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Cohort Profile

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Cohort Profile: The Epidemiology of Chronic Diseases Cohort (EpiDoC)

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Why was the cohort set up?

Non-communicable chronic diseases are the leading cause of death and the main contributor to disease burden worldwide, accounting for 86% of all deaths in Portugal.[1] Several modifiable behavioural risk factors, such as unhealthy dietary habits, physical inactivity, tobacco use and harmful use of alcohol, are the main risk factors for these diseases. Thus, the existence of epidemiological data on chronic diseases and their determinants (i.e. socioeconomic and demographic factors), associated factors and consequences are important public health tools for designing and developing strategies to tackle the burden of non-communicable diseases.

In 2011, a prospective cohort study called Epidemiology of Chronic Diseases (EpiDoC) aimed to create a large population database for medical and health-related research in Portugal. To our knowledge, the EpiDoC study constitutes one of the first Portuguese prospective large cohort studies, including a representative sample of the Portuguese population, with the primary aim of examining the health determinants and outcomes of chronic non-communicable diseases and their impact on health care resource consumption. The EpiDoC study was designed by researchers from NOVA Medical School in Lisbon with close collaboration between social and biomedical scientists, ensuring a thorough multidisciplinary approach.

The first wave of this cohort study, named EpiDoC 1 (EpiReumaPt), occurred between September 2011 and December 2013. Its primary aim was to assess rheumatic and musculoskeletal disease (RMD) prevalence and its burden in Portugal. This wave had two phases: the first consisted of a face-to-face interview, and the second included a detailed clinical evaluation of RMD performed by rheumatologists. This baseline assessment also enabled the creation of a population-based biobank (i.e. DNA, serum and total blood samples) for identifying genetic predictors and serum risk factors for chronic diseases. Musculoskeletal imaging data were also collected, in particular peripheral dual energy X-ray (DXA) in all second phase participants and X-ray of the affected joint(s).

Similar to other cohort studies,[1,2] the scope of the EpiDoC study has expanded over time. So far, two subsequent waves have been completed: EpiDoC 2 (March 2013–July 2015) and EpiDoC 3 (September 2015–July 2016). In both waves, data were collected through a phone interview. EpiDoC 2 (CoReumaPt) focused on lifestyle behaviours and their determinants, with a secondary goal of identifying innovative patient solutions for coping with disability.

EpiDoC 3 (Saúde.Come) assessed inequalities in access to healthy food and health services, with a focus on food insecurity and its determinants and health consequences.

The EpiDoC study was performed according to the principles established by the Declaration of Helsinki and revised in 2013 in Fortaleza. Ethical approval was obtained from the National Committee for Data Protection (Comissão Nacional de Proteção de Dados) and NOVA Medical School Ethics Committee. Ethical committees of regional health authorities also approved the study.

Who is in the cohort?

Setting

EpiDoC is a prospective closed cohort study including a nationally representative sample of adults (≥18 years old) who were non-institutionalized and living in private households in Portugal Mainland and Islands (Azores and Madeira).[3] Portugal is a south-western European country with a resident population of 10 562 178, of whom 8 million are adults (4 072 122 men and 4 585 118 women).[4] During the past two decades, life expectancy in Portugal has been increasing. Data from the World Health Organization indicate that life expectancy in Portugal was 83.9 years for women and 78.2 years for men in 2015. In addition, as in other European countries, the Portuguese population has been undergoing demographic changes. The Portuguese population pyramid shows an increasing number of individuals at the top and a decreasing number at the bottom, indicating a new structure of the Portuguese population with fewer young people and more elderly. In 2015, the old-age dependency ratio was 31.1 per 100 persons of working age, which is the ratio between the number of persons aged ≥65 years (i.e. when individuals are generally economically inactive) and those aged 15–64 years.[5]

Portugal is divided into seven regions according to the Nomenclature of Territorial Units for Statistics II (NUTS II): Norte, Centro, Lisboa e Vale do Tejo, Alentejo, Algarve, Região Autónoma dos Açores (the Azores) and Região Autónoma da Madeira (Madeira). At the NUTS II level, the Norte region has the largest population density (34.7%), followed by Lisboa e Vale do Tejo (26.6%) and Centro (22.4%) (Figure 1). The other NUTS II regions (Alentejo, Algarve, the Azores, and Madeira) encompass small towns and villages with lower population densities and higher desertification rates.

Figure 1. Portuguese population density distribution according to the 7 NUTS II.

Participant recruitment

Considering the primary aim of EpiDoC 1, the sample size was calculated based on the estimated prevalence of rheumatic diseases with a 95% confidence interval (CI), and standardized for age and sex according to the total adult population of the studied areas. Assuming that the expected prevalence of rheumatic diseases was between 0.5% and 1%, and expecting a drop-out rate of 50%, it was estimated that a total of 9000 individuals should be recruited. To obtain regional representativeness, the sample size was stratified according to dimensions and characteristics of the seven Portuguese regions. Population recruitment was conducted by Centro de Estudos e Sondagens de Opinião da Universidade Católica Portuguesa (CESOP-UCP), and multistage random sampling was used for participant selection.

In EpiDoC 1, candidates for participation were visited at their homes by a team of trained interviewers. Locations were selected as the primary unit of sampling according to the Census 2001. Selected households and their addresses were identified using a random selection of points in the map of each location, where the interviewer began a systematic step count (defined for each locality based on its size). Each selected household was visited, with no previous contact, up to three times (including evenings and weekends) if no candidate participant was present during the first visit. In each household, an individual ≥18 years old with permanent residence and the most recently completed birthday was selected to be a participant in the EpiDoC study. Before participant interviews, the EpiDoC team gave information about study details and aims at local churches, primary care centres and municipalities. Local priests, health providers and municipality employers helped us to spread the information and motivate participation.

EpiDoC 1 (2011–13)

EpiDoC 1 enrolled 10 661 participants and was primarily designed to estimate the prevalence of RMDs. To provide a comprehensive understanding of the burden of RMDs, this wave had the secondary aim of evaluating quality of life, physical function, mental health, work status and health care resource consumption, with the purpose of identifying differences in these and other outcomes between individuals with and without RMDs.[3]

EpiDoC 1 data collection consisted of two phases. Phase 1 involved face-to-face interviews conducted by a team of trained interviewers (non-physicians) through door-to-door visits. Phase 2 involved clinical observations with physical examination performed by rheumatologists, for participants identified as potentially having an RMD (using a screening questionnaire applied at Phase 1) and 20% of asymptomatic individuals. All procedures occurred between September 2011 and December 2013.

Of the 10 661 participants selected in Phase 1, 7451 had a positive RMD screening and 3210 had a negative RMD screening. A total of 8152 participants were contacted in Phase 2: 7451 with a positive RMD and 701 (∼20%) without an RMD as previously defined in the study protocol. Of these, 4275 did not attend a clinical observation by a rheumatologist. Therefore, at the end of Phase 2, there were 3877 clinical observations with physical examination performed by rheumatologists; 3198 participants received validation of an RMD diagnosis and 679 did not have an RMD diagnosis.

In Phase 1, a structured questionnaire using a computer-assisted personal interview (CAPI) system was used to collect data. Questions on rheumatic symptoms were asked, and an algorithm for screening each RMD was applied. An individual was considered to have a positive screening: if he/she mentioned a previously known RMD; if any of the specific disease algorithms in the screening questionnaires were positive; or if the participant reported muscle, vertebral or peripheral joint pain in the previous 4 weeks.[3] Phase 2 was performed by rheumatologists at the local primary care centre for all participants who were identified as having a positive RMD screening. All clinical laboratory and imaging data were verified by a team of three experienced rheumatologists, and diagnoses were confirmed according to validated criteria.[3]

All participants enrolled in EpiDoC 1 (10 661 participants) were invited to participate in a follow-up study, of whom 10 153 (95.2%) signed consent forms and agreed to participate. For follow-up waves (EpiDoC 2 and 3), data were collected using a structured questionnaire administered by phone call interviews using a CAPI system. A core questionnaire was used in each EpiDoC wave, with additional questions added according to the focus of each wave. In EpiDoC 2 and 3, when a participant was not available, additional attempts were made at different times up to a maximum of six attempts. The last contact attempt had to follow the previous contact by least 1 month; only then was the contact attempt abandoned.

EpiDoC 2 (2013–15)

EpiDoC 2 was the first follow-up wave, with data collected between March 2013 and July 2015. EpiDoC 2 included 7591 participants (out of 10 153 eligible participants) representative of the adult Portuguese population, resulting in a response rate of 71.2% from EpiDoC 1. Considering that the main risk factors for non-communicable diseases are unhealthy lifestyle behaviours, EpiDoC 2 employed the core structured questionnaire but included more detailed questions on lifestyle behaviours, such as physical activity, dietary habits, tobacco and alcohol use and sleeping habits. Questions regarding innovative patient solutions for coping with disability were also included.

EpiDoC 3 (2015–16)

EpiDoC 3 occurred between September 2015 and July 2016 and included 5653 participants, resulting in a response rate of 55.7% from EpiDoC 1. This wave continued to employ the core structured questionnaire but included questions on food insecurity, its determinants and its health consequences. This particular interest in food insecurity was based on a growing awareness of social inequalities in health and modifiable risk factors for chronic diseases, such as dietary patterns, as well as the economic crisis faced by Portugal in previous years.

Cohort characteristics

The participation rate declined from EpiDoC 1 to EpiDoC 3, similar to most other population-based studies.[2,6] Table 1 presents the characteristics of participants in the cohort. There were no significant differences in any categories of variables between the three waves.

How often have they been followed up?

The EpiDoC study employed cross-sectional and longitudinal study designs (Figure 2). As it used a closed cohort, no new participants were added in any wave. Table 2 presents the attrition rates between EpiDoC 1 and 2, EpiDoC 1 and 3, and EpiDoC 2 and 3.

Table 1. Characteristics of the participants in the cohort

	EpiDoC 1	EpiDoC 2	EpiDoC 3	Census 2011
Sex	*n* = 10 661	*n* = 7591	*n* = 5653	*n* = 8 657 240
Female	6551 (52.6%)	4784 (52.2%)	3607 (52.5%)	4 585 118 (53.0%)
Age group	*n* = 10 661	*n* = 7591	*n* = 5648	
18–29	1182 (22.1%)	621 (18.4%)	355 (15.4%)	1 470 782 (17.0%)
30–39	1511 (18.8%)	975 (18.7%)	605 (19.1%)	1 598 250 (18.5%)
40–49	1906 (17.3%)	1437 (18.2%)	1049 (18.3%)	1 543 392 (17.8%)
50–59	1801 (14.8%)	1437 (16.2%)	1143 (15.9%)	1 400 011 (16.2%)
60–69	1915 (12.9%)	1440 (13.2%)	1112 (13.7%)	1 186 442 (13.7%)
70–74	849 (5.8%)	645 (6.2%)	491 (6.7%)	496 438 (5.7%)
≥75	1497 (8.4%)	1036 (9.1%)	893 (11.0%)	961 925 (11.1%)
Ethnicity/race	*n* = 10 629	*n* = 7574	*n* = 5638	
Caucasian	10 342 (96.0%)	7423 (97.1%)	5536 (97.2%)	No comparable data
Black	221 (3.4%)	119 (2.5%)	81 (2.3%)	
Asian	8 (0.1%)	3 (0.0%)	2 (0.1%)	
Romany	20 (0.3%)	7 (0.1%)	5 (0.1%)	
Other	38 (0.3%)	22 (0.3%)	14 (0.3%)	
Years of education				
(mean ± SD)	7.41 ± 4.1	8.66 ± 3.90	8.80 ± 3.94	
Education level	*n* = 10 585	*n* = 7546	*n* = 5615	
0–4 years	4726 (33.2%)	3272 (31.7%)	2392 (30.9%)	3 239 724 (37.4%)
5–9 years	2175 (22.6%)	1547 (21.3%)	1122 (19.6%)	2 134 401 (24.6%)
10–12 years	1920 (23.8%)	1391 (24.8%)	1049 (25.6%)	1 560 958 (18.0%)
>12 years	1764 (20.4%)	1336 (22.2%)	1052 (24.0%)	1 741 567 (20.1%)
NUTS II	*n* = 10 661	*n* = 7591	*n* = 5648	
Norte	3122 (34.9%)	2240 (35.8%)	1659 (36.5%)	3 007 823 (34.7%)
Centro	1997 (22.8%)	1504 (23.3%)	1087 (23.2%)	1 938 815 (22.4%)
Lisboa	2484 (26.7%)	1588 (25.4%)	1131 (24.8%)	2 300 053 (26.6%)
Alentejo	669 (7.3%)	422 (7.2%)	320 (7.2%)	633 691 (7.3%)
Algarve	352 (3.8%)	245 (3.8%)	183 (3.7%)	370 704 (4.3%)
Azores	1029 (2.2%)	793 (2.1%)	657 (2.5%)	192 357 (2.2%)
Madeira	1008 (2.3%)	799 (2.4%)	611 (2.4%)	213 797 (2.5%)
Marital status	*n* = 10 652	*n* = 7586	*n* = 5644	
Single	1935 (29.4%)	1285 (28.4%)	922 (28.5%)	No comparable data
Married	6111 (50.2%)	4591 (53.2%)	3457 (53.4%)	
Divorced	810 (7.4%)	556 (6.8%)	391 (6.1%)	
Widow(er)	1414 (8.2%)	910 (7.3%)	697 (7.6%)	
Consensual union	382 (4.8%)	244 (4.2%)	177 (4.4%)	
BMI	*n* = 10 109	*n* = 6922	*n* = 5174	
Underweight	167 (2.2%)	111 (2.0%)	88 (2.1%)	No comparable data
Normal	4063 (45.5%)	2670 (45.5%)	2009 (44.5%)	
Overweight	3799 (35.1%)	2788 (37.1%)	2098 (37.7%)	
Obese	2080 (17.1%)	1353 (15.4%)	979 (15.7%)	
Monthly household income	*n* = 7613	*n* = 5558	*n* = 4167	
<500€	1994 (19.9%)	1331 (18.0%)	945 (16.66%)	No comparable data
501€ to 750€	1707 (21.7%)	1257 (20.8%)	949 (20.91%)	
751€ to 1000€	1268 (18.8%)	943 (19.0%)	717 (19.89%)	
1001€ to 1500€	1141 (17.2%)	852 (17.5%)	638 (16.97%)	
1501€ to 2000€	657 (9.9%)	511 (10.9%)	386 (11.08%)	
2001€ to 2500€	379 (5.9%)	295 (5.7%)	246 (6.37%)	
2501€ to 3000€	222 (3.0%)	188 (3.8%)	148 (3.98%)	
3001€ to 4000€	146 (1.8%)	108 (2.1%)	83 (1.94%)	
>4000€	99 (1.9%)	73 (2.2%)	55 (2.20%)	

SD, standard deviation.

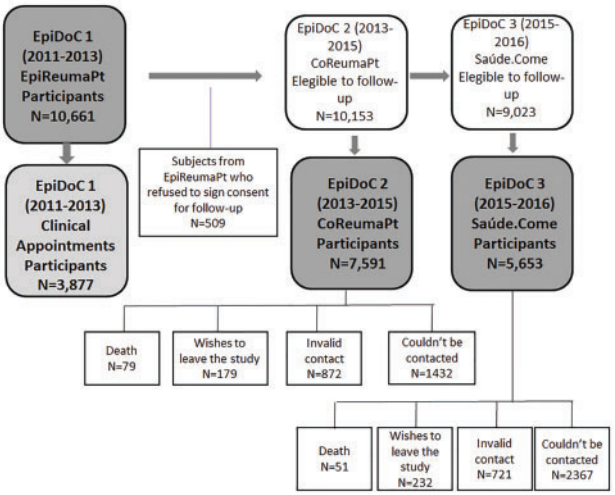

Figure 2. Flowchart of EpiDoC study.

Loss to follow-up

The participation rate in EpiDoC 3 was of 53.03%. The attrition was most pronounced in younger adults (18–29 years old). Of the 10 661 participants in EpiDoC 1,509 (4.8%) refused to sign the consent form for follow-up. Of the resulting 10 153 eligible participants for EpiDoC 2, 79 (0.8%) had died, 179 (1.8%) wished to leave the study and 917 (9.0%) had an invalid contact. Thus, a total of 1639 participants were lost to follow-up; these subjects had a mean age of 55 years, and 962 (58.7%) were women. Between EpiDoC 2 and 3, 51 (0.6%) participants had died, 232 (2.6%) wished to leave the study and 721 (8.0%) had an invalid contact. Thus, a total of 1004 participants were lost to follow-up; these individuals had a mean age of 56 years, and 620 (61.8%) were women. Figure 1 shows the flowchart of the EpiDoC study.

What has been measured?

Data collection included measures for five domains that were central to the longitudinal study: sociodemographic characteristics, lifestyle characteristics, health and clinical characteristics, health care resource consumption, a population-based biobank (total blood, serum and DNA) and imaging data (peripheral DXA and X-ray of the affected joint) (Table 3). For reasons of longitudinal comparison, most measurement tools were used consistently across waves. However, some measurement tools were updated or improved, new measurement tools were added and old measurement tools were removed as needed.

Of the measurements obtained across all three waves, lifestyle variables included smoking habits, alcohol intake and physical exercise. Health variables included anthropometric measures, self-reported chronic diseases, rheumatic diseases, a health assessment questionnaire (HAQ)[7] and the European Quality of Life Survey with five dimensions and three levels (EQ-5D-3L).[8,9] Employment variables included employment status, retirement due to disease, retirement due to RMD, work absenteeism due to disease, work disability due to RMD, unemployment due to disease, unemployment due to RMD, number of working hours/week and changed employment status due to RMD. Health care resource variables included hospitalization events (in previous 12 months since last contact), their reason and their duration. Concerning falls and bone fractures, variables included any falls or bone fractures and the number and location of bone fractures. Sociodemographic data, including sex, age, ethnicity, years of education and education level, and marital status, were collected only in EpiDoC 1, based on the assumption that these characteristics would not change over time. Other information obtained only in EpiDoC 1 were household income, household composition, coffee intake and health information from the 36-item Short Form Survey (SF-36).[10]

Information obtained only in EpiDoC 1 and 2 were the Hospital Anxiety and Depression Scale (HADS)[11] and home care assistance (in previous 12 months or since last contact), its provider and its payer.

Information obtained only in EpiDoC 2 and 3 included: sleep habits; frequency of watching TV, using computer/videogames/tablets and using the internet; number of meals per day; frequency of soup, vegetable, fruit, meat, fish, milk/dairy and water consumption; numbers of medical appointments (in previous 12 months or since last contact), private versus public medical appointments, private medical appointments with or without insurance, public medical appointments in a hospital/health care centre and private or public medical appointments by specialty.

Information obtained only in EpiDoC 3 were frequency of olive oil, wine, beans, fat and sugar consumption; attitudes toward food; a food insecurity scale; and characteristics of food acquisition and preparation.

Population-based biobank and imaging data were collected in EpiDoC 1 during medical appointments at the local primary care centre. Blood samples were collected from 3608 participants (DNA, serum and whole blood). Taking into consideration the imaging reservoir, there were a total of 3342 participants who had a forearm bone mineral density evaluation through peripheral DXA. Also, bone mineral assessment (BMA) using a high-resolution digital X-ray machine (D3A, France) was collected from 2422 wrists and 2228 calcaneus bones. Simple X-rays were performed to examine 438 hands, 122 hips, 479 knees, 1265 lumbar spines, 691 thoracic spines and 206 cervical spines, according to participants' musculoskeletal complaints. All data collected, including biobank and imaging data, are detailed in Table 3.

Table 2. Characteristics of the participants in the cohort (attrition rate)

	EpiDoC 1 vs EpiDoC2 (attrition rate)	EpiDoC 2 vs EpiDoC3 (attrition rate)	EpiDoC 1 vs EpiDoC3 (attrition rate)
Total	28.80%	25.53%	46.97%
Sex			
Female	26.97%	24.60%	44.94%
Age group			
18–29	47.46%	42.83%	69.97%
30–39	35.47%	37.95%	59.96%
40–49	24.61%	27.00%	44.96%
50–59	20.21%	20.46%	36.54%
60–69	24.80%	22.78%	41.93%
70–74	24.03%	23.88%	42.17%
≥75	30.79%	13.80%	40.35%
Ethnicity/race			
Caucasian	28.22%	25.42%	46.47%
Black	46.15%	31.93%	63.35%
Asian	62.50%	33.33%	75.00%
Romany	65.00%	28.57%	75.00%
Other	42.11%	36.36%	63.16%
Education level			
0–4 years	30.77%	26.89%	49.39%
5–9 years	28.87%	27.47%	48.41%
10–12 years	27.55%	24.59%	45.36%
>12 years	24.26%	21.26%	40.36%
NUTS II			
Norte	28.25%	25.94%	46.86%
Centro	24.69%	27.73%	45.57%
Lisboa	36.07%	28.78%	54.47%
Alentejo	36.92%	24.17%	52.17%
Algarve	30.40%	25.31%	48.01%
Azores	22.93%	17.15%	36.15%
Madeira	20.73%	23.53%	39.38%
Marital status			
Single	33.59%	28.25%	52.35%
Married	24.87%	24.70%	43.43%
Divorced	31.36%	29.68%	51.73%
Widow(er)	35.64%	23.41%	50.71%
Consensual union	36.13%	27.46%	53.66%
BMI			
Underweight	33.53%	20.72%	47.31%
Normal	34.29%	24.76%	50.55%
Overweight	26.61%	24.75%	44.77%
Obese	34.95%	27.64%	52.93%
Monthly household income			
<500€	33.25%	29.00%	52.61%
501€ to 750€	26.36%	24.50%	44.41%
751€ to 1000€	25.63%	23.97%	43.45%
1001€ to 1500€	25.33%	25.12%	44.08%
1501€ to 2000€	22.22%	24.46%	41.25%
2001€ to 2500€	22.16%	16.61%	35.09%
2501€ to 3000€	15.32%	21.28%	33.33%
3001€ to 4000€	26.03%	23.15%	43.15%
>4000€	26.26%	24.66%	44.44%

Table 3. Data collected over EpiDoC study

	EpiDoC 1 EpiReumaPt (CESOP) 10 661	EpiDoC 1 EpiReumaPt (medical appointments) 3877	EpiDoC 2 CoReumaPt 7591	EpiDoC 3 Saúde.Come 5653
Sociodemographic and economic data				
Sex	X			
Age	X			
Ethnicity	X			
Nationality	X			
Years of education and educational level	X			
Marital status	X			
Employment status	X		X	X
Household income	X			X
Household composition	X			X
Number of people <18 y in household	X			X
Number of people >65 y in household				X
Region (NUT II)	X			
Location and district	X			
Home & neighbourhood characteristics	X			
Single-parent families				X
Income perception				X
Anthropometric data				
Self-reported height (in cm)	X	X	X	X
Self-reported weight (in kg)	X	X	X	X
Body mass index (kg/m^2)	X	X	X	X
Self-reported chronic diseases				
High blood pressure, diabetes, high cholesterol level, pulmonary disease, cardiac disease, gastrointestinal disease, neurological disease, allergies, mental disease, neoplastic disease, thyroid and parathyroid disease, hyperuricaemia and urinary disease	X	X	X	X
Rheumatic diseases				
Rheumatoid arthritis, spondyloarthritis, psoriatic arthritis, osteoarthritis, osteoporosis, gout, polymyalgia rheumatica, systemic lupus erythematosus, fibromyalgia, periarticular diseases, low back pain, inflammatory low back pain, chondrocalcinosis and other RMD	X	X	X	X
Who diagnosed RMD	X		X	X
Rheumatic complaints	X	X	X	X
Medical history		X		
Physical examination		X		
Anxiety, depression, physical function and quality of life				
Hospital Anxiety and Depression Scale (HADS)	X		X	
Health Assessment Questionnaire (HAQ)	X		X	X
Short Form Health Survey (SF-36)	X			
European Quality of Life questionnaire (EQ-5D-3L)	X		X	X
Falls and bone fractures				
Suffered any fall, where the fall happened (home, street, work), number of falls (home, street, work), suffered any bone fracture, number of bone fractures and location of bone fracture	X		X	X
Health and employment				
Retired due to disease, retired due to RMD, work absenteeism due to disease, work disabled due to	X		X	X

(Continued)

Table 3. Continued

	EpiDoC 1 EpiReumaPt (CESOP) 10 661	EpiDoC 1 EpiReumaPt (medical appointments) 3877	EpiDoC 2 CoReumaPt 7591	EpiDoC 3 Saúde.Come 5653
RMD, unemployed due to disease, unemployed due to RMD, number working h/week and changed employment status (past year) due to RMD				
Health and economic				
Chronic disease management difficulties, medication non-adherence due to economic constraints, and reduction in visits to medical appointments due to economic constraints				X
Hospitalizations, home care assistance and medical appointments				
Was hospitalized (past 12 months/since last contact), reason and duration of hospitalization, home care assistance (past 12 months/since last contact, currently), who provides and who pays for home care assistance, medical appointments (past 12 months/since last contact), number private/public medical appointments, private medical appointments with/without insurance, public medical appointments in hospital/health care centre, number private/public medical appointments by specialty, health care system (ADSE, subsystems, private insurance), medications and other treatments, medicine(s) currently taking, other treatments (physical and rehabilitation medicine, behavioural therapy etc.) and alternative treatments (acupuncture, homeopathy etc.)	X		X	X
Lifestyle data				
Smoking habits (current/past smoker, number of cigarettes, smoking duration)	X		X	X
Alcohol intake (frequency, number of units)	X		X	X
Coffee intake	X			
Physical exercise (frequency, type, age when started)	X		X	X
Sleep habits (h/day)			X	X
Frequency of watching TV			X	X
Frequency of using computer/videogames/tablets			X	X
Frequency of using internet			X	X
Dietary intake and behaviours				
Frequency of soup, vegetables, fruit, meat, fish, milk/dairy, water consumption			X	X
Adherence to Mediterranean diet				X
Food insecurity				X
Patient innovation to cope with disability			X	
Biobank and imaging data				
Serum, whole blood, DNA, peripheral BMD (wrist), X-ray of the affected joint (hand, hip, knee), calcaneus and wrist BMA		X		

What has it found? Key findings and publications

Over 24 peer-reviewed journal publications based on EpiDoC data have been published to date, covering a wide range of scientific domains. A full list of publications can be found on our website[http://cedoc.unl.pt/epidoc-unit/]. Sample overviews of study data are shown in Tables 1, 2 and 4. Here, we summarize key findings.

In EpiDoC 1, we characterized socioeconomic features of the Portuguese adult population. From a social and health point of view, an alarming finding was that one-fifth of the adult Portuguese population had a monthly

Table 4. Prevalence and 95% of confidence interval of reported chronic diseases and lifestyle habits

	EpiDoC 1		EpiDoC 2		EpiDoC 3	
	$n = 10\,661$		$n = 7591$		$n = 5653$	
Reported diseases						
Chronic diseases	$n = 10\,661$	95% CI	$n = 7591$	95% CI	$n = 5653$	95% CI
High blood pressure	3369 (23.1%)	21.9–24.9	2538 (24.1%)	22.7–25.5	1872 (24.8%)	23.1–26.7
Diabetes	1217 (8.3%)	7.6–9.1	877 (8.6%)	7.8–9.5	690 (9.2%)	8.1–10.4
High cholesterol level	3360 (24.4%)	23.2–.25.7	2595 (25.9%)	24.5–27.4	1831 (25.3%)	23.6–27.2
Lung disease	637 (5.4%)	4.6–6.3	496 (5.7%)	4.8–6.7	213 (2.8%)	2.4–3.3
Cardiac disease	1366 (10.5%)	9.4–11.6	1034 (11.9%)	10.5–13.4	704 (9.8%)	8.7–11.1
Gastrointestinal disease	1837 (14.9%)	13.8–16.1	1411 (16.1%)	14.7–17.6	544 (8.8%)	7.6–10.3
Neurological disease	418 (3.3%)	2.8–3.9	311 (3.4%)	2.8–4.1	212 (2.9%)	2.4–3.4
Allergies	2287 (21.2%)	19.9–22.7	1720 (22.8%)	21.2–24.5	548 (10.3%)	8.6–12.3
Mental disease	1619 (12.9%)	11.7–14.1	1274 (14.1%)	12.4–16.0	1008 (13.4%)	12.3–14.5
Cancer	439 (3.4%)	2.8–4.2	364 (4.0%)	3.3–4.9	318 (4.6%)	3.8–5.5
Hyperuricaemia	690 (5.2%)	4.7–5.8	514 (5.4%)	4.8–5.9	130 (1.9%)	1.5–2.4
Renal colic	885 (7.0%)	6.4–7.8	716 (8.4%)	7.3–9.6	250 (4.3%)	3.4–5.4
Rheumatic disease	2994 (21.2%)	20.0–22.5	2552 (25.5%)	24.0–27.1	2096 (29.5%)	27.5–31.5
Lifestyle habits						
Alcohol						
Never	4625 (37.2%)	35.6–38.8	3150 (37.1%)	35.2–39.2	1945 (30.6%)	28.2–33.2
Occasionally	3967 (42.6%)	40.9–44.3	2437 (39.6%)	37.7–41.7	2020 (39.6%)	37.4–42.0
Daily	2050 (20.2%)	18.9–21.6	1693 (23.2%)	21.7–24.8	1565 (29.8%)	27.7–31.9
Smoking habits						
Never/occasionally	8800 (76.8%)	75.1–78.4	4447 (54.4%)	52.3–56.4	3584 (58.8%)	56.3–61.3
Past smoking[a]	Not applicable		1522 (21.1%)	19.6–22.6	1149 (21.1%)	19.4–23.0
Present smoker	1854 (23.2%)	21.6–24.9	1289 (24.5%)	22.4–26.7	802 (20.0%)	17.6–22.7
Physical activity						
Regular	3499 (37.0%)	35.3–38.6	3442 (50.1%)	48.1–52.1	2147 (40.8%)	38.5–43.2
Not regular	7155 (63.0%)	61.3–64.6	3976 (49.8%)	47.9–51.9	3498 (59.2%)	56.8–61.5

[a]Past smoker was not included at baseline.

family income of <500€.[3] Indeed, data from EpiDoC 2 showed that poverty and a low education level are associated with an unhealthy lifestyle and higher prevalence of chronic diseases.[12]

Social inequality in health is a major concern within public health, with food insecurity being one of its main drivers. Food insecurity is defined as a difficulty in achieving a healthy diet due to economic constraints, and is a well-known determinant of health. EpiDoC 3 showed a high prevalence of food insecurity and its associations and unhealthy dietary behaviours. Food insecurity was associated with several non-communicable diseases, lower quality of life and higher health care resource consumption.[13] Publications using EpiDoC data have raised questions and informed policy makers about the need to reduce food insecurity, not only to improve individual health status but also to reduce public health costs.

Considering health and health-related characteristics, high blood pressure, high cholesterol level, allergies and RMDs were frequently self-reported among the Portuguese adult population. The prevalence of RMDs in Portugal is similar to that reported in other countries,[14–19] namely Portugal's close neighbour Spain.[20] Another interesting finding was the high proportion of individuals presenting typical features of one or more RMDs, who did not have a previous diagnosis (1532 out of 3877 participants).[21] This could be explained by the scarce number of rheumatologists in Portugal (1: 100 000 inhabitants)[22] and the lack of awareness among the population about these diseases, as RMD symptoms are frequently accepted as part of the normal ageing process. These results helped support a new national network for hospital reference of rheumatology, developed by the National Directorate General of Health in collaboration with the EpiDoC research team.

The RMD with the highest prevalence in Portugal was low back pain (26.4%; 95% CI, 23.3-29.5%), which was significantly more frequent in women than in men (29.6% vs 22.8%; $P = 0.040$). Low back pain increased with age, and its prevalence was highest in the 46–55-year age group (27.7%; 95% CI 23.1-32.4%).[21]

Regarding the impact of RMDs on health-related quality of life, physical function and mental health among the Portuguese population, EpiDoC data showed that patients with RMDs have more health care resource consumption, were more often hospitalized and had more homecare support needs in the previous 12 months, compared with participants with no RMDs.[12,21,23] In EpiDoC 1, a meaningful number ($n = 488$, 30.9%) of people claimed to have retired prematurely due to RMDs.[24] This translates to many years of working life already lost and many others still potentially lost. Indirect costs due to self-reported RMDs are also substantial, equivalent to at least 0.5% of the gross domestic product.[21] These results emphasize the burden of RMDs and the need to develop RMD awareness, which is a strong argument encouraging policy makers to increase the amount of resources allocated to the treatment of rheumatic patients.

EpiDoC 1 also showed a high prevalence of other chronic diseases among Portuguese adults such as dyslipidaemia (24.4–25.9%), hypertension (23.1–24.8%) and diabetes (7.6–9.1%). The elderly are a particularly vulnerable population for chronic diseases, among whom the coexistence of two or more chronic diseases is particularly high (78.3%), leading to low quality of life and disability.[25] The most common chronic diseases in the elderly were hypertension (57.3%), rheumatic disease (51.9%), hypercholesterolaemia (49.4%) and diabetes (22.7%). Among older adults, 66.6% were physically inactive and 22.3% were obese, particularly among Azoreans (33.0%). Similar results were found for Portuguese adults, of whom more than half did not exercise (63.0%) and more than 15% were obese.[25]

EpiDoC 2 estimated a prevalence of anxiety and depression among Portuguese elderly of 9.6% and 11.8%, respectively. Seniors with anxiety or depression were more likely to self-report higher levels of physical disability and lower quality of life.[26]

Biological and clinical data have been used in national studies of older adult lifestyles,[23,27] the impact of falls and fractures, vitamin D level, sun exposure, dairy consumption and oral health, as well as international collaborative projects on mitochondrial DNA and BMA and bone texture in osteoarthritis.[28]

In conclusion, EpiDoC publications have improved our understanding of socioeconomic and health inequalities among Portuguese adults, particularly the elderly. These studies demonstrate that unhealthy lifestyles are more prevalent among the most socioeconomically vulnerable groups and are associated with a higher prevalence of chronic non-communicable diseases and higher health care resource consumption. The EpiDoC study has also shed light on the burden of rheumatic diseases in Portugal. It shows a need to rethink the rheumatology support network and to provide better care to rheumatic patients. EpiDoC ongoing work is aimed at revealing the determinants and burden of multimorbidity and other chronic non-communicable diseases, namely mental and cardiovascular diseases. Particular attention will be directed at better understanding unmet elderly health needs.

What are the main strengths and weaknesses?

The main strengths of the EpiDoC study are its general population base and sample size, availability of repeated measures and extensive biobank blood collection. Another strength is its interdisciplinary research cooperation, with a team comprising physicians, psychologists, epidemiologists, nutritionists, statisticians, laboratory technicians and others. The different purposes of the three waves are also a strength, as they have expanded the scope of the EpiDoC study to become a more complete cohort study.

The EpiDoC study also has some weaknesses, such as its attrition rate, which is similar to that of other studies[29,30] and was not significantly different between the three waves. In EpiDoC 2 and EpiDoC 3, data were collected by phone interviews; however, we attempted to reduce attrition bias by using reminders for scheduled visits and sending periodic newsletters and reminders to all participants. Another limitation is that diseases were self-reported, although a detailed and comprehensive questionnaire included a screening for RMD symptoms. All measurement tools (HADS, EQ-5D-3L, SF-36 and HAQ) were validated and the screening of RMDs was validated by an algorithm supplemented by expert rheumatologist opinion. Each wave survey was composed of a structured comprehensive questionnaire which was tested for feasibility, participant comprehension and language.[3,12]

Can I get hold of the data? Where can I find more information?

The EpiDoC Unit promotes research networking—both national and international—and develops collaborative projects. Data from our cohort studies and projects are freely available for researchers who submit a research proposal to the scientific committee. More details about questionnaire content and clinical measurements can be found on our website [http://cedoc.unl.pt/epidoc-unit/]. A research proposal editable form can be downloaded and sent to [rute.sousa@nms.unl.pt]. An EpiDoC steering committee will evaluate all proposals for future studies and collaborations, to access data and use of biological samples.

Profile in a nutshell

- EpiDoC is a prospective population-based closed cohort study that collects health information. The study primarily aimed to address rheumatic diseases, but its scope has broadened to other chronic diseases, namely cardiovascular, gastroenterological, pulmonary, anxiety and depression and neurological diseases.
- Three health surveys of the general adult population (aged ≥18 years) in Portugal were completed: EpiDoC 1 (September 2011–December 2013), EpiDoC 2 (March 2013–July 2015) and EpiDoC 3 (September 2015–July 2016).
- EpiDoC surveys have spanned a total of 5 years, with an attrition rate of approximately 25%. EpiDoC 1, 2 and 3 had 10 661, 7591 and 5663 participants, respectively.
- The EpiDoC sample is representative of the Portuguese population. In EpiDoC 1, 6551 (52.6%) participants were women, and most were Caucasian (n = 10 342, 96.0%) and married (n = 6111, 50.2%). In EpiDoC 2, 4784 (52.2%) participants were women, and the mean age of all participants was 48.0 ± 18.0 years. In EpiDoC 3, 3607 (52.5%) participants were women, and the mean age of all participants was 49.64 ± 18.11 years.
- EpiDoC data are available to researchers who submit research proposals to the scientific committee. More details can be found on our website [http://cedoc.unl.pt/epidoc-unit/].

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