

remaining at EDSS  $\leq 3$ . Costs associated with disability would be reduced from €938.1 million to €841.1 million, driven by reduced informal care (€47.8 million savings) and community services costs (€16.0 million savings). Total direct cost savings for the cohort would approach €34.3 million (€7,027 per patient). Total indirect cost savings would exceed €160.0 million (€32,795 per patient). **CONCLUSIONS:** The results of this model suggest that use of PEG-IFN compared with GA in the treatment of RRMS in Spain is a potential cost-saving strategy that could moderate healthcare resource use and improve patient outcomes. Additional research using real-world comparative effectiveness studies should be conducted

## PND35

## HEALTHCARE, SICKNESS ABSENCE, AND DISABILITY PENSION COST TRAJECTORIES IN FIVE YEARS FOLLOWING MS DIAGNOSIS: REGISTER-BASED PROSPECTIVE COHORT STUDIES IN SWEDEN

Karampampa K<sup>1</sup>, Gyllenstein H<sup>2</sup>, Yang F<sup>2</sup>, Murley C<sup>2</sup>, Friberg E<sup>2</sup>, Hillert J<sup>2</sup>, Alexanderson K<sup>2</sup>

<sup>1</sup>Karolinska Institutet, Stockholm, AB, Sweden, <sup>2</sup>Karolinska Institutet, Stockholm, Sweden

**OBJECTIVES:** To explore healthcare, sickness absence (SA), and disability pension (DP) cost trajectories among people with multiple sclerosis (PwMS) following diagnosis, accounting for socioeconomic characteristics and comorbidities. **METHODS:** All PwMS in Sweden, 25-60 years old at MS diagnosis, according to the National Patient Register, were included. Microdata were linked from several nationwide registers. Four cohorts, based on diagnosis year (2006-2009) were followed prospectively, for 5 years, regarding 1) direct costs: healthcare and out-of-pocket expenditure, and prescribed drugs, and 2) indirect costs: SA and DP. Average per patient costs were calculated, in 2017 Swedish Krona (SEK). A group-based trajectory Poisson model was used, mapping cost progression and assessing heterogeneity based on socioeconomic characteristics (age, gender, education, type of living area, geographic region, country of birth, marital status), and comorbidities at diagnosis year. **RESULTS:** Five cost trajectories were identified among the 3272 PwMS. One, where 32.2% of PwMS belonged, had high direct and indirect costs, first increasing and then decreasing. This was in line with the average direct costs in the overall study population, increasing the 1st year, and then declining 3 years after (e.g., for the 2009 cohort, from SEK 87,796 to 97,801, and then to 80,394). Another trajectory had low direct and indirect costs, first decreasing and then increasing, possibly explained by the decrease in SA over time and increase in DP, indicating a shift from short-term to long-term social security benefits. A 3rd trajectory, where only 2.4% of PwMS belonged, had high direct and indirect costs, which decreased substantially after 4 years. Finally, the last two trajectories had either high direct or indirect costs. Socioeconomic consequences and comorbidities differed significantly across trajectory groups. **CONCLUSIONS:** There is heterogeneity across subgroups of newly diagnosed PwMS; their socioeconomic and health outcomes differ significantly, leading to different cost trajectories over time.



## PND36

## COSTS OF MULTIPLE SCLEROSIS IN DENMARK: A REGISTER BASED STUDY

Emneus M<sup>1</sup>, Green A<sup>2</sup>, Sortso C<sup>1</sup>, Sørup Yssing C<sup>1</sup>, Zeeberg Steenstrup N<sup>3</sup>, Fast T<sup>1</sup>, Komkova A<sup>4</sup>

<sup>1</sup>Institute of Applied Economics and Health Research, Copenhagen, Denmark, <sup>2</sup>University of Southern Denmark, Odense, Denmark, <sup>3</sup>The Danish Multiple Sclerosis Society, Copenhagen, Denmark, <sup>4</sup>Institute of Applied Economics and Health Research, Copenhagen, 84, Denmark

**OBJECTIVES:** Multiple sclerosis (MS) presents at a relatively young age and incidence among women is double as high as among men. There is no cure for the progressive forms of MS but Disease Modifying Treatment (DMT) might slow progression in the relapsing forms. This study aims to analyze the costs of MS in Denmark in 2014. **METHODS:** The unique Danish registers allow us to include all individuals with MS in Denmark. In 2014, all individuals with MS (N=14,786, period prevalence) were ascertained and characterized by treatment from the Danish health and social registers and matched with controls by age and gender. Attributable costs of MS in 2014 were analyzed by comparing the healthcare, nursing and productivity loss costs between the cohorts. **RESULTS:** The estimated attributable costs of MS in 2014 in Denmark were 3.2 billion DKK (1 Euro=7.45 DKK). Expressed as attributable costs per person-year with MS healthcare costs were 84,786 DKK (hereof pharmaceuticals 2,740 DKK, primary care 10,715 DKK and secondary care 71,331 DKK). Nursing care accounted for 59,345 DKK and productivity loss due to unemployment and early retirement 72,460 DKK. On average, women had 15% lower total attributable costs than men. The number of patients in DMT have increased rapidly over time and in 2014 constituted 52% of the MS population. Total attributable costs for patients in DMT were 233,965 DKK per person-year compared to 214,275 DKK for patients not in DMT. **CONCLUSIONS:** MS has a major impact on societal costs. MS-patients in DMT have 5.3 times higher secondary care costs due to medication in an outpatient setting, while MS-patients not in DMT are on average older and have about 4.5 times higher nursing costs.



## PND37

## COST OF MOTOR NEURONE DISEASE IN CYPRUS

Kyriakou M<sup>1</sup>, Athanasakis K<sup>2</sup>, Polyzos N<sup>3</sup>, Galanis P<sup>4</sup>, Konstantakopoulou O<sup>5</sup>, Kaitelidou D<sup>5</sup>, Theodorou M<sup>6</sup>

<sup>1</sup>Open University of Cyprus, Nicosia, Cyprus, <sup>2</sup>National School of Public Health, Athens, Greece, <sup>3</sup>Democritus University of Thrace, Komotini, Greece, <sup>4</sup>Center for Health Services Management and Evaluation, National and Kapodistrian University of Athens-Greece/Open University of Cyprus, Latsia, Cyprus, <sup>5</sup>Center for Health Services Management and Evaluation, National and Kapodistrian University of Athens, Athens, Greece, <sup>6</sup>Open University of Cyprus, Latsia, Nicosia, Cyprus



**OBJECTIVES:** Motor Neurone Disease is a progressive neurodegenerative disease that impairs initially the muscles of the limbs and gradually progress by affecting the rest of the body (i.e. the speech, the swallowing process and the respiratory system). There is currently no effective cure for the specific disease; hence the treatment remains symptomatic and supportive. The aim of this study was to evaluate and quantify the cost that Motor Neurone Disease entails, particularly in the case of Cyprus. **METHODS:** A quantitative survey was conducted in order to identify and record the cost of services, of medical equipments and consumables, used by the Cypriot patients. The study population was comprised of 45 patients that met the participation criteria and represent a percentage of 57% of the population of the patients, according to the 2014 records of the Cyprus Institute of Neurology and Genetics. **RESULTS:** According to the data recorded and processed, the average annual cost of Motor Neurone Disease in Cyprus was estimated at €25,942.00 per patient. This figure lies within the EU cost range, which according to the relevant literature is between €15,252.00 and €36,380.00. The highest portion of the total cost (37.8%) was attributed to private spending on the 24hour home care of the patients. The next highest portion of the total cost was attributed to private spending on health care and residential nursing (12% of the total cost). It was observed that 68% of the total cost that Motor Neurone Disease entailed was privately covered, while the remaining 32% was covered by the Government. **CONCLUSIONS:** It is clear that Motor Neurone Disease significantly affects the financial situation of the patients and of their families. The costs entailed arise relatively soon and progress throughout the life of the patient; hence the Government should provide additional funding for covering such costs.

## PND38

## ECONOMIC IMPACT OF MULTIPLE SCLEROSIS IN PATIENTS WITH LOW PHYSICAL DISABILITY

Ruiz Beato E<sup>1</sup>, García-Domínguez JM<sup>2</sup>, Martínez-Ginés ML<sup>2</sup>, Medrano N<sup>3</sup>, Maurino J<sup>3</sup>

<sup>1</sup>Roche Farma Health Economics and Outcomes Research Unit, Madrid, Spain, <sup>2</sup>Hospital Universitario Gregorio Marañón, Madrid, Spain, <sup>3</sup>Roche Farma Medical Department, Madrid, Spain

**OBJECTIVES:** In multiple sclerosis (MS), unemployment occurs even at levels of disability, which are not typically associated with overt physical impairment. The aim of this study was to assess the impact on labour activity in MS patients and their caregivers. **METHODS:** A multicenter, non-interventional, cross-sectional study in adult patients with relapsing-remitting MS (RRMS) or primary progressive MS (PPMS) according to McDonald 2010 criteria was conducted. The Expanded Disability Status Scale (EDSS) and the 23-item Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ-23) were used to assess disability and working performance, respectively. Only indirect costs were considered using the human capital method including labour costs, professional support costs and informal caregivers' costs. **RESULTS:** A total of 199 subjects were studied (mean age: 43.9 ± 10.5 years, 60.8% female, 86.4% with RRMS). Median EDSS score was 2.0 (interquartile range: 1.0-3.5); 85% (n=171) with an EDSS score  $\leq 4.5$ . Mean physical, psychological/cognitive and external barriers MSWDQ-23 subscores were 35.4 ± 25, 29.4 ± 22 and 39.7 ± 31.3, respectively. The number of employed patients decreased after the diagnosis from 70.6% to 47.2% and increased the number of retired patients (23.6%). Mean age of retirement was 43.6 ± 10.5 years. Ten percent of the population had sick leaves (absenteeism was shown in 90.9% and 30.9% of the student and the employed populations, respectively). Professional support in their daily life activities was needed in 28.1% of patients. Costs for sick leave, labour absenteeism, premature retirement and premature work disability/pensioner were €416.6 ± 2,030.2, €763.4 ± 3,161.8, €5,810.1 ± 13,159 and €1,816.8 ± 9,630.7, respectively. Cost for professional support and informal caregiving activities were €1,026.9 ± 4,622 and 301.8 ± 1,160, respectively. **CONCLUSIONS:** Patients with multiple sclerosis and low levels of physical disability also imposes a substantial economic burden with high indirect costs (labour costs, professional support and informal caregiving).



## PND39

## MULTIPLE SCLEROSIS BURDEN OF ILLNESS STUDY FOR TURKEY

Senturk A<sup>1</sup>, Altintas A<sup>2</sup>, Sagduyu Kocaman A<sup>3</sup>, Irkeç C<sup>4</sup>, Yandim Kusu D<sup>5</sup>, Agan Yildirim K<sup>6</sup>, Eraksoy M<sup>7</sup>, Kurtuncu M<sup>7</sup>, Terzi M<sup>8</sup>, Turkoglu R<sup>9</sup>, Yanik L<sup>10</sup>, Kod E<sup>10</sup>, Erdogan-Ciftci E<sup>10</sup>, Becit G<sup>10</sup>, Donmez S<sup>10</sup>, Safak K<sup>10</sup>, Gokalp T<sup>10</sup>, Erdogan A<sup>10</sup>

<sup>1</sup>AXEL Health Solutions, Ankara, Turkey, <sup>2</sup>Koc University Hospital, Istanbul, Turkey, <sup>3</sup>Acibadem University Hospital, Istanbul, Turkey, <sup>4</sup>Gazi University Faculty of Medicine, Ankara, Turkey, <sup>5</sup>MedAmerikan Medical Center, Istanbul, Turkey, <sup>6</sup>Marmara University Pendik Research and Training Hospital, Istanbul, Turkey, <sup>7</sup>Istanbul University Istanbul Faculty of Medicine, Istanbul, Turkey, <sup>8</sup>19 Mayıs University Faculty of Medicine, Samsun, Turkey, <sup>9</sup>Haydarpasa Numune Research and Training Hospital, Istanbul, Turkey, <sup>10</sup>Roche Mustahzarları San. A.Ş., Istanbul, Turkey

**OBJECTIVES:** Multiple Sclerosis (MS) is a major public health problem in Turkey with high cost implications. The objective of this study is to analyze the economic burden of illness for MS in Turkey, both from the payer's and society's perspective. **METHODS:** The study consists of two parts, estimating direct and indirect costs of MS. Direct costs are assessed in two phases. Initially, in order to identify the direct costs of medicines, physician admissions, physiotherapy and diagnostic test requirements related with MS, a Delphi Panel was conducted with the participation of 9 neurologists. The second phase consisted of utilizing the insights gathered from the Panel, MS prevalence data for Turkey and Health Implementation Notification price lists. For the indirect costs, human capital approach has been preferred. Data sets from labor statistics and population/age distribution published by Turkish Statistical Institute (TurkStat) have been used. **RESULTS:** There are



approximately 31,926 MS patients in Turkey. The direct costs including diagnosis, treatment of MS attacks and symptoms, for RRMS, PPMS, SPMS are found to be 705,745,333 TRY (~134 mEUR) in total for the payer. Medicines make only 61% of this direct burden of illness in MS. The indirect costs and economic losses caused by loss of productivity due to MS, are consisting of factors such as absenteeism, early retirement, early death, and cost of caregivers, which is a service required by most MS patients, and indirect costs sum up to 1,879,454,246 TRY (~358 mEUR) for the society. **CONCLUSIONS:** Cost studies provide an evidence-based guidance for decision-makers. Direct and indirect costs can be analyzed for a comprehensive evaluation of budget impact and comparison of alternative medicines. Innovative medicines in the field of MS prevent disease progression and hence it can be expected that these are going to result in an overall public benefit in the future.

#### PND40

##### COST OF HEALTHCARE RESOURCE USE BY PATIENTS WITH MULTIPLE SCLEROSIS IN FRANCE ACCORDING TO DISEASE SEVERITY

Detourmay B<sup>1</sup>, Debouverie M<sup>2</sup>, Pereira O<sup>3</sup>, Soudant M<sup>4</sup>, Jomaa K<sup>5</sup>, Courouve L<sup>1</sup>, Epstein J<sup>4</sup>, Guillemin F<sup>4</sup>

<sup>1</sup>Cemka-Eval, Bourg-la-Reine, France, <sup>2</sup>CHU de Nancy - Hôpital Central, Nancy, France, <sup>3</sup>DRSM du Nord-Est, Nancy, France, <sup>4</sup>CHRU de Nancy-Hôpitaux de Brabois, Vandœuvre-lès-Nancy, France, <sup>5</sup>BIOGEN, Nanterre, France

**OBJECTIVES:** To estimate the direct cost of healthcare resource use by patients with multiple sclerosis (MS) in France in 2014 according to disease severity. **METHODS:** The study was based on the data from the registry of MS in Lorraine (RELSEP) combined with data provided by the main compulsory health insurance linked to the national hospital database (PMSI). All adults MS patients included in the registry in 2013-2014 and not deceased over the period were identified. Costs were identified using the local health insurance database covering salaried workers only. Full hospital pathway of patients was reconstructed after re-identification of individual cases in the PMSI. Mean total costs per patient by disease severity were estimated on a monthly basis taking into consideration potential evolution of MS over the year. Costs of MS exacerbations were estimated using a regression analysis. **RESULTS:** Over the study period, 2166 patients figuring in the RELSEP were included in the study. Ambulatory costs were available for 1,333, and 627 were identified as being hospitalized at least once over 2013-2014. Average annual direct costs for MS patients were estimated to €12,296 in 2014. Ambulatory costs represented 87.8% and were mainly driven by costs of drugs (any type) (60.6%) and paramedics visits (11.2%). Monthly direct costs were higher in patients with severe disease (€ 1,249 for EDSS 7-9) than in patients with mild or moderate disease (€ 992 for EDSS 0-3; € 953 for EDSS 4-6) ( $p=0,006$ ). Drugs costs were higher in patients with mild disease and conversely costs associated with paramedics, medical devices and transportation were higher in severe MS. Unit cost of exacerbation was estimated to €2,052 to €2,193. **CONCLUSIONS:** MS contributes substantially to health care expenditure in France. Directs costs were mainly driven by drug costs and were highly related to disease severity.



#### PND41

##### HEALTHCARE COSTS OF PATIENTS WITH SPINAL MUSCULAR ATROPHY

D'Angiolella LS<sup>1</sup>, Belisari A<sup>2</sup>, Mantovani LG<sup>1</sup>, Sansone V<sup>3</sup>, Vita G<sup>4</sup>, Pane M<sup>5</sup>

<sup>1</sup>University of Milan Bicocca, Monza, Italy, <sup>2</sup>Fondazione Charta, Milano, Italy, <sup>3</sup>Milan NEMO Center, Milano, Italy, <sup>4</sup>University of Messina, Messina, Italy, <sup>5</sup>Policlinico Gemelli Hospital, Rome, Italy

**OBJECTIVES:** Spinal muscular atrophy (SMA) is an autosomal recessive disorder caused by mutations or deletions in the Survival Motor Neuron (SMN1) gene. The most severe form is type 1, characterized by early onset of clinical signs (0-6 months) while in type 2 signs occur at 7-18 months. Unlike type 1, type 2 patients achieve the ability to sit unsupported, but never the ability to walk independently. In type 3 (onset after 18 months), independent ambulation is achieved but can be subsequently lost. SMA is a complex disorder involving different healthcare specialists; therefore, a multidisciplinary approach is a key element for its management. The consequences of the disease on patients and caregivers are relevant. A new treatment, nusinersen, is available and is expected to positively impact SMA management. The aim of our research was to estimate the burden of SMA in Italy in the pre-nusinersen era. **METHODS:** The contribution of experts in SMA was requested to describe type, frequency and cost of resources absorbed in caring for SMA. A disease subtype-specific questionnaire was implemented (type 1-3) to get information on the experience of three clinicians responsible for SMA centers in the north, center and south of Italy. Data were collected according to respiratory, gastrointestinal-nutritional and orthopedic care. A mean annual direct healthcare costs of SMA patients in Italy was calculated. **RESULTS:** The main cost drivers are respiratory care for type 1 and orthopedic care for type 2 and 3 patients. On an annual basis, the highest mean cost was estimated for SMA type 1, and progressively decreasing in SMA 2 and 3. Given the differentiated life expectancy by type, on a lifetime basis type 2 and 3 patients incur more costs than those with type 1. **CONCLUSIONS:** The economic burden of SMA is relevant, with nature and amount of resources being dependent on disease type.



#### PND42

##### BURDEN OF MULTIPLE SCLEROSIS IN RUSSIA AND EUROPE

Tolkushin A<sup>1</sup>, Davydovskaya M<sup>2</sup>, Smirnova A<sup>2</sup>, Ermolaeva T<sup>2</sup>, Andreev D<sup>2</sup>, Kokushkin K<sup>2</sup>

<sup>1</sup>State Budgetary Institution of Moscow City "Clinical Trials and Healthcare Technology Assessment Scientific-Research Centre of Moscow Department of Healthcare", Moscow, Russia, <sup>2</sup>State Budgetary Institution of Moscow City "Clinical Trials and Healthcare Technology Assessment Scientific-Research Centre of Moscow Department of Healthcare", Moscow, Russian Federation

**OBJECTIVES:** To compare the economic burden of multiple sclerosis (MS) in European countries and in Russia **METHODS:** The results of the cross-sectional



observational retrospective study of the socio-economic burden of MS "New insights into the burden and costs of MS in Europe" (G.Kobelt et al. 2017; 16 countries) were taken as a main data source. Direct and indirect costs were posted in the study. We conducted an in-depth comparative cost structure analysis in the countries. The total cost for each country based on the prevalence of MS was calculated. We used the the following ratios: DMTs share of total cost, total cost to GDP per capita. Costs were adjusted to 2015 roubles. 1 euro = 68 roubles in 2015 and 66 roubles in 2017 (mean, from [ratestats.com](http://ratestats.com)) **RESULTS:** Mean total average cost per patient with MS per year for all European country examined was about 2M ±882K roubles, for Russia 671K roubles. (minimum value). The average direct costs per patient reaches 949K ±370K roubles in general, in Russia 464K roubles (the minimum value). The DMTs costs in the total costs were highest in Russia (57.16%). Average value 30.97% ±14.36%. The lowest DMTs costs share in total costs were in the UK (11.49%), Netherlands (10.07%) and Sweden (10.04%). The total MS burden ranged from 393B roubles (Germany) to 8.8B roubles (Hungary), in Russia 78.8B roubles. The rate of total costs to GDP per capita for all countries was 84.64% ±23.06%, for Russia 41.05% (minimum value). **CONCLUSIONS:** In Russia, the economic burden of MS (including direct and indirect costs) is relatively small in comparison with European countries; while the share of DMTs costs in Russia is the highest among the countries surveyed.

#### PND43

##### CLINICAL CHARACTERISTICS AFFECTING DIRECT COSTS IN MULTIPLE SCLEROSIS

Cozzolino P<sup>1</sup>, Cortesi PA<sup>1</sup>, Capra R<sup>2</sup>, Cesana G<sup>1</sup>, Mantovani LG<sup>1</sup>

<sup>1</sup>University of Milano-Bicocca, Monza, Italy, <sup>2</sup>Multiple Sclerosis Center, Spedali Civili di Brescia, Brescia, Italy

**OBJECTIVES:** Poor quality data are available on association between clinical characteristics and costs of Multiple Sclerosis (MS). This study aim to fill this gap identifying clinical characteristics possibly influencing direct costs of MS patients. **METHODS:** A cost of illness study was conducted. Clinical information of patients treated in a major MS Center located in Lombardy, in the period 2004-2010, was linked with administrative data of Lombardy Healthcare System. We estimated the association between clinical characteristics (Expanded Disability Status Scale (EDSS) score, MS courses, Disease Modifying Therapies (DMT), and relapse) and mean cost per patient-year, using a generalized linear model (GLM) adjusting for age and sex. Only medical resources consumed for MS management and treatment have been included in the cost estimation. **RESULTS:** We have been able to link clinical and administrative data for 869 patients (83.9% Relapsing remitting (RRMS), 8.5% Secondary Progressive (SPMS), and 7.2% Primary progressive (PPMS)). RRMS reported the highest cost per patient-year with a mean of €5,623 in EDSS 0-3, €8,675 in EDSS 3.5-6.5 and €7,451 in EDSS 7-9. The PPMS patients reported the lower annual mean cost per patient in all EDSS groups, however the GLM results showed no significant difference between MS courses (RRMS, PPMS and SPMS). Conversely, GLM results showed a statistically significant increase in costs associated to higher EDSS categories compared to EDSS 0-3 ( $\exp(\beta) = 1.388$  and  $\exp(\beta) = 3.044$ , for EDSS 3.5-6.5 and EDSS 7-9, respectively). Relapse occurrence and the use of Disease Modifying Therapies (DMT) revealed a greater effect on cost per patient/year ( $\exp(\beta) = 6.023$  and  $\exp(\beta) = 4.412$  respectively). **CONCLUSIONS:** This study provides important information on the clinical characteristics associated to the MS direct costs. The results can help to better understand the burden of different MS patients based on their clinical characteristics.



#### PND44

##### A NEW APPROACH FOR ESTIMATING AND VISUALISING SOCIETAL COSTS: AN EXAMPLE IN MULTIPLE SCLEROSIS IN ENGLAND

Doran S<sup>1</sup>, Aldhouse NV<sup>2</sup>, Bennett E<sup>2</sup>, Fletcher-Louis M<sup>1</sup>

<sup>1</sup>DRG Abacus, Bicester, UK, <sup>2</sup>DRG Abacus, Manchester, UK

**OBJECTIVES:** Costs associated with chronic conditions extend beyond direct healthcare costs. We explored the societal costs of multiple sclerosis (MS) in England and the stakeholders affected during the course of an illustrative 'patient cost journey'. **METHODS:** Three archetypes were developed, representing patients with MS with varying characteristics (e.g. age, employment status, income, disability level). Over a 20-year time horizon, patients were assumed to undergo disease progression at varying rates. Desk research was conducted to identify stakeholders and budgets impacted by MS-related societal costs. A targeted literature review was conducted in Medline to identify publications reporting societal costs of MS, supplemented by hand-searching of relevant reference lists and websites. **RESULTS:** Nine relevant studies were identified in the targeted literature review and were used alongside desk research results to inform cost inputs. Cost categories included: employer, central government income (revenue losses), patient/caregiver, National Insurance contributions (revenue losses), National Insurance Fund (payments), and local authority. Estimated costs are presented for one of the three archetypes; a patient aged 30 years in the early stages of MS with difficulty adhering to injectable therapies, who progresses to higher disability levels at an early stage of their disease. Societal costs are estimated at £2,635 in Year 5, increasing to £59,375 in Year 20. The distribution of costs changes over time. At Year 5, with few relapses and minimal disability progression, costs largely fall on employers (lost productivity [£2,122]). At 20 years, increased disability, care requirements, early retirement, and home modifications result in higher costs to the patient/caregiver (£28,610), National Insurance contributions (revenue losses; £6,183) and Fund (payments; £17,901), local authority (£3,261), and central government tax revenue (£3,419). **CONCLUSIONS:** Societal costs are an often under-appreciated aspect of chronic diseases; illustrative 'patient cost journeys' can be used to demonstrate and visualise these costs, highlighting the multiple stakeholders upon whom they fall.

