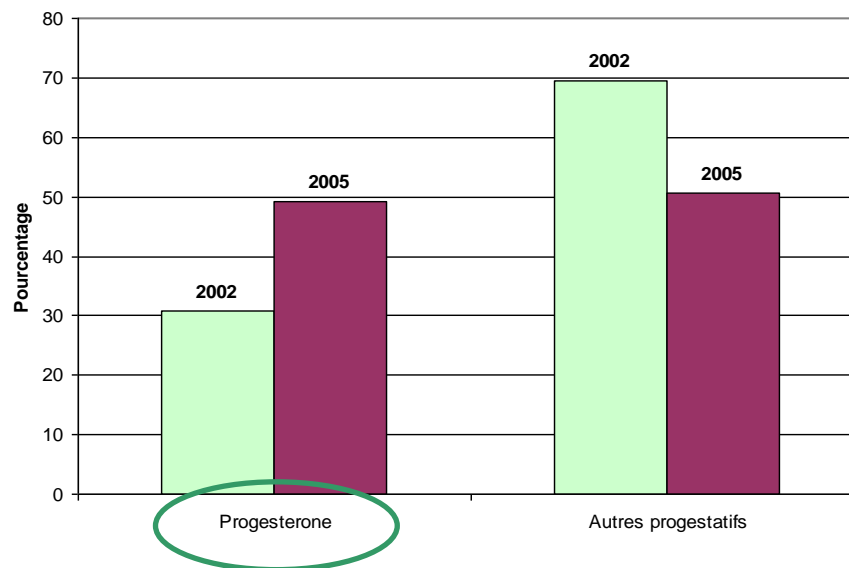
Menopause hormone therapy and breast cancer risk

Trend in MHT use among E3N participants

Prevalence of MHT use



Progestagen component of MHT



E4N

Epidemiology 4 knowledge





E4N – PARTS OF THE PROTOCOL

Part 1

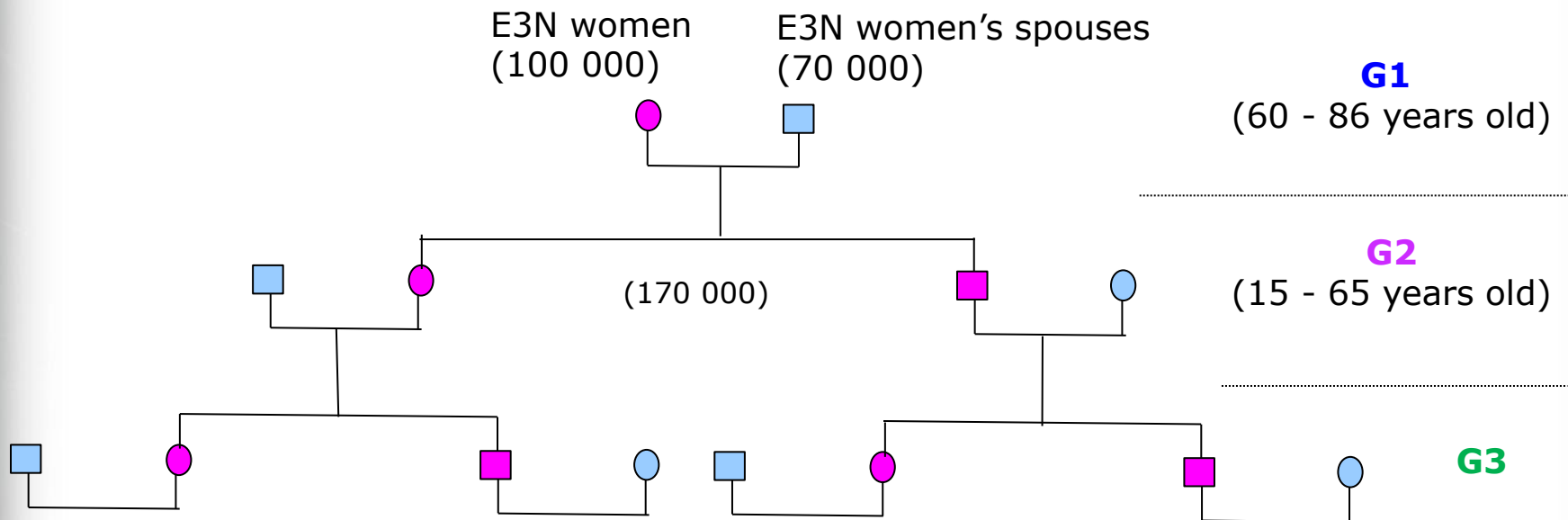
- Develop researches on other diseases than cancer in the E3N cohort
- Include spouses of E3N women

Part 2

- Create a new cohort by including children and grand-children of E3N women

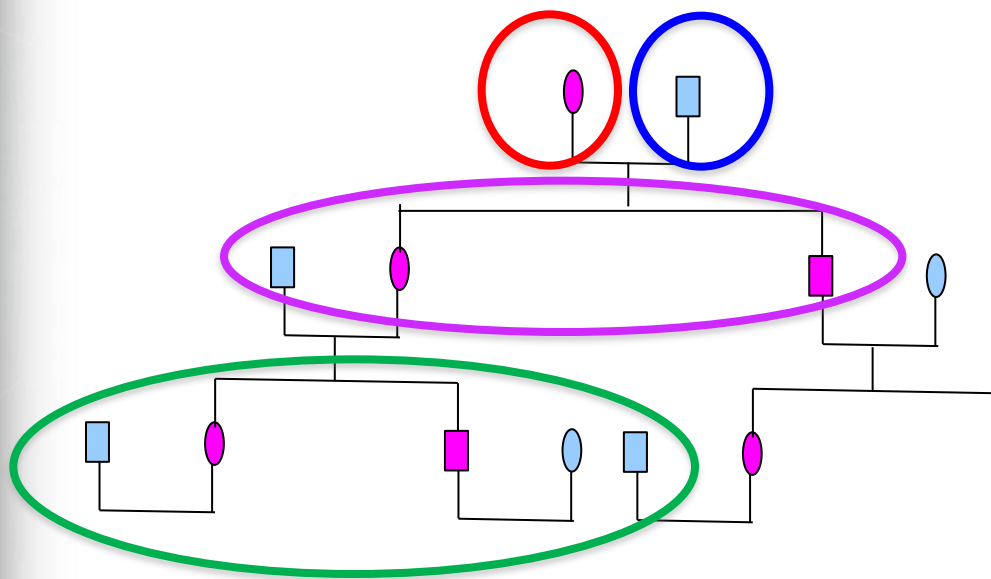
Part 3

- Create a family cohort with children and their spouses and children



■ : E3N participants, or individuals directly linked to an E3N participant

■ : Spouses (men and women)



G1: 100 000 E3N women
G1': 70 000 live spouses
→ 30 000 expected in E4N

G2: E3N women have 170 000 children
→ 50 000 children expected in E4N with their own spouses

G3: 20 000 grand-children expected



E4N – OBJECTIVES GENERATION G1

- Expand E3N beyond cancer: cardiovascular diseases, asthma, fractures, loss of autonomy...
- Study risk factors for male major chronic diseases: among 30 000 participants, after 5 years, over 1 000 cases of prostate cancer and CVD expected
- Investigate incidence of cognitive decline / loss of autonomy in couples
- Collect genetic information on parents and grandparents



E4N – OBJECTIVES GENERATIONS G2 AND G3

- Study risk factors for major chronic diseases occurring in young adults
- Study the influence of environmental factors (“modern” lifestyle) on health
- Evaluate the influence of environmental exposures early in life on the subsequent risk of adult diseases
- Collect genetic information on parents and grandparents: **“family cohort”**, best setting to discover susceptibility genes and gene-environment interactions
- Take into account interactions between basic sciences, clinical research and public health approaches

Generation 1:

- Paper questionnaires: similar to E3N
- Saliva sample (if possible and accepted, blood and/or urine?)

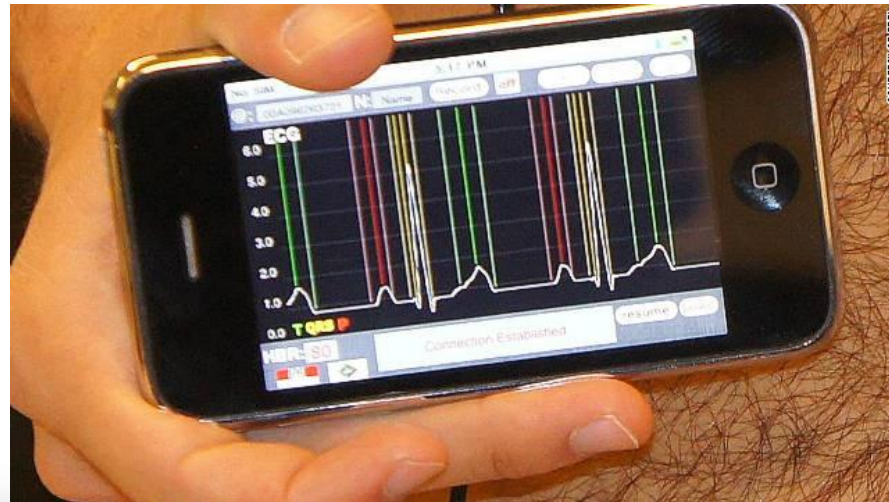
Generations 2 and 3:

- Web-based questionnaires / automated collection of information, whenever possible
- Development of **innovative tools** to recruit, collect information, and maintain the participation
- Saliva sample (if possible and accepted, blood and/or urine?)

- Confidentiality
- Security of the database
- Quality control of all procedures

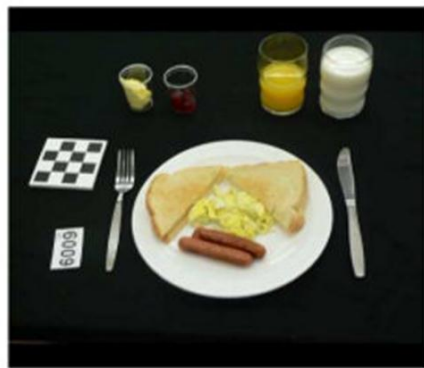
- Easy-to-fill questionnaires
"5-2-2" : 5 questions, 2 minutes, every 2 months
- Tools proposed to visualise one's own data

E4N – DATA COLLECTION VIA SMARTPHONES

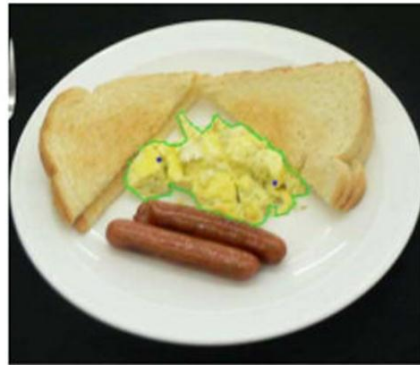


E4N – DATA COLLECTION VIA SMARTPHONES

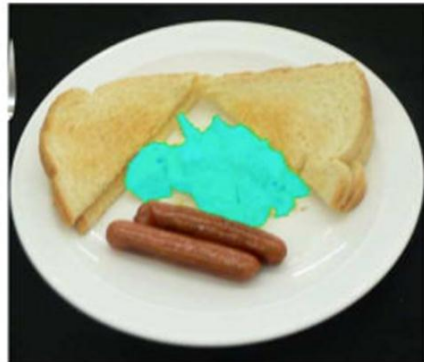
On-going research projects on form recognition...



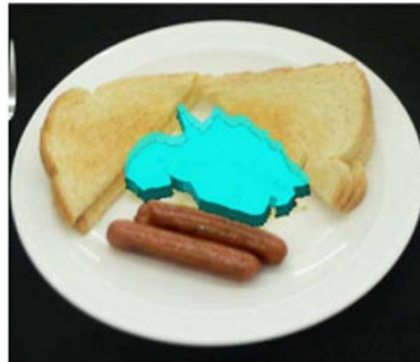
(a)



(b)



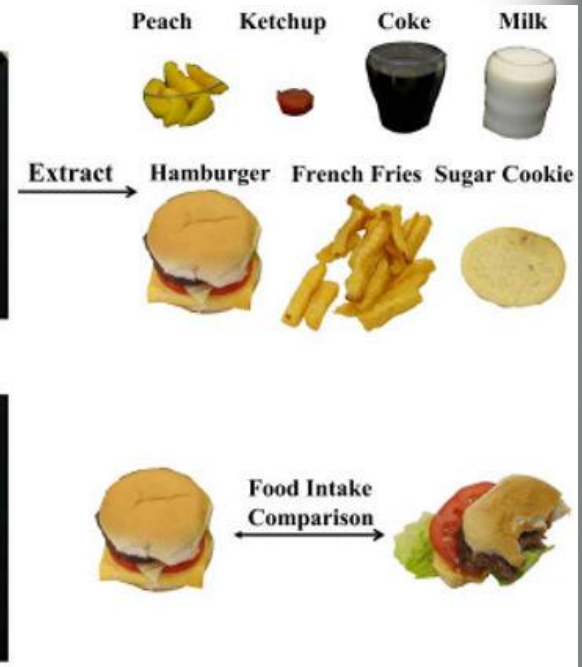
(c)



(d)



After Meal



Ex: Diet record with photos

Give information in return

➤ Individual level:

- Vaccination monitoring, blood analyses,
- Nutrition facts, physical activity data...

➤ Collective level:

- Visualization
- Comparisons

The image shows two parts: a registration form on the left and a diagram on the right.


Registration Form:

- 104,469 patients
- 500+ conditions
- Who's like you?
- Share your experience. The more you share, the more it will be to find experts like you... Start by adding a condition, location or treatment.
- I have:
- I take:
- I am: Male Female
- My Age:
- Join Now! (It's free)

Diagram:

- Top right: "Get your health in order. Join PatientsLikeMe." with a question mark icon.
- Center: A row of human icons with a "YOU" icon highlighted. Below them is the "patientslikeme" logo.
- Bottom right: A blue arrow points from the "YOU" icon to a "your profile" icon, which is connected to a line graph showing an upward trend.

Access to E4N database via an Internet link or via smartphone messages.



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- E4N selected as an **Investment for the future**

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But

- First, acceptance of the E3N women to give addresses of their own children
- Second, high participation rate of the children
 - to be included
 - and to be followed
- are **ESSENTIAL for E4N to be successful**

Thank you
for your
attention





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