RCSI UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

SCHOOL OF POPULATION HEALTH
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Financial and Personal Burden of Arthritis

Results from the 2024 Arthritis Ireland Cost Survey 2024

Final report

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Foreword

Dear reader,

Welcome to Arthritis Ireland's Financial and Personal Burden of Arthritis 2024 research report on the personal financial cost for individuals living with arthritis. After many years of extensive planning, we are excited to unveil the first ever comprehensive Irish study that details the personal financial burden faced by those living with arthritis.

Arthritis is the leading cause of disability in Ireland. It damages joints, causing severe pain, stiffness, immobility, and even deformity. It prevents people from performing basic, everyday tasks—picking up a child, getting dressed, holding down a job, or socialising with others. Beyond the physical impact, there is the huge toll that arthritis can take on people's mental health. Many living with the condition say they find it hard to get out of bed in the morning, or that the relentless pain experienced during a flare severely impacts their ability to cope, affecting not just themselves, but also their relationships with family and loved ones. This is the harsh reality of living with arthritis.

For individuals living with arthritis, accessing essential healthcare services, taking prescribed medications, and utilising support services like physiotherapy and occupational therapy are necessities, not luxuries. These measures are crucial for managing their condition, preventing further damage, and reducing flare-ups. However, as this report highlights, many people with arthritis must cover these necessary expenses out of their own personal finances, even when their illness prevents them from working or pursuing careers on a full-time basis. Indeed, many are forced to withdraw from employment due to the severity of their condition.

This research study has shown that individuals with arthritis incur substantial personal costs, both emotionally and financially, in managing their condition. As a society, we must do more to support those living with this debilitating disease, alleviating their financial burden and making their daily lives less challenging.

We are deeply grateful to everyone who completed the survey and participated in this valuable research. We also extend our heartfelt thanks to those who co-developed the survey and contributed to the findings in this report. Additionally, we would like to thank our sponsors and the research team at RCSI School of Population Health, without whom this research would not have been possible.

Over 1,600 people took part in this survey, underscoring the strong desire among those living with arthritis to share their experiences. Many participants provided personal comments about their situations, which are both stark and compelling. We encourage you to read these comments at the end of this report. The overwhelming response and input clearly show that these individuals want their voices to be heard and for others to understand the personal sacrifices that they and their loved ones make to improve their health, wellbeing, and disease management. Members of the arthritis community have expressed their frustration that their condition is often hidden and clouded by myths. They are eager to bring the reality of living with arthritis into the open.

We understand that change is a gradual process. However, the reality is that the number of people living with arthritis in Ireland is set to increase in the coming years. By taking practical and measured steps now to alleviate the financial burden on those affected, we can improve health outcomes and significantly reduce their financial strain. It is time for our political leaders and policymakers to rise to the challenge and address these issues directly.

We will not rest until the voices of our community are heard and their burden is eased.

Tim O'Sullivan
Chair

Gráinne O'Leary
Chief Executive

Contents

List of Tables **v**

List of Figures **vi**

1 Main findings **1**
1.1 Respondents . . . 1
1.2 Health status . . . 2
1.3 Use of healthcare services . . . 3
1.4 Personal expenses . . . 3
1.5 Employment status . . . 3
1.6 Help at home . . . 4
1.7 Time spent on healthcare and transport . . . 4

2 Background **5**

3 Methodology **7**
3.1 Personal expenses related to arthritis . . . 7
3.2 Co-design of online cost questionnaire . . . 8
3.3 Questionnaire administration . . . 9
3.4 Data preparation . . . 10
3.5 Analytical methods . . . 10

4 Results **13**
4.1 Respondents . . . 13
4.1.1 Demographics . . . 13
4.1.2 Arthritis and comorbidity . . . 15
4.1.3 Financial support . . . 17
4.1.4 Health insurance . . . 17
4.1.5 Life insurance . . . 17
4.2 General health and wellbeing . . . 18
4.2.1 General health status . . . 18
4.2.2 Sleep quality . . . 21
4.2.3 EQ-5D health status . . . 22

4.3 Healthcare services use and expenses . . . 24
4.3.1 Healthcare services use . . . 26
4.3.2 Healthcare expenses . . . 28
4.4 Medical expenses . . . 29
4.5 Mobility and assistance products and services . . . 31
4.6 Summary of expenses for healthcare, medication, mobility assistance, home help . . . 34
4.7 Impact on employment . . . 36
4.8 Help at home . . . 38
4.9 Time spent on healthcare and transport . . . 38

5 Discussion **40**
5.1 Summary of main findings . . . 40
5.2 Methodological challenges . . . 41
5.3 Strengths and weaknesses . . . 42
5.4 Perspectives . . . 43

A Appendix **i**
A.1 Acknowledgement . . . i
A.2 Ethical approval . . . i
A.3 Funding . . . i
A.4 Authors' role in the project . . . ii
A.5 Online questionnaire . . . iii
A.6 Responses to open-ended cost question . . . xxi
A.7 Other comments about the survey . . . xxx

List of Tables

3.1 Rheumatic and musculoskeletal diseases included in the survey and their abbreviations 7

4.1 Characteristics of respondents by sex, age, years with diagnosis and education 15
4.2 Repondents' identification of different types of rheumatic and musculoskeletal diseases 16
4.3 Repondents' other health conditions 17
4.4 General health as reported by participants 19
4.5 Comparison of general health state between survey participants and Healthy Ireland survey 21
4.6 Sleep quality as reported by respondents 22
4.7 EQ-5D mean score and 95% confidence interval 24
4.8 Summary of data related to use of health services 25
4.9 Summary of data related to use of overnight health services 25
4.10 Average number of healthcare provider visits 27
4.11 Personal expenses on healthcare 29
4.12 Summary of use and personal expenses on medication 30
4.13 Personal expenses on medical products 31
4.14 Summary of publicly /personally funded mobility and assistance products and services 32
4.15 Personal expenses on mobility and assistance products and services 34
4.16 Total personal expenses 36
4.17 Current employment status by age 37
4.18 Weekly work hours for participants in current employment 37
4.19 Income loss due to arthritis for those actively employed 38
4.20 Employment status of respondents aged less than 65 years by type of arthritis 38
4.21 Combined time spent availing of healthcare services and travelling to and from healthcare providers 39

List of Figures

4.1 Geographical distribution of respondents 14
4.2 General health status by age group 20
4.3 Sleep quality by age group 21
4.4 EQ-5D health status 23
4.5 Average use of healthcare services 26
4.6 Average expenses for healthcare services 28
4.7 Medical costs 30
4.8 Personal expenses on mobility and assistance products and services 33
4.9 Mean personal expenses 35

1 Main findings

This report summarises the personal expenses related to arthritis. We conducted an online questionnaire survey for people who are affiliated with Arthritis Ireland - the Irish patient organisation for people living with arthritis. More than 1600 individuals from the network took part and provided information about their personal circumstances, current health status and personal expenses for healthcare services, medication and medical products, assistance, and help at home related to their disease. This report analyses the data from the questionnaire and describes the personal burden of arthritis on patients and their families.

When we refer to arthritis in this report, we mean a group of diseases within the broader definition of rheumatic and musculoskeletal diseases and not just the clinically defined diseases such as rheumatoid arthritis, osteoarthritis, or psoriatic arthritis. When we refer to personal expenses, we mean the money that people with arthritis personally have paid to receive healthcare services and other forms of care and support.

1.1 Respondents

The online questionnaire was completed by 1612 individuals across Ireland.

- 85% were female, 14% were male
- The mean age was 60 years. 35% were under 55 years of age, 31% were aged between 55 and 64 years, 24% were aged 65-74 years, and almost 10% were aged 75 years or older
- On average, respondents had been living with arthritis for 12 years. Female respondents had been living with arthritis for longer than male respondents. Older respondents had been living with arthritis for longer than younger respondents
- More than half of the respondents had third level education and a quarter had second level education. A large group of respondents had completed other forms of education
- A third of respondents had rheumatoid arthritis, 30% had osteoarthritis and 13% had psoriatic arthritis. The remaining respondents had other diseases related to arthritis
- Almost 40% of respondents had no other health conditions. 23% of all respondents reported having hypertension, 14% had a lung disease, 11% had a mental health condition, and 40% reported as having other diseases

- A third of the respondents had medical cards, 23% had GP cards, and 73% were registered with a Drug Payment Scheme
- 70% of respondents had private health insurance
- 46% of respondents had a life insurance policy

1.2 Health status

We compared the health status of the respondents with the health status of respondents in the national Healthy Ireland 2021-2023 surveys. The health impact of respondents living with arthritis was considerably worse compared to the health status of the general population:

- 55% of respondents with arthritis reported having poor or fair health. This compares to 2.5% of the general population. 45% of respondents reported having good, very good, or excellent health. This compares to 97.5% of the general population
- Sleep interruptions were a common feature. Nearly 20% of respondents reported that arthritis severely impacted on their sleeping patterns. 40% and 28% of respondents reported they had occasional or slight problems with sleep. Just 11% indicated that they have no sleep problems due to their arthritis
- 70% of respondents reported having problems with mobility. 97% reported problems with pain and discomfort, 80% reported problems with usual activity, 65% reported problems with anxiety and depression and 35% reported problems with self-care
- On a scale of 0 to 1, where 1 indicates perfect health and 0 death, the mean score among respondents was 0.58 (95%CI 0.567, 0.599). This is substantially worse compared to the general population who have reported mean scores above 0.90
- On this scale, female respondents reported as having worse health status (0.574 (95%CI 0.557, 0.592) compared to male respondents (0.644 (95%CI 0.606, 0.681)
- Younger respondents aged 35-44 years reported a better health status score (0.608 (95%CI 0.557, 0.681) than the older respondents aged 75 years and older (0.546 (95%CI 0.491, 0.602))
- Respondents with primary and second level education reported worse health scores than respondents with third level education, although the difference was not statistically significant after adjustment for sex and age
- Respondents with poor general health status reported the worst scores 0.304 (95%CI 0.264, 0.344). Respondents with very good or excellent general health status reported the best score 0.767 (95%CI 0.732, 0.803)
- 'Respondents who had been diagnosed for a longer period had lower health status scores (0.559 (95%CI 0.533, 0.584)) compared to those who had been diagnosed for less than two years (0.628 (95%CI 0.581, 0.675))

1.3 Use of healthcare services

The questionnaire asked the respondents about their use of healthcare services related to their arthritis diagnosis. 1107 respondents answered this part of the questionnaire. Based on the analysis, in the last 12 months respondents:

- Had an average of 27 visits to a healthcare provider
- Female respondents had more visits to healthcare providers than male respondents (28 visits vs 22 visits)
- Had an average of 5.7 GP visits (among respondents who attended their GP)
- 8.8% of the respondents had been hospitalised
- Among respondents who were hospitalised, the average number of admissions was 1.6 and on average they spent 2.7 days in hospital

1.4 Personal expenses

The analysis of personal expenses showed that in the last 12 months:

- Arthritis imposed a mean personal expense of €3538 per respondent
- More than half of these expenses (55% or €1980) were related to personal expenses for health-care services
- 20% or €975 related to personal expenses related to medication and related medical products
- 14% or €478 related to personal expenses for required assistance due to arthritis
- A small proportion of respondents (7%) indicated as receiving help at home and the personal expenses of such help amounted to €105 per person

1.5 Employment status

Respondents indicated their current employment status.

- 58% of respondents aged under 65 years were in active employment, and 31% had retired either voluntarily or due to arthritis
- Among the respondents in employment, 63% were in full-time employment and 37% were in part-time employment
- Among those employed part-time, 60% reported that arthritis was the reason for their part-time employment status
- 70% of respondents in current employment indicated that they had experienced a loss of €3111 in annual income due to arthritis

1.6 Help at home

A small proportion of respondents (116 of 893, 7.2%) indicated that they had received help at home related to arthritis during the last 12 months.

- 10% of respondents indicated that they received help at home paid for by the state or local government. This group received on average 143 hours of state or local government-funded help
- 43% of respondents indicated that they had paid for private help at home. This group received on average 319 hours of self-funded help at home
- Respondents who indicated that they received help at home, received an average of 734 hours of unpaid informal help from spouse/partner, children, relatives, friends/neighbours

1.7 Time spent on healthcare and transport

In addition to their personal expenses, respondents were also asked to indicate the average time they spent availing of healthcare services and the time they used for transport from their home to the healthcare providers (and back) in the last 12 months.

- On average, each respondent spent 105 hours availing of healthcare services
- Respondents with poor health status spent on average 156 hours on visits to healthcare providers, compared to respondents with excellent health who spent on average 60 hours
- Respondents living in rural areas spent on average 30% more time at healthcare service visits and travelling to and from these visits than those living in urban areas

2 Background

For people living with a disease and ill health, there is limited evidence reporting on the associated personal cost burden to the individual. Furthermore, it is not well understood who is bearing these private costs and the extent of individual expenses. Such private expenses may relate to particular health problems and personal circumstances. This is the first time personal costs and the burden related to arthritis in Ireland have been captured and reported.

The private costs to individuals has been explored for people living with cancer in Ireland. In their recent report[1], the Irish Cancer Society have estimated that the average additional cost for people living with cancer is more than €756 per month, which includes personal costs for medication, hospitalisation and private physiotherapy services. This report also highlighted that people living with cancer may experience a substantial reduction in income and change in their employment status as a direct consequence of cancer.

A report analysed the healthcare costs related to osteoarthritis and rheumatoid arthritis for Irish people aged 50 years and older[2] in 2013. This reported the use of GP and hospital services over 12 months based on data from 8000 respondents from the The Irish Longitudinal Study on Ageing (TILDA) survey. They estimated the variation in General Practitioner (GP) contacts, outpatient and A&E departments, and inpatient admissions for people across different age groups, sex, education and health status. However, their cost analysis took the perspective of the healthcare services provider and did not consider the private and personal expenses of each respondent.

A study conducted in Germany[3] estimated the direct costs related to rheumatoid arthritis by considering the patient perspective. This study was based on data from a clinical trial and a cost questionnaire that was administered quarterly. In this questionnaire respondents only reported on their healthcare utilisation related to arthritis. The results reported were specific to non-physician service utilisation, medication, devices and aids. They found that in 2005 a mean yearly associated cost was €417 per respondent, with nearly half of this cost related to physiotherapy and related services, 24% to medication, 9% to physicians and 14% to transportation. Only 1% of the average costs were related to devices and aids. However, it is difficult to generalise these results to a broader (and Irish) population, due to the nature of the identification of respondents in this study.

Personal costs are important because they can impact how patients approach and adhere to

[1] Irish Cancer Society, The Real Cost of Cancer. Research conducted by Kantar 2019

[2] E. Doherty, C. O'Neill, Estimating the health-care usage associated with osteoarthritis and rheumatoid arthritis in an older adult population in Ireland. Journal of Public Health | Vol. 36, No. 3, pp. 504–510, 2013

[3] J L Hülsemann, T Mittendorf, S Merkesdal, S Zeh, S Handelmann, J- M von der Schulenburg, H Zeidler, J Ruof Ann Rheum Dis 2005;64:1456–1461

clinical treatment and rehabilitation services. A recent review of out-of-pocket studies focusing on rheumatoid arthritis[4] identified only six relevant research studies reporting on patients' private costs. They also demonstrate a lack of equity for those living with arthritis due to the significant financial burden that they must bear due to their condition. This suggests that the research evidence in this area remains largely limited.

Against this background, Arthritis Ireland approached the RCSI Healthcare Outcome Research Centre to explore the opportunities of analysing personal costs related to arthritis. After a careful planning phase, which included seeking formal approval from the RCSI's Ethical Committee, a questionnaire was co-designed with patient representatives and staff from Arthritis Ireland. We administered the online questionnaire among members of the Arthritis Ireland's network.

This report documents the results from the online arthritis cost questionnaire. Based on the responses, we have analysed who has responded to the questionnaire, their health status and well-being, use of healthcare services, personal expenses for obtaining healthcare services, employment consequences, use of paid and unpaid home help, and the time spent at healthcare visits including transportation time to and from healthcare providers.

[4]Parvaneh Heidari, Wendy Cross, Kimberley Crawford. Do out-of-pocket costs affect medication adherence in adults with rheumatoid arthritis? A systematic review. Semin Arthritis Rheum. 2018 Aug;48(1):12-21

3 Methodology

This report is based on information collected from an online questionnaire which was completed by people living with arthritis in Ireland. Respondents were invited to take part in the online survey through direct email invitations from Arthritis Ireland or through their newsletters and social media platforms.

When we refer to arthritis in this report, this represents a broad group of diseases within the broader group of rheumatic and musculoskeletal diseases and not just clearly defined diagnoses such as rheumatoid arthritis, osteoarthritis, or psoriatic arthritis. Table 3.1 shows the different conditions we have included in the questionnaire and the abbreviations used throughout the text and tables.

Table 3.1: Rheumatic and musculoskeletal diseases included in the survey and their abbreviations

Condition	Abbreviation
Gout	Gout
Rheumatoid arthritis	RA
Osteoarthritis	OA
Psoriatic arthritis	PsA
Juvenile idiopathic arthritis	JIA
Sjögren's syndrome	Sjögren's
Axial spondyloarthritis	AxSpa
Fibromyalgia	Fibro
Polymyalgia rheumatica	Polymyalgia
Raynaud's	Raynaud's
Lupus (SLE)	Lupus
Scleroderma	Scleroderma
Down syndrome associated arthritis	DA

3.1 Personal expenses related to arthritis

The cost analysis focuses on the personal cost related to arthritis. This is different from many other cost analyses which usually focus on the healthcare provided and funded by the healthcare system such as the Health Services Executive (HSE) or health insurers. Similarly, personal costs are rarely

included in Health Technology Assessments or economic evaluations where the analyses tend to focus on the costs for the healthcare services only and disregard the personal expenses of individuals. The concern is that in addition to the healthcare costs funded by public or private health funding bodies, people living with arthritis bear a considerable financial burden related to their condition. For example, private payment occurs for visits to general practitioners (GPs) and purchase of prescription and over-the-counter medications. In addition, due to their condition, some people may need to pay privately for additional support such as physiotherapy, help in their home, and adaptations of their home. People with arthritis may need to spend a significant amount of money and time on transportation to healthcare providers in addition to their financial outlays. Such costs related to the time and expense of transportation to healthcare providers are typically borne by the individuals who need the healthcare service.

3.2 Co-design of online cost questionnaire

Identification of personal expenses is challenging and very few guidelines and examples are available in an Irish context. However, the methodology for analysing costs is well-defined and involves different phases including identification of relevant cost items, measurement, and valuation of the most relevant components.

From the outset of this study, it was clear that information on personal expenses related to arthritis should be obtained from people who have personal experiences and live with arthritis. Arthritis Ireland convened a group of people living with arthritis, people with professional experience with arthritis, and economic researchers to co-design the cost questionnaire. At first, the group met to set the scene and brainstorm a wide range of potentially relevant cost items. In subsequent meetings, draft versions of the questionnaire were discussed and adjusted in line with recommendations from the group. The cost questionnaire was first piloted by a small group of people living with arthritis and later by a larger group of patient advisers associated with Arthritis Ireland.

The final version of the questionnaire (available in Appendix) explained its purpose to the respondents and specified that the survey was anonymous and participation voluntary. To complete the questionnaire, respondents were asked to consent to participate and to allow their information to be used for research purposes.

Other sections of the questionnaire included:

- Information about the respondents: year of birth, gender, the first three letters of their postcode, and education level
- Information about rheumatic and musculoskeletal and other related conditions
- General health and wellbeing: general health based on five categories ranging from poor to excellent health, a question on respondents' quality of sleep, and a health status measure based on the EQ-5D instrument which included questions across five dimensions: mobility, self-care, usual activities, pain and discomfort, anxiety and depression. Each dimension is described in five levels ranging from no problems to extreme problems

- Healthcare service use: based on 28 health service providers, respondents were asked to indicate how many times during the last 12 months they used these services. Additionally, time spent at the appointment, transport time and total amount paid for these services were captured. The amount of money spent on medication and other medicinal products during the last 12 months was also collected
- Respondents were also asked about the financial support for healthcare such as GP and medical cards, and drug payment schemes. Further, they were asked if they have private health insurance and life insurance
- Mobility and assistance: respondents were asked about mobility and assistance they had received during the last 12 months, how much they paid for these themselves, and how much was publicly funded
- Help at home: respondents were asked if they had received any help at home relating to their arthritis condition. Only people who received help at home were asked more detailed questions about the nature of this help
- Ability to work: respondents were asked about their current employment situation, weekly hours worked, the impact of arthritis on the respondent's ability to work and on other activities, the main source of income, and the level of income
- Transport: respondents were asked about different types of transport they used when attending appointments with their healthcare providers. Additionally, respondents were asked about the amount of time they spent travelling to their appointments

Finally, respondents were given a free text opportunity to describe any additional expenses related to their arthritis condition they had spent money on in the last 12 months, which had not been specifically asked about in the survey and to provide other additional comments.

3.3 Questionnaire administration

The survey was administered using Smartsurvey, an online survey and questionnaire tool. It was promoted to potential respondents through two channels: emails sent to the Arthritis Ireland network and posts shared on Arthritis Ireland's social media platforms. Data collection commenced on May 20th, 2024, with an initial email sent to 13,406 recipients, containing a unique QR code for survey participation. Two reminder emails, featuring the same QR code, were subsequently sent on June 11th and June 21st.

The survey was distributed on the following social media platforms, using a QR code different from the one used in the email.

- X – 7 posts
- Instagram- 6 posts + 1 story share
- LinkedIn – 4 posts
- Facebook- 9 posts
- Arthritis Ireland Facebook support group – 2 posts

When the survey closed on July 4th, 2024, there were 877 complete and 570 incomplete responses originating from the email recruitment, and 151 complete and 127 incomplete responses from the social media platforms.

The median response time was 17 minutes, though there was considerable variation in how long respondents took to complete the survey.

3.4 Data preparation

The questionnaire was completed anonymously and therefore the same individuals may have completed it more than once. To prevent having several responses from the same respondent, we identified responses from individuals with similar gender, year of birth and postcodes as responses from the same person. From this, we used the first complete response and included this in the analysis. If earlier partial responses were available as well as a complete response, we used the complete response and excluded the partial responses from analysis.

Some respondents gave consent to take part in the survey but did not complete the full survey. We only included valid responses and identified all missing information.

For some questions with an 'other' category, respondents had an option to provide text based responses e.g. education, arthritis and other related conditions. All free text responses were reviewed and included in categories where possible by a data analyst. If some responses were difficult to categorise, these were maintained in the 'other' category.

In Appendix A we provide the responses to two free text questions from the questionnaire. Some responses were edited for clarity to secure anonymity and disguise reference to any particular individuals.

3.5 Analytical methods

The data from the online questionnaire was analysed using descriptive methods, and where appropriate, mean differences across some groups were estimated using regression analysis. A more detailed explanation of these methods is summarised below.

Descriptive information was organised into meaningful categories. For most analyses, respondent age was categorised into 10-year age groups, and for the analysis of employment data we

categorised age into two groups: below 65 and over 65 years. We categorised the duration of arthritis diagnosis into meaningful groups consisting of: less than 2 years, 2-5 years, 6-10 years and over 10 years.

One of the main challenges related to the identification of different forms of rheumatic and musculoskeletal disorders. Respondents could select from 13 different types of diseases where they could indicate as many as were applicable. With these data, we were able to identify more than 150 combinations of rheumatic and musculoskeletal diseases. With consultation from our co-designers, we agreed on a meaningful way of categorising these diseases. For the final analysis, the diseases were ordered according to frequent diseases with and without combination. Rheumatic and musculoskeletal disorders are described across 26 separate categories excluding an "other" category and "no disease reported" category. Following discussions among the author group and advice from independent senior researchers, we decided not to report on a small number of respondents as a way to maintain their anonymity. This was supported by the fact that all respondents consented to the use of their anonymous data, and that - in principle - it should not be possible to identify any individual respondents. However, there is a possibility that some respondents may still be able to identify their responses across some of the reported results in this report.

In the section about financial support, several "Yes"/"No" questions were asked e.g. does the respondent have a GP card. In these analyses, we included responses to these two valid responses only, and all other responses including missing answers were excluded from the analysis. This is important when interpreting these results, as the results are specific to the proportion of respondents who provided a valid answer and not to all respondents.

Similar principles were applied in the analysis of general health and wellbeing, where we reported across different categories of health status and compared general health status across age categories.

For the healthcare cost analysis, we considered respondents with valid responses to be those who reported at least one visit to any of the 28 healthcare providers. For each service provider, we counted the number of users as those with at least one visit, and the proportion of users in relation to the population with valid healthcare cost responses. For the group of users, we estimate the mean number of visits, mean time in minutes spent on all visits, and the mean cost (€).

Some respondents did not respond to questions about the time spent for each visit. To allow us to calculate the total time spent with each particular care provider, we replaced the missing values with the mean value of respondents who had completed these questions.

In order to assess the cost, if a respondent did not include an expense for a specified visit, we assumed that they did not incur any personal costs for this service. In this case, we expected expenses to relate to GP services and direct hospital contacts such as A&E visits and hospital admissions.

Similarly, we reported other costs related to medication and personal expenses related to arthritis, home adaptations and medical appliances, and expenses for help in the home.

We reported the cost of the various components as the mean cost for all respondents who completed the cost questionnaire. Some of these costs are lower than the costs described above because

the denominator is the full population, rather than only the respondents who have used the indicated services.

We further analyse the variation of the healthcare costs by age, duration with arthritis and health status categories. The reported mean cost is adjusted for age and sex.

For employment, we conducted a descriptive analysis of the current work situation. For respondents in paid employment, we analysed their weekly work hours, income, and reported income loss as a consequence of arthritis. We further analysed the reported impact of arthritis on work and regular daily activities.

Help at home was analysed for respondents who indicated that they have availed of help at home. This is a relatively small proportion of the whole group of respondents, which we analyse descriptively.

Across each section, the first table reports the nature of the raw data. This allows assessments of the number of respondents and the number of missing responses. In follow-up analyses, we estimated the mean values for the entire relevant group of respondents. Throughout the report, we have identified the group of respondents who have provided some data on each section, and we report the mean values for this group of respondents and not for all respondents. This is important when interpreting the estimated mean figures.

To indicate the statistical variation in the data we have reported either the standard deviation (SD) or the 95% confidence interval. SD is a common measure when reporting means. A high number relative to the mean indicates large variation. In the subgroup analyses, we report mean and 95% confidence intervals instead of particular statistical tests (t-test or ANOVA). The confidence interval indicates the range of the true value of the mean with 95% probability. Confidence intervals are used because the study recruited only a small sample of the overall population, so by having an upper and lower confidence limit, it is possible to infer that the true population value lies between these two points. In other words, it represents how good we think our estimate is. If you construct a confidence interval with a 95% confidence level, it means that you are confident that 95 out of 100 times the estimate will fall between the upper and lower values specified by the confidence interval.

Despite some guidelines suggesting the use of alternative measures due to the skewed nature of the reported cost data, we have used the standard parametric methods to calculate confidence intervals, given the relatively large sample of responses from the questionnaire.

We estimated the standardised group mean differences using ordinary least regression or logistic regression analyses, adjusting for sex, age, and other categorical variables. Any statistical differences between groups were captured using a p-value measure. A p-value represents how likely the difference between groups is due to chance. A p-value lower than 0.05 indicates that the difference is statistically significant, with values above 0.05 indicating no statistical significant differences. Due to the cross-sectional nature of the data analysed, limited number of respondents in each subgroup, and sometimes a large proportion of respondents with no or low healthcare service use, the explanatory power of the regression models is not particularly high (indicated by a low R^2). Despite these precautions, the regression models are sufficiently robust to indicate noticeable patterns in the data.

4 Results

4.1 Respondents

This section describes the survey respondents who provided information about their year of birth, sex, year of their first arthritis diagnosis, the first three letters/numbers of their postcode and their level of education or training.

4.1.1 Demographics

Table 4.1 describes the survey respondents. 85% were female and 14% were male. A small proportion of respondents indicated as being "Non binary" or preferred not to say (n=14). The age of respondents ranged from 18 to 92 years with the median age of 60 years. The female respondents were significantly younger than the male respondents (58 vs 61 years, p=0.003). There were no statistically significant gender differences across the 10-year age categories (p=0.181).

The geographical distribution of respondents is shown in Figure 4.1. A quarter of the respondents were from Dublin, but there was a good representation of respondents across most Irish counties.

Respondents had received the first arthritis diagnosis between one and 68 years, with 9 years as the median duration. There was no difference between females and males (p=0.410) although more respondents in the younger age groups had received their diagnosis in a shorter time period. 7.5% of the respondents did not indicate the year of their first diagnosis.

A statistically larger proportion of the female respondents indicated having a university education than men (59% vs 44%, p<0.001), and fewer females reported having a second level education compared to male respondents (30% vs 44%, p<0.001).

Figure 4.1: Geographical distribution of respondents

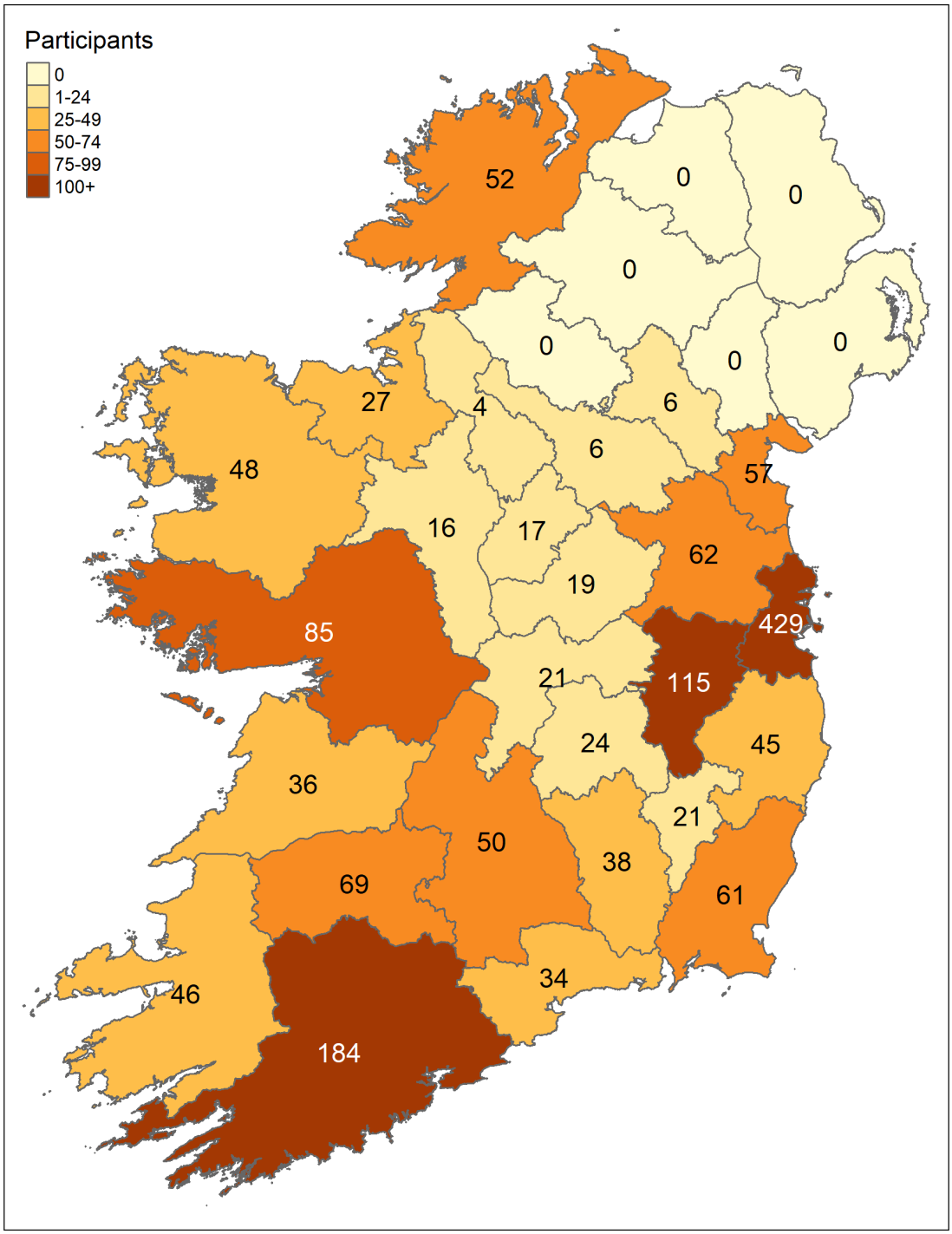


Table 4.1: Characteristics of respondents by sex, age, years with diagnosis and education

	All
N	1,612
Sex	
Female	1,367 (84.8%)
Male	231 (14.3%)
Other	14 (0.9%)
Age group	
<35	80 (5.2%)
35-44	168 (10.9%)
45-54	307 (19.8%)
55-64	478 (30.9%)
65-74	366 (23.7%)
>75	148 (9.6%)
Years with arthritis	
Less than 2 years	167 (10.4%)
2-5 years	345 (21.4%)
6-10 years	319 (19.8%)
Over 10 years	655 (40.6%)
Not reported	126 (7.8%)
Education/training	
Primary education	47 (2.9%)
Secondary education	480 (29.9%)
University education	870 (54.2%)
Other education	207 (12.9%)

4.1.2 Arthritis and comorbidity

Table 4.2 summarises respondents' identification of their arthritis disease, based on a range of different types of arthritis diseases (see Table 3.1). Respondents could also select the "other" option with a free text option for additional descriptions. These responses were reviewed and from more than 150 combinations of different diseases, they were ordered and subsequently arranged as shown in the table. The group of "other" diagnoses could not be assigned to any of the listed combinations. 91 respondents did not respond to this section of the questionnaire.

Table 4.3 summarises respondents' additional health conditions (comorbidities), not categorised as arthritis or rheumatic diseases. Respondents could indicate having multiple health conditions. 37.9% of respondents reported having no other medical conditions other than arthritis, 23% of all respondents reported having hypertension, 14% reported having asthma, COPD or some other form of lung disease, 10.7% of respondents indicated as having a mental health condition. A further 24% reported having conditions other than those shown in the table.

Table 4.2: Repondents' identification of different types of rheumatic and musculoskeletal diseases

	All
N	1,612
Arthtitis diagnoses	
01 Rheumatoid Arthritis (RA)	299 (18.5%)
02 RA & fibromyalgia (fibro)	74 (4.6%)
03 RA & OA	64 (4.0%)
04 RA & JIA	25 (1.6%)
05 RA & PsA	18 (1.1%)
06 RA & Raynaud's	10 (0.6%)
07 RA & Sjögren's	10 (0.6%)
08 RA & OA & fibro	21 (1.3%)
09 RA & other	92 (5.7%)
10 Osteoarthritis (OA)	378 (23.4%)
11 OA & fibro	26 (1.6%)
12 OA & Gout	20 (1.2%)
13 OA & PsA	18 (1.1%)
14 OA & polymyalgia	12 (0.7%)
15 OA & Raynaud's	12 (0.7%)
16 OA & PsA & fibro	14 (0.9%)
17 OA & Other	48 (3.0%)
18 Psoriatic arthritis (PsA)	172 (10.7%)
19 PsA & fibro	20 (1.2%)
20 PsA & AxSpA	10 (0.6%)
21 PsA & other	27 (1.7%)
22 Axial spondyloarthritis	58 (3.6%)
23 Fibromyalgia	32 (2.0%)
24 Juvenile idiopathic arthritis	12 (0.7%)
25 Gout	11 (0.7%)
98 Other	38 (2.4%)
99 None	91 (5.6%)

Abbreviations:

RA: Rheumatoid arthritis; OA: Osteoarthritis; PsA: Psoriatic arthritis; JIA: Juvenile idiopathic arthritis; Sjögren's: Sjögren's syndrome; AxSpa: Axial spondyloarthritis; Fibro: Fibromyalgia; Polymyalgia: Polymyalgia rheumatica; Raynaud's: Raynaud's; Lupus: Lupus (SLE)

Table 4.3: Repondents' other health conditions

	All
N	1,612
No other conditions	589 (37.9%)
Diabetes	80 (5.2%)
Asthma, COPD, other lung disease	220 (14.2%)
Cancer	53 (3.4%)
Hypertension	361 (23.2%)
Cardiovascular	106 (6.8%)
Stroke	17 (1.1%)
Neurological	16 (1.0%)
Mental health	166 (10.7%)
Other conditions	378 (24.3%)

4.1.3 Financial support

Respondents were asked if they had received financial support for their healthcare. These questions were formulated with response options "Yes" or "No" and only respondents who answered these questions were included in the analysis. 370 of 1098 respondents (34%) indicated they had a medical card, 237 out of 1155 respondents (22%) indicated that they had a GP card, and 784 of 1068 respondents (73%) indicated that they are registered with the Drugs Payment Scheme. A larger proportion of the older respondents had a GP or medical card, as these are only available to people aged over 70 years and/or with annual income below a certain level.

4.1.4 Health insurance

Respondents were asked if they had private health insurance that covers some of the cost of their healthcare. Of the 1098 respondents, 770 respondents (70%) indicated that they had private health insurance. The mean payment for private health insurance per respondent was €2043 (SD 1328). 60% of those with private health insurance indicated that they had received reimbursement, with a mean amount reimbursed per respondent of €976 (SD 2429).

A greater proportion of respondents aged over 65 years, and with a university or other education level, had private health insurance. Respondents with osteoarthritis were more likely to have private health insurance compared to respondents with other types of arthritis. Among the respondents who had private health insurance, no clear pattern of the amount of reimbursement could be identified.

4.1.5 Life insurance

Respondents were asked if they had life insurance. A total of 494 of 1074 respondents (46%) replied to this question. 76 or 7% indicated that they had no life insurance because they were not approved,

when they tried to purchase a policy. 111 of 684 respondents (16%) indicated that they were aware that their premium was increased due to their arthritis. Life insurance was more common for respondents who were male, younger and with a university level education.

4.2 General health and wellbeing

Three instruments were used to measure respondents' general health and wellbeing.

The General Health question is a single measure with five categories ranging from "poor" health to "excellent" health. This question is frequently used in population surveys and was included in the Irish 2022 census. However, the categories used in the census differed slightly, (excellent health is reworded as very good, and poor health is reworded as very poor), making comparisons potentially invalid. However, other data sources such as the population-level Healthy Ireland surveys 2021-2023 have used the same categories as in the cost of arthritis questionnaire. This allowed us to compare the overall health status of respondents and to compare their health status to the general population's health status.

Survey respondents were also asked about their sleep quality with a single question with five categorical answers. Respondents could indicate whether their "sleep is not interrupted" to "unable to sleep". We have no access to comparative data, and present these results descriptively.

Finally, respondents were asked to describe their current health status using the standard EQ-5D instrument. This is a frequently used measure for health-related quality of life and is a recommended measure by HIQA for health technology assessment in Ireland. The instrument consists of five dimensions: mobility, self-care, usual activities, pain and discomfort, anxiety and depression. Each dimension can be described in five levels ranging from "no problems" to "extreme problems/unable to do". A recent research programme conducted at University of Galway developed a measurable index, where 1 denotes "perfect health" and 0 "death" [1]. An index below 0 indicates health status worse than death. We analysed the EQ-5D data from arthritis respondents for each of the five dimensions and assigned an index score using the University of Galway's scoring algorithm.

4.2.1 General health status

Table 4.4 reports on the self-reported general health status of the respondents across different subgroups. 20.4% of respondents reported "poor" health status, while 34.4% reported "fair" and 32.1% "good" health status. 13.2% of respondents reported to have "very good" or "excellent" health status. The differences in general health status were statistically significant between male and female respondents ($p=0.002$). There are also indications of a strong age gradient suggesting a higher proportion of older female respondents reported worse health status ($p<0.05$) than older male respondents.

Figure 4.2 illustrates the variation in health status between age groups. A greater proportion of older respondents reported poorer health status than younger respondents. The highest proportion

[1] Hobbins, A., Barry, L., Kelleher, D. et al. Utility Values for Health States in Ireland: A Value Set for the EQ-5D-5L. PharmacoEconomics 36, 1345–1353 (2018). https://doi-org.zorac.aub.aau.dk/10.1007/s40273-018-0690-x

of respondents reporting excellent health status were those aged 45-54 years.

Table 4.4: General health as reported by participants

	General health status				
	Poor	Fair	Good	Very good/excellent	All
N	314 (20.4%)	530 (34.4%)	495 (32.1%)	203 (13.2%)	1,542 (100.0%)
Sex					
Female	279 (88.9%)	444 (83.8%)	421 (85.1%)	166 (81.8%)	1,310 (85.0%)
Male	30 (9.6%)	84 (15.8%)	72 (14.5%)	33 (16.3%)	219 (14.2%)
Other	5 (2.5%)	<5 (-)	<5 (-)	<5 (-)	13 (7.5%))
Age group					
<35	22 (7.3%)	30 (5.8%)	16 (3.4%)	7 (3.7%)	75 (5.1%)
35-44	42 (13.9%)	61 (11.9%)	43 (9.1%)	15 (7.9%)	161 (10.9%)
45-54	100 (33.0%)	100 (19.5%)	73 (15.4%)	24 (12.6%)	297 (20.1%)
55-64	104 (34.3%)	183 (35.7%)	123 (25.9%)	50 (26.3%)	460 (31.1%)
65-74	28 (9.2%)	102 (19.9%)	153 (32.3%)	68 (35.8%)	351 (23.7%)
>75	7 (2.5%)	37 (7.2%)	66 (13.9%)	26 (13.7%)	136 (9.2%)
Education/training					
Primary education	<5 (-)	16 (3.0%)	14 (2.8%)	11 (5.4%)	43 (2.8%)
Secondary education	89 (28.3%)	150 (28.4%)	158 (31.9%)	59 (29.1%)	456 (29.6%)
University education	178 (56.7%)	285 (54.0%)	260 (52.5%)	115 (56.7%)	838 (54.4%)
Other education	45 (14.3%)	77 (14.6%)	63 (12.7%)	18 (8.9%)	203 (13.2%)
Diagnosis					
RA	35 (11.1%)	105 (19.8%)	103 (20.8%)	53 (26.1%)	296 (19.2%)
RA & other	56 (17.8%)	96 (18.1%)	54 (10.9%)	14 (6.9%)	220 (14.3%)
OA	38 (12.1%)	99 (18.7%)	153 (30.9%)	86 (42.4%)	376 (24.4%)
OA & other	28 (8.9%)	26 (4.9%)	34 (6.9%)	13 (6.4%)	101 (6.5%)
PsA	35 (11.1%)	63 (11.9%)	55 (11.1%)	18 (8.9%)	171 (11.1%)
Other	122 (38.9%)	141 (26.6%)	96 (19.4%)	19 (9.4%)	378 (24.5%)

Figure 4.2: General health status by age group

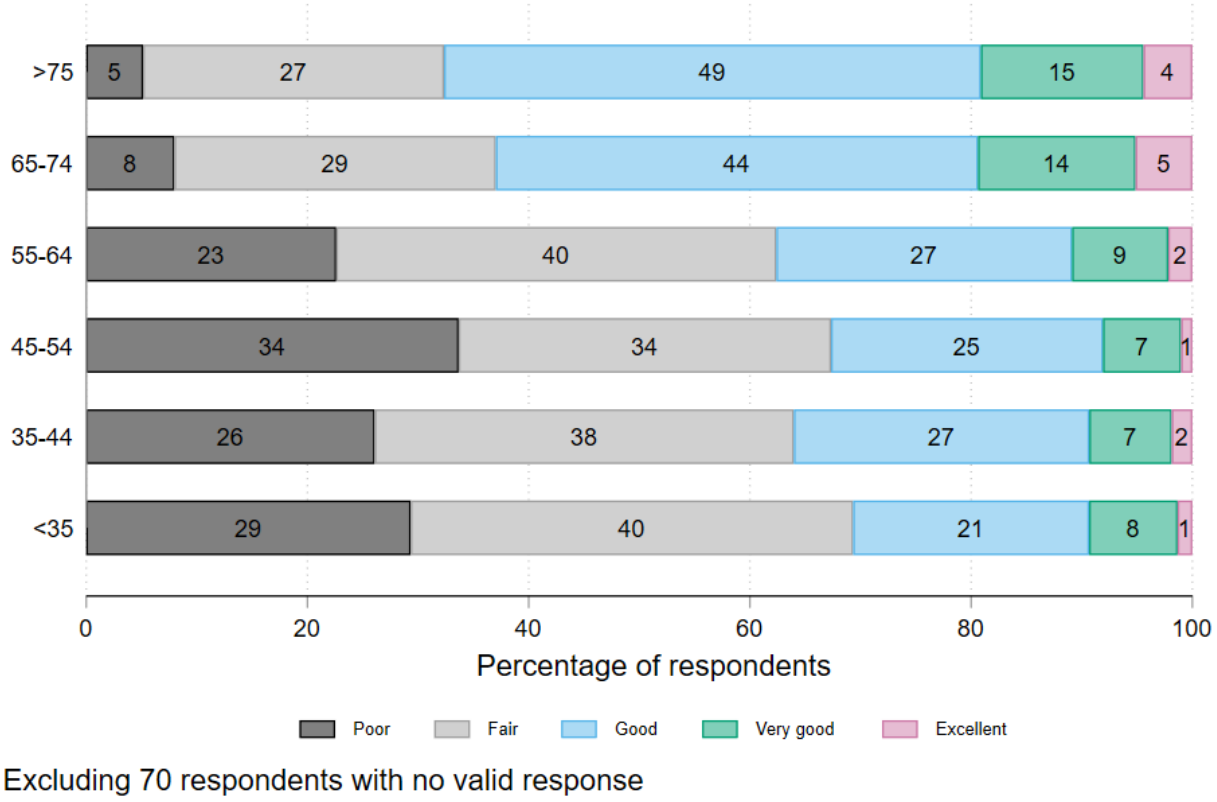


Table 4.5 compares the self-reported general health status of the respondents to the general population's health status from the Healthy Ireland survey. 13.2% of these respondents reported as having "poor" or "fair" health, compared to 54.8% for the Arthritis Ireland population. Similarly, 97.5% of respondents in the Healthy Ireland survey reported as having "good", "very good", or "excellent" health, compared to 45.3% of the Arthritis Ireland respondents. These substantial differences were statistically significant ($p<0.001$). There are also indications of a stronger age gradient for the Arthritis Ireland respondents suggestions of a higher proportion of older female respondents reported worse health status ($p<0.05$) than older male respondents.

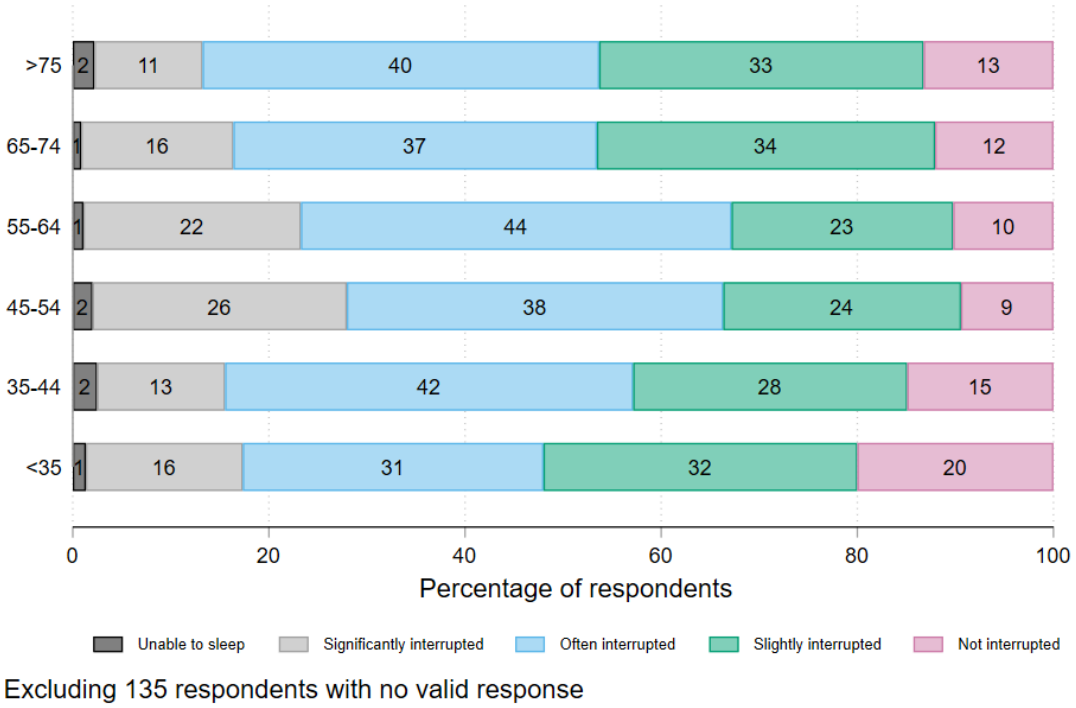
Table 4.5: Comparison of general health state between survey participants and Healthy Ireland survey

	Group	
	AI Survey n=1542	HI Survey n=22,308
General health state		
Poor	20.4%	0.5%
Fair	34.4%	2.0%
Good	32.1%	13.0%
Very good	10.3%	42.9%
Excellent	2.9%	41.6%

4.2.2 Sleep quality

Table 4.6 shows the sleep quality of respondents across different sub-groups. 20.5% of respondents reported having "serious" sleep disturbances, 39.8% reported frequent and nearly 39.6% reported rare sleep disturbances, due to their arthritis. The differences in sleep quality between males and females and age groups were not statistically significant. Figure 4.3 illustrates the variation in sleep quality by age groups. Respondents aged 45-54 years had the greatest proportion reporting "significant" sleep interruptions.

Figure 4.3: Sleep quality by age group



Excluding 135 respondents with no valid response

Table 4.6: Sleep quality as reported by respondents

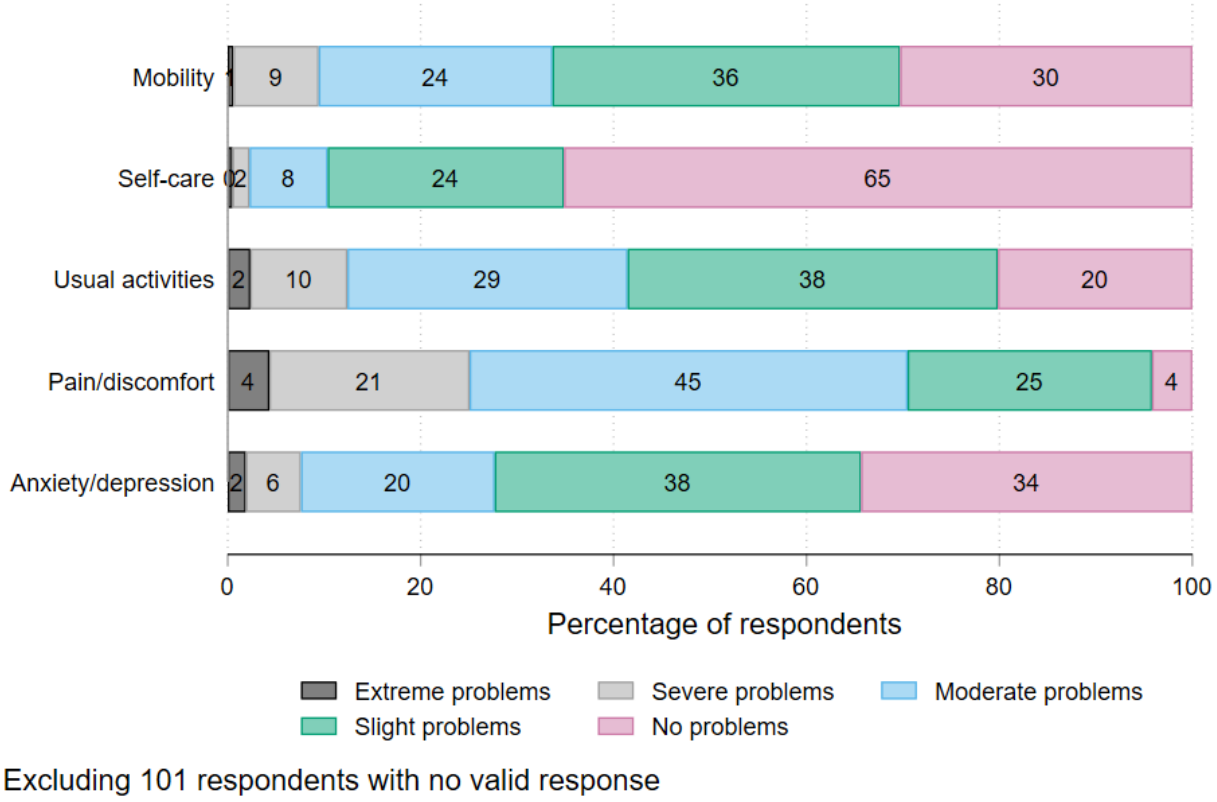
	Sleep problems			
	Serious	Often	Rare	Total
N	316 (20.5%)	613 (39.8%)	610 (39.6%)	1,539 (100.0%)
Sex				
Female	284 (89.9%)	536 (87.4%)	487 (79.8%)	1,307 (84.9%)
Male	26 (8.2%)	74 (12.1%)	119 (19.5%)	219 (14.2%)
Other	6 (2.5%)	<5 (-)	<5 (-)	13 (7.5%))
Age group				
<35	13 (4.3%)	23 (3.9%)	39 (6.7%)	75 (5.1%)
35-44	25 (8.3%)	67 (11.4%)	69 (11.8%)	161 (10.9%)
45-54	83 (27.4%)	114 (19.3%)	100 (17.1%)	297 (20.1%)
55-64	107 (35.3%)	202 (34.2%)	151 (25.9%)	460 (31.1%)
65-74	57 (18.8%)	129 (21.9%)	162 (27.7%)	348 (23.6%)
>75	18 (5.9%)	55 (9.3%)	63 (10.8%)	136 (9.2%)
Education/training				
Primary education	11 (3.5%)	19 (3.1%)	12 (<2.5%%)	42 (2.7%)
Secondary education	103 (32.7%)	176 (28.7%)	175 (28.7%)	454 (29.5%)
University education	153 (48.6%)	332 (54.2%)	353 (58.0%)	838 (54.5%)
Other education	48 (15.2%)	86 (14.0%)	69 (11.3%)	203 (13.2%)
Diagnosis				
RA	29 (9.2%)	101 (16.5%)	166 (27.2%)	296 (19.2%)
RA & other	67 (21.2%)	90 (14.7%)	61 (10.0%)	218 (14.2%)
OA	61 (19.3%)	142 (23.2%)	172 (28.2%)	375 (24.4%)
OA & other	29 (9.2%)	46 (7.5%)	26 (4.3%)	101 (6.6%)
PsA	28 (8.9%)	67 (10.9%)	77 (12.6%)	172 (11.2%)
Other	102 (32.3%)	167 (27.2%)	108 (17.7%)	377 (24.5%)

4.2.3 EQ-5D health status

Figure 4.4 shows the distribution of EQ-5D health status for 1539 respondents across the five dimensions and levels. 70% of respondents reported problems with mobility, 35% have problems with self-care, 80% have problems with usual activities. 97% of respondents reported problems with pain and discomfort and 65% reported problems with anxiety and depression. We identified statistically significant differences between male and females in mobility and usual activities (males were less likely to report problems). No clear age gradient was identified.

Table 4.7 shows the EQ-5D index scores and 95% confidence intervals by different groups. Males had a significantly higher score (0.64) than females (p=0.004). Respondents with primary (0.52) and secondary (0.53) level education reported the lowest health scores. Arthritis diagnosis for +10 years had the lowest score (0.55). Poor EQ-5D score (0.30) was associated with poor general health.

Figure 4.4: EQ-5D health status



Excluding 101 respondents with no valid response

Table 4.7: EQ-5D mean score and 95% confidence interval

	n	Mean	(95%CI)
All	1511	0.583	(0.567-0.599)
Sex: Female	1286	0.574	(0.557-0.592)
Male	213	0.644	(0.606-0.681)
Other	12	0.419	(0.154-0.684)
Age: <34	74	0.575	(0.489-0.660)
35-44	159	0.608	(0.557-0.658)
45-54	296	0.560	(0.524-0.597)
55-64	455	0.564	(0.535-0.592)
65-74	334	0.643	(0.614-0.673)
>75	133	0.546	(0.491-0.602)
Primary education	41	0.528	(0.445-0.610)
Secondary education	440	0.532	(0.500-0.564)
University education	830	0.615	(0.595-0.636)
Other education	199	0.574	(0.533-0.614)
RA	286	0.712	(0.685-0.739)
RA & other	217	0.475	(0.432-0.519)
OA	367	0.598	(0.567-0.628)
OA & other	99	0.496	(0.433-0.559)
PsA	172	0.677	(0.637-0.716)
Other	370	0.510	(0.475-0.546)
Arthritis: <2 years	163	0.628	(0.581-0.675)
2-5 years	334	0.607	(0.574-0.639)
6-10 years	309	0.599	(0.567-0.631)
>10 years	642	0.559	(0.533-0.584)
General Health: Poor	309	0.304	(0.264-0.344)
Fair	515	0.572	(0.549-0.594)
Good	485	0.695	(0.676-0.715)
Very good	158	0.753	(0.711-0.795)
Excellent	43	0.820	(0.756-0.884)

Based on data from 1511 respondents.

4.3 Healthcare services use and expenses

Respondents were asked to indicate the number of visits to different healthcare providers related to their arthritis disease in the last 12 months. Respondents also reported the average duration of each visit and the total amount they paid for each healthcare service. These expenses do not consider potential reimbursements from private health insurance.

Table 4.8: Summary of data related to use of health services

	n users	% users	Average per user Visits	Cost [€]	SD Cost [€]
Health Service					
GP service	971	87.7	5.6	225	605
Out of hours GP service	157	14.2	2.4	106	178
Hospital Outpatient app.	579	52.3	3.6	283	973
Hospital A&E visit	184	16.6	1.8	130	296
Private Consultant app.	592	53.5	2.9	490	418
Surgeon Appointment	233	21.0	2.8	373	702
Blood Tests	942	85.1	4.0	79	98
X-ray/MRI	652	58.9	2.3	191	294
Public Health Nurse	88	7.9	5.4	23	61
Physiotherapy Services	535	48.3	7.6	382	590
Occupational Therapy	90	8.1	3.0	30	96
Speech and Language Therapy	5	0.5	5.6	0	0
Orthoptist/Prosthetists	60	5.4	2.2	425	669
Dietician Services	69	6.2	2.4	181	266
Optician Services	586	52.9	1.5	266	244
Dental Services	617	55.7	2.6	504	2,772
Chiropody Services	230	20.8	4.3	191	244
Psychological/Counselling	129	11.7	10.6	455	545
Day Care Centre	8	0.7	20.9	666	952
Rehab/Respite Care	12	1.1	2.7	126	265
Chiropractor	41	3.7	4.7	296	243
Alt.therapy/Compl.med.	248	22.4	9.9	476	507
Pharmacy Consultation	188	17.0	5.7	196	349

Based on data from 1107 respondents.

Table 4.9: Summary of data related to use of overnight health services

	n users	% users	Average per user Admissions	Nights	Cost [€]	SD Cost [€]
Overnight health service						
Planned Inpatients stay	98	8.9	1.6	2.7	3,136	6,299
Emergency Inpatients stay	76	6.9	1.5	1.1	1,808	10,518
Rehab/respite care	21	1.9	1.1	1.3	982	2,165

Based on data from 195 respondents.

4.3.1 Healthcare services use

Table 4.8 summarises respondents' visits to various healthcare providers and Table 4.9 summarises the use of various overnight health services in the last 12 months. 971 (88%) of respondents had visited their general practitioner (GP), with an average of 5.6 visits. On average, these respondents paid €226 for their GP visits. 85.1% of respondents underwent four blood tests costing €79.

Table 4.9 shows that during the last 12 months, 98 (8.9%) of respondents were hospitalised as planned inpatients. These respondents had an average of 1.6 admissions and spent on average 2.7 days in hospital. The mean private cost spent by each respondent on their inpatient stays was €3136. Fewer respondents reported using emergency hospital admissions and admissions to rehabilitation and/or respite care.

Figure 4.5: Average use of healthcare services

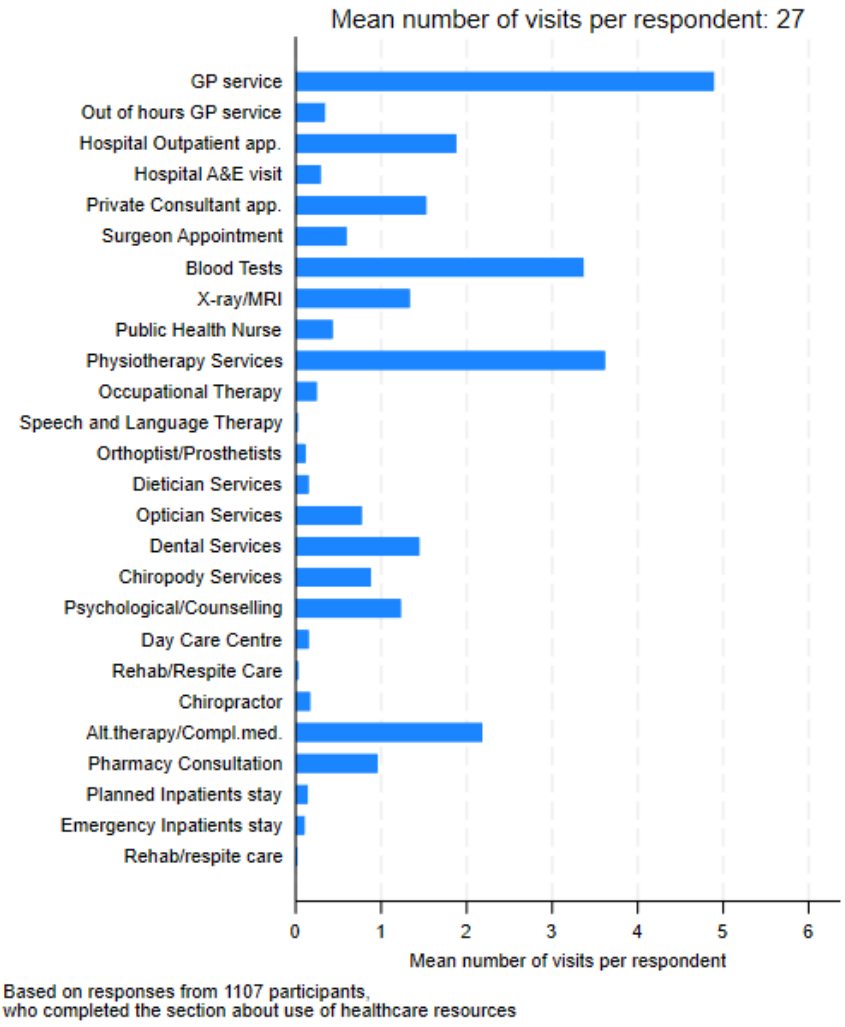


Figure 4.5 shows the average number of visits to different types of healthcare services for all the respondents who completed this section of the questionnaire. On average, each respondent had visited a healthcare provider 27 times in the last 12 months. Table 4.10 shows the variation in the

number of visits and 95% confidence intervals by different respondent sub-groups. On average, females reported 28 visits (95%CI 26-29) while males reported 22 visits (95%CI 18-27). This difference was statistically significant, with females reporting on average 7 more visits than males. Respondents with rheumatoid arthritis and other conditions had the highest number of visits, averaging 35.3. Respondents with arthritis for 10+ years had an average of 27.6 visits in the last 12 months. Differences by age for other groups were not statistically significant.

Table 4.10: Average number of healthcare provider visits

	n	Visits	(95%CI)
All	1107	26.9	(25.4-28.4)
Sex: Female	939	27.7	(26.1-29.3)
Male	160	22.4	(17.5-27.3)
Other	8	26.2	(13.3-39.2)
Age: <34	45	25.1	(20.3-30.0)
35-44	110	29.2	(24.6-33.8)
45-54	219	28.3	(25.1-31.5)
55-64	348	26.3	(23.8-28.7)
65-74	242	24.9	(21.7-28.2)
>75	103	25.8	(21.2-30.3)
Primary education	28	27.1	(19.0-35.2)
Secondary education	312	26.2	(22.7-29.8)
University education	617	26.3	(24.5-28.1)
Other education	149	30.7	(26.7-34.7)
RA	208	22.5	(19.3-25.6)
RA & other	149	35.3	(29.0-41.5)
OA	263	20.3	(18.2-22.4)
OA & other	69	28.2	(23.6-32.8)
PsA	134	26.7	(23.1-30.3)
Other	284	31.6	(28.4-34.8)
Arthritis: <2 years	124	27.5	(21.4-33.5)
2-5 years	238	26.6	(23.7-29.6)
6-10 years	234	25.8	(22.4-29.1)
>10 years	474	27.6	(25.4-29.8)
General Health: Poor	227	37.4	(32.9-41.8)
Fair	386	27.3	(24.9-29.7)
Good	350	23.8	(21.5-26.2)
Very good	108	16.9	(14.0-19.9)
Excellent	35	15.7	(11.3-20.1)

Based on data from 1107 respondents.

4.3.2 Healthcare expenses

Figure 4.6: Average expenses for healthcare services

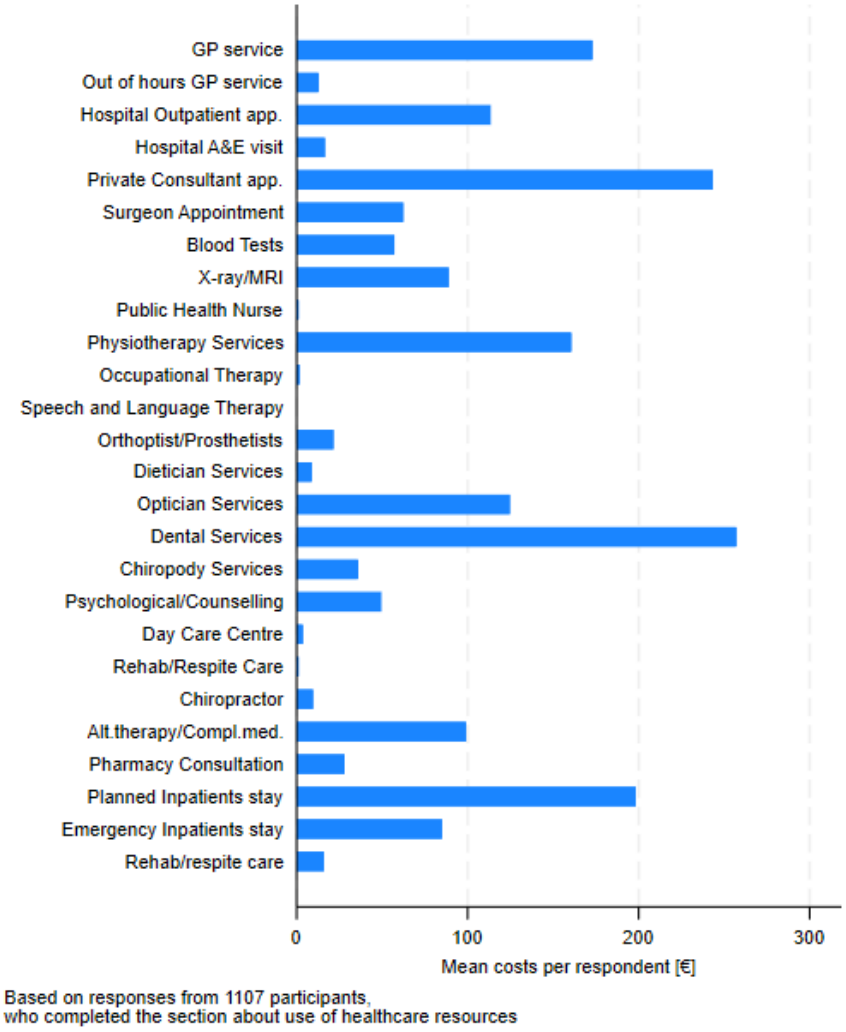


Figure 4.6 shows the average personal costs spent by respondents for different types of healthcare services. In the last 12 months, each respondent spent an average of €1980 on different healthcare services.

Table 4.11 shows the mean costs by different respondent sub-groups and 95% confidence intervals. On average, females spent €2000 (95%CI 1772-2229) and males spent €1814 (95%CI 797-2831). This difference was not statistically significantly different. Similarly, the variation of the reported mean costs was not statistically significant across the remaining groups. However, we observe a pattern across education groups, with respondents with a primary level education reported lower private healthcare expenses compared to respondents with a university education (€1074 vs €2220). We observe a similar pattern among respondents who reported poor health status to have lower private healthcare expenses compared to respondents with excellent health status (€2216 vs €2878).

Table 4.11: Personal expenses on healthcare

	n	Mean [€]	(95%CI)
All	1107	1980	(1738-2223)
Sex: Female	939	2000	(1772-2229)
Male	160	1814	(797-2831)
Other	8	2962	(-253-6177)
Age: <34	45	1594	(1199-1989)
35-44	110	1863	(1480-2246)
45-54	219	1773	(1447-2099)
55-64	348	1933	(1603-2262)
65-74	242	2140	(1422-2857)
>75	103	1656	(1152-2160)
Primary education	28	1074	(703-1445)
Secondary education	312	1479	(1260-1699)
University education	617	2220	(1865-2576)
Other education	149	2206	(1272-3140)
RA	208	1884	(1055-2714)
RA & other	149	2248	(1759-2737)
OA	263	1724	(1358-2090)
OA & other	69	3165	(1128-5202)
PsA	134	1681	(1424-1938)
Other	284	2001	(1685-2318)
Arthritis: <2 years	124	1761	(1235-2288)
2-5 years	238	1945	(1663-2227)
6-10 years	234	2011	(1534-2488)
>10 years	474	2109	(1632-2586)
General Health: Poor	227	2216	(1838-2595)
Fair	386	2252	(1735-2769)
Good	350	1573	(1339-1808)
Very good	108	1540	(1117-1964)
Excellent	35	2878	(-927-6683)

Based on data from 1107 respondents.

4.4 Medical expenses

Table 4.12 summarises the medical expenses of respondents in the last 12 months. 871 (78.7%) respondents reported that they have purchased prescription medication and had spent on average €650. 25.2% of respondents had spent an average of €375 on personal grooming.

Figure 4.7 shows the mean amount spent on all medical and other products for all respondents. In the last 12 months, each respondent spent on average €975 on different medication products.

Table 4.12: Summary of use and personal expenses on medication

	n users	% users	Average cost [€]	SD cost [€]
Products				
Prescription medication	871	78.7	650	770
Over the counter medication	681	61.5	172	187
Supplements	586	52.9	258	295
Other medication	74	6.7	246	308
Sexual health	44	4.0	196	201
Personal grooming	279	25.2	375	421
Other products	100	9.0	352	452

Based on data from 1107 respondents.

Figure 4.7: Medical costs

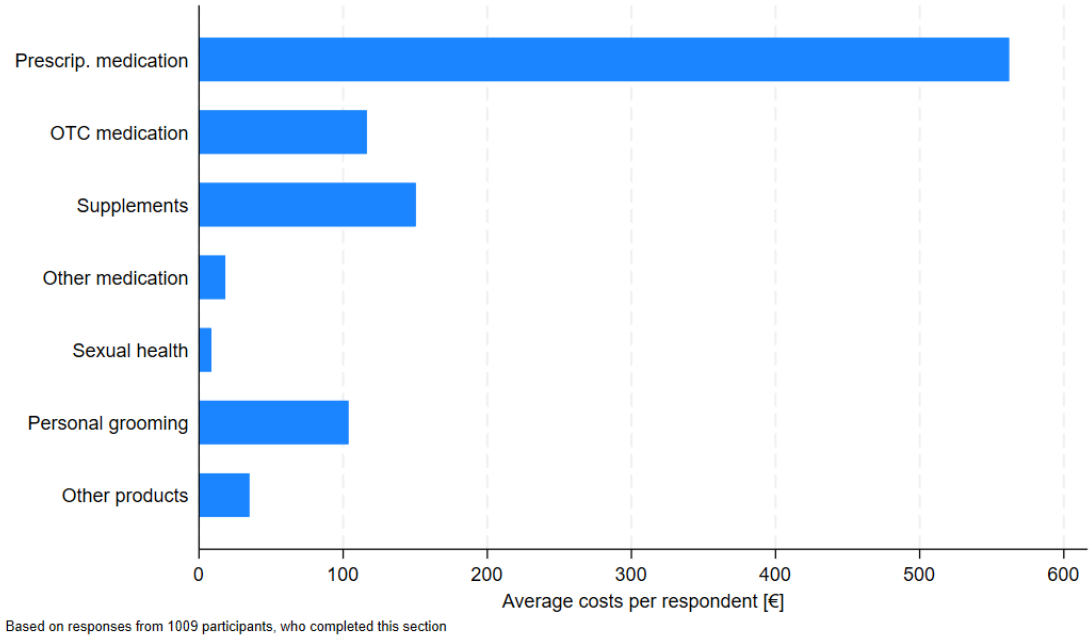


Table 4.13 summarises the mean personal expenses by different respondent sub-groups. On average, younger respondents had more expenses compared to respondents aged 65 and older (€1226 vs €840). This pattern is to be expected due to the likely effect of medical and GP cards among older respondents. We observed an association of personal costs on medication with respondent's general health status. Respondents with poor health status spent more on medications compared to respondents with excellent health (€1185 vs €612).

Table 4.13: Personal expenses on medical products

	n	Mean [€]	(95%CI)
All	1107	975	(918-1031)
Sex: Female	939	973	(918-1028)
Male	160	964	(752-1175)
Other	8	1421	(358-2484)
Age: <34	45	820	(627-1013)
35-44	110	1226	(1054-1399)
45-54	219	1162	(1027-1297)
55-64	348	958	(879-1037)
65-74	242	840	(701-979)
>75	103	667	(535-798)
Primary education	28	512	(338-686)
Secondary education	312	860	(752-969)
University education	617	1063	(987-1139)
Other education	149	923	(784-1062)
RA	208	958	(839-1076)
RA & other	149	1117	(985-1248)
OA	263	595	(498-693)
OA & other	69	998	(770-1226)
PsA	134	1149	(980-1318)
Other	284	1176	(1050-1302)
Arthritis: <2 years	124	833	(648-1017)
2-5 years	238	979	(888-1070)
6-10 years	234	1063	(932-1193)
>10 years	474	987	(895-1079)
General Health: Poor	227	1185	(1058-1312)
Fair	386	1051	(946-1156)
Good	350	879	(784-975)
Very good	108	685	(566-804)
Excellent	35	612	(452-772)

Based on data from 1107 respondents.

4.5 Mobility and assistance products and services

Table 4.14 shows respondents' reported costs on mobility and assistance products and services in the last 12 months, divided as publicly and privately funded. The greatest proportion of respondents, 24.1% had privately funded and spent €330 on average for bathroom adaptations. 10% of respondents spent an average of €3,042 on publicly funded kitchen adaptations. Figure 4.8 shows that on average, respondents spent €478 on mobility and assistance products and services.

Table 4.14: Summary of publicly /personally funded mobility and assistance products and services

	Funding source							
	Publicly funded				Personally funded			
	n users	% users	Mean cost [€]	SD cost [€]	n users	% users	Mean cost [€]	SD cost [€]
Arthritis related assistance								
Bathroom adaptations	24	2.4	1,755	3,413	243	24.1	330	259
Kitchen adaptations	101	10.0	3,042	4,960	<5	-	4	20
Bedroom adaptations	5	0.5	671	3,463	7	0.7	562	1,004
Appliances	41	4.1	1,362	3,228	5	0.5	46	133
New clothing or alterations	9	0.9	456	1,650	26	2.6	111	128
New footwear or alterations	96	9.5	1,246	3,120	<5	-	56	216
Wheelchairs	10	1.0	179	735	<5	-	272	606
Walker or roller frame	80	7.9	646	1,777	11	1.1	363	616
Wheelchair ramp	<5	-	29	108	136	13.5	1,331	2,885
Home heating/cooling	72	7.1	333	539	<5	-	1,375	5,153
Other assistance	29	2.9	170	250	38	3.8	728	1,655

Based on data from 1009 respondents.

Table 4.15 summarises the mean costs spent on mobility and assistance products by different sub-groups of respondents (€478). On average, females spent more than males (€486 vs €346). Respondents with rheumatoid arthritis and other conditions spent the most on mobility and assistance products, on average €715 in the last 12 months. Respondents with an arthritis diagnosis of 10+ years (€542), and with poor health (€655) also reported more personal expenses.

Figure 4.8: Personal expenses on mobility and assistance products and services

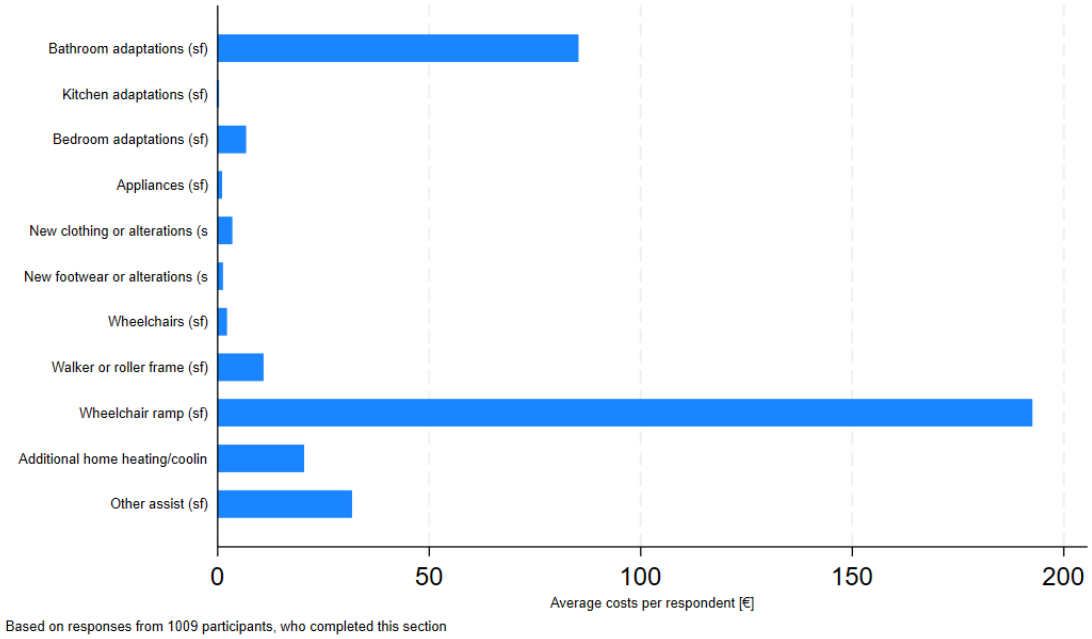


Table 4.15: Personal expenses on mobility and assistance products and services

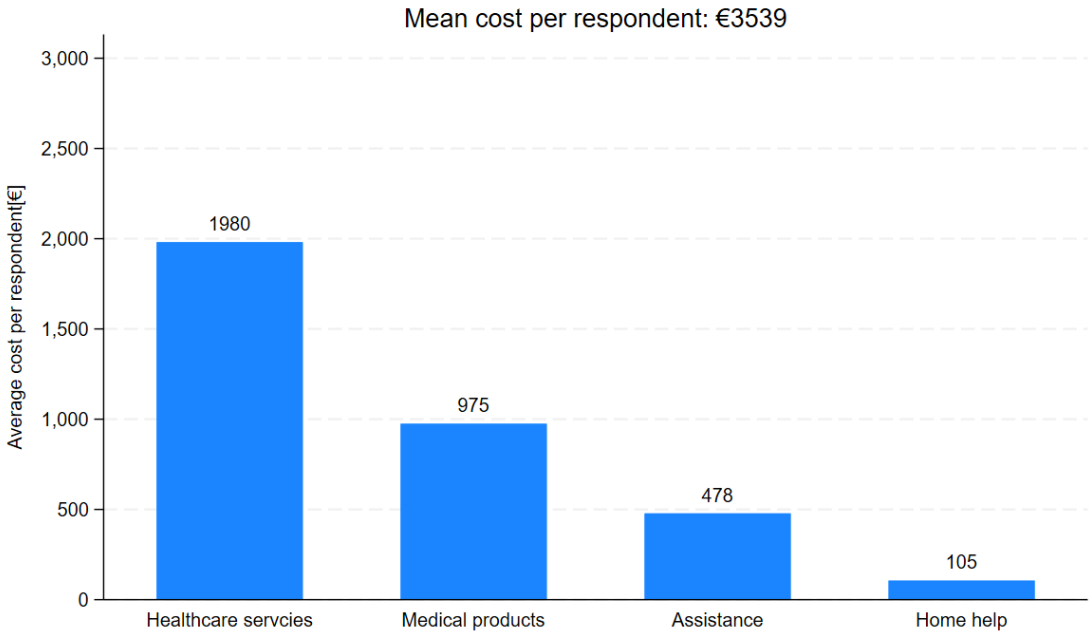
	n	Mean [€]	(95%CI)
All	1107	478	(392-564)
Sex: Female	939	486	(391-580)
Male	160	346	(230-461)
Other	8	2243	(-1883-6369)
Age: <34	45	364	(276-452)
35-44	110	725	(221-1229)
45-54	219	337	(285-388)
55-64	348	470	(311-628)
65-74	242	437	(318-556)
>75	103	722	(288-1156)
Primary education	28	233	(181-285)
Secondary education	312	424	(338-510)
University education	617	486	(362-611)
Other education	149	606	(276-937)
RA	208	318	(251-385)
RA & other	149	715	(347-1083)
OA	263	396	(238-554)
OA & other	69	623	(187-1058)
PsA	134	558	(182-934)
Other	284	474	(376-572)
Arthritis: <2 years	124	315	(261-370)
2-5 years	238	472	(241-703)
6-10 years	234	416	(301-531)
>10 years	474	542	(393-691)
General Health: Poor	227	655	(381-929)
Fair	386	471	(352-590)
Good	350	447	(290-603)
Very good	108	318	(239-397)
Excellent	35	223	(213-233)

Based on data from 1107 respondents.

4.6 Summary of expenses for healthcare, medication, mobility assistance, home help

Figure 4.9 shows the mean total personal expenses by different types of services in the last 12 months. The average estimated personal cost was €3538 per respondent. Table 4.16 shows the analysis of total private cost by different respondent sub-groups.

Figure 4.9: Mean personal expenses



Regression analysis of the total personal expenditure due to arthritis did not identify statistically significant differences between males and females, although on average, males had spent €680 less than females (p=0.105). Respondents aged between 45 and 84 had higher costs than younger respondents and lower costs than older respondents. Similarly, the cost differences across the cost components (healthcare, medication and medical products, assistance and home help) did not show any statistically significant variation.

Regression analysis indicated a statistically significant difference in total personal expenses for respondents with different categories of general health. The sex and age standardised mean costs with excellent health state were €1349 (95%CI -423;3212) per respondent, while the average cost for respondents with fair or poor health status was €3581 (95%CI 3068;4094) and €4281 (95%CI 3598;4965).

The standardised mean expense based on duration with arthritis did not indicate statistical difference and varied from €2687 to €3437 for respondents with 2 years and 10+ years with an arthritis diagnosis.

Table 4.16: Total personal expenses

	n	Mean [€]	(95%CI)
All	1107	3539	(3260-3817)
Sex: Female	939	3573	(3301-3844)
Male	160	3177	(2130-4224)
Other	8	6752	(-749-14252)
Age: <34	45	2823	(2274-3371)
35-44	110	3889	(3124-4653)
45-54	219	3379	(2964-3793)
55-64	348	3454	(3059-3849)
65-74	242	3561	(2788-4333)
>75	103	3169	(2425-3912)
Primary education	28	1863	(1452-2274)
Secondary education	312	2838	(2570-3106)
University education	617	3893	(3484-4302)
Other education	149	3844	(2812-4876)
RA	208	3254	(2406-4103)
RA & other	149	4267	(3598-4937)
OA	263	2788	(2369-3207)
OA & other	69	4867	(2729-7005)
PsA	134	3464	(2929-3998)
Other	284	3772	(3334-4210)
Arthritis: <2 years	124	2985	(2391-3580)
2-5 years	238	3473	(3048-3898)
6-10 years	234	3633	(3054-4211)
>10 years	474	3746	(3227-4266)
General Health: Poor	227	4173	(3635-4711)
Fair	386	3896	(3340-4452)
Good	350	2999	(2654-3344)
Very good	108	2607	(2139-3075)
Excellent	35	3757	(-71-7586)

Based on data from 1107 respondents.

4.7 Impact on employment

Table 4.17 shows the employment status of respondents by age in the last 12 months. 36.9% of respondents aged under 65 years were in full time employment, and 21.5% were in part time employment, of which 60% were in part time employment due to arthritis. 30.8% of respondents in this age group indicated that they had retired or were unable to work, with 20% of respondents indicating this was due to arthritis.

The weekly work hours for 427 respondents who were in current employment are shown in Table 4.18. 262 (61.5%) were in full-time employment. Of the 165 (38.7%) in part-time employment, 90 (54.5%) indicated that this related to their arthritis. Table 4.19 shows that 295 (70.4%) out of 419 respondents currently employed had experienced a loss of income due to arthritis in the last 12 months. These respondents had on average an income loss of €3111.

Table 4.20 shows the employment status for respondents under 65 years by arthritis type (n=632). 66.5% of respondents were actively employed, while 33.5% of respondents in this age group had retired either by choice or due to arthritis. Among respondents in active employment, 23.6% had RA and 19.3% has PsA. Respondents with other conditions besides arthritis were more likely to have retired before the age of 65 years.

Table 4.17: Current employment status by age

	Age group		
	<65 years	>65 years	All
N	688 (67.9%)	325 (32.1%)	1,013 (100.0%)
Current employment status			
Full time employment	254 (36.9%)	8 (2.5%)	262 (25.9%)
Part time employment by choice	59 (8.6%)	12 (3.7%)	71 (7.0%)
Part time employment due to arthritis	89 (12.9%)	<5 (-)	93 (9.2%)
Job seeking/unemployed/student	18 (2.6%)	5 (1.5%)	23 (2.3%)
Caregiver/volunteer	28 (4.1%)	13 (4.0%)	41 (4.0%)
Retired by choice	24 (3.5%)	187 (57.5%)	211 (20.8%)
Retired early due to arthritis	54 (7.8%)	62 (19.1%)	116 (11.5%)
Unable to work due to arthritis	134 (19.5%)	6 (1.8%)	140 (13.8%)
Other	28 (4.1%)	28 (8.6%)	56 (5.5%)

Table 4.18: Weekly work hours for participants in current employment

	Weekly work hours				
	<20	20-30	30-40	>40	All
N	81 (19.0%)	83 (19.4%)	196 (45.9%)	67 (15.7%)	427 (100.0%)
Current employment status					
Full-time	0 (0.0%)	17 (20.5%)	178 (90.8%)	67 (100.0%)	262 (61.4%)
Voluntarily part-time	40 (49.4%)	27 (32.5%)	8 (4.1%)	0 (0.0%)	75 (17.6%)
Not voluntarily part-time	41 (50.6%)	39 (47.0%)	10 (5.1%)	0 (0.0%)	90 (21.1%)

Table 4.19: Income loss due to arthritis for those actively employed

	Age group		
	<65 years	>65 years	Total
N	398 (95.0%)	21 (5.0%)	419 (100.0%)
Has income loss n (%)	281 (70.6%)	14 (66.7%)	295 (70.4%)
Mean Income loss [€]	2986 (6041)	5891 (14811)	3111 (6624)

Note: 8 participants have no indication of age

Table 4.20: Employment status of respondents aged less than 65 years by type of arthritis

	Employment status		
	Actively employed	Retired	All
N	420 (66.5%)	212 (33.5%)	632 (100.0%)
Diagnosis			
RA	99 (23.6%)	25 (11.8%)	124 (19.6%)
RA & other	42 (10.0%)	45 (21.2%)	87 (13.8%)
OA	65 (15.5%)	34 (16.0%)	99 (15.7%)
OA & other	19 (4.5%)	15 (7.1%)	34 (5.4%)
PsA	81 (19.3%)	20 (9.4%)	101 (16.0%)
Other	114 (27.1%)	73 (34.4%)	187 (29.6%)

4.8 Help at home

Respondents were asked if they received help at home in the last 12 months. 116 (7.2%) of 893 respondents who responded indicated that they had received help at home. 12 (10%) respondents indicated that they had received help at home from the state or local authority for an average of 143 hours.

In addition, 50 respondents (43%) indicated that they had paid for private help at home for an average of 319 hours.

Although 57 (50%) respondents indicated that they had received help at home, they did not specify if it was funded privately or by the state/local authority.

116 respondents indicated that they had received on average 734 hours of unpaid help from their informal care providers (spouse/partner, children, relatives, friends/neighbours).

4.9 Time spent on healthcare and transport

Table 4.21 summarises the average time spent by respondents at healthcare service visits and the time travelled to and from these healthcare services, in the last 12 months. On average, each respondent spent 105 hours (95%CI 93-116) travelling to and from healthcare services. Respondents aged 55-64 spent the most time on healthcare visits, totalling 107 hours, including travel time. Respondents with poor health spent 156 hours, compared to respondents with excellent health status who

spent 60 hours on healthcare services and transport.

Table 4.21: Combined time spent availing of healthcare services and travelling to and from healthcare providers

	n	mean [h]	(95%CI)
All	1087	105	(93-117)
Sex: Female	926	105	(94-116)
Male	153	105	(52-157)
Other	8	162	(18-306)
Age: <34	45	80	(54-105)
35-44	108	102	(78-125)
45-54	217	99	(80-117)
55-64	343	107	(85-128)
65-74	237	86	(72-101)
>75	98	105	(76-135)
Primary education	28	105	(59-152)
Secondary education	304	98	(69-127)
University education	607	105	(91-120)
Other education	147	119	(93-146)
RA	206	71	(55-86)
RA & other	147	166	(106-225)
OA	253	79	(67-91)
OA & other	67	110	(77-142)
PsA	133	101	(57-145)
Other	281	123	(103-143)
Arthritis: <2 years	121	111	(46-176)
2-5 years	235	105	(84-125)
6-10 years	227	103	(82-124)
>10 years	468	105	(89-121)
General Health: Poor	225	156	(115-197)
Fair	380	109	(90-128)
Good	343	85	(71-99)
Very good	103	63	(39-87)
Excellent	35	60	(28-91)

Extrapolated with data from 1087 respondents.

Respondents from more rural areas, Carlow, Clare, Donegal, Kildare, Longford and Louth spent 30% longer on visits and transportation to healthcare providers compared to respondents from Dublin, after standardisation for sex, age, education, diagnosis and general health. However, there is large variation in the time spent among a smaller proportion of respondents from less populated areas, which potentially impacts the strength of these findings.

5 Discussion

5.1 Summary of main findings

In this report we have analysed the personal expenses that people living with arthritis bear due to their disease. We conducted an online survey among people from the Arthritis Ireland network. More than 1600 individuals took part in the survey and partially or fully completed different sections of the questionnaire. Having this many responses is highly satisfactory, as it reduces the likelihood of the analysis being skewed by a small number of selected respondents.

The results in this survey have come from respondents across all of Ireland. In addition to being well representative of respondents' sex, age group, and a wide range and combination of rheumatic and musculoskeletal diseases. Furthermore the responses also accurately reflect respondents' related comorbidities and length of time living with a rheumatic or musculoskeletal disease.

The analysis focused on capturing respondents' self-reported general health status and sleep patterns. We captured this information using standardised and validated instruments. We captured health-related quality of life using the EQ-5D instrument and calculated a score using an Irish developed algorithm. This allowed us to compare the respondents' survey data with data from general population surveys. This highlighted that people living with arthritis had much poorer health-related quality of life compared to the general population in Ireland. Similarly, we were able to identify that a larger proportion of respondents living with arthritis described their general health status as poor or fair, and fewer respondents described their general health as good or excellent. This pattern was closely related to respondents' age, where a larger proportion of older respondents described their general health status as poor compared to younger respondents.

In the analysis of sleep patterns, we found that a large proportion of all respondents reported having poor sleeping patterns due to their arthritis. Similarly, a large proportion of all respondents reported that they have experienced problems in terms of mobility, self-care, usual activities, pain and discomfort, and anxiety and depression. This analysis suggested that poor health-related quality of life was strongly related to age, type of rheumatic and musculoskeletal disease and the length of time living with the disease. It also appears that respondents' health-related quality of life was poorer among those with less education.

We analysed respondents' use of a wide range of healthcare and other services in the last 12 months and respondents' associated personal expenses when using these services. Among almost 70% of the respondents who filled out this section of the questionnaire, each respondent had on average 27 visits to different healthcare providers. The total average amount respondents spent on

these healthcare services was €1980. In addition to these expenses, respondents spent an additional €976 on medical products, €479 on assistance and €105 on help at home. We estimated that arthritis imposed a mean personal expense of €3541 per respondent.

In addition to the personal expenses, we estimated that each respondent spent a significant amount of their personal time availing and travelling to and from healthcare services.

Two-thirds of respondents who responded to the survey section on employment status were under the age of 65 years. Over 30% of these respondents indicated that they are unable to work or have retired early due to their disease.

The results from the cost survey clearly demonstrate that rheumatic and musculoskeletal diseases impose a considerable personal burden on individuals living with these diseases.

5.2 Methodological challenges

When interpreting the results from this analysis, it is important to be aware of the potential biases related to the respondents and their responses. As mentioned, respondents were invited through the network of Arthritis Ireland. The email mailing list includes more than 13,400 addresses and the majority of respondents (1456 or 84%) responded to these emailed invitations. The remaining respondents engaged with the survey from posts on social media platforms. The participation rate of the email invitees was 11%, which is relatively low but not unusual. However, as we have no access to information about the people in the network, we cannot make any assessment of how well the respondents represent people in the network.

It is highly likely that the people who chose to take part in the survey are a select group. They are likely to be more interested and perhaps more aware of their personal expenses than the average person in the network. Certainly, these individuals were sufficiently interested and willing to spend approximately 20 minutes to complete the relatively complicated online survey. However, for some, this may have been too complicated, as less than 70% of respondents who started the survey, actually completed the full questionnaire.

In contrast, individuals who were more enthusiastic about the theme of this survey, have completed it more than once. We identified multiple responses from the same person based on information about their sex, age, post code, and year of diagnosis. From this information combined, we were able to sufficiently identify unique respondents. From this, we identified that 90 people had completed the questionnaire twice, and 9 others had completed the questionnaire more than twice. To prevent over-representation of these respondents, we only included the earliest full response from these individuals in the overall analysis.

Designing a cost survey can be challenging, due to many other costs that could potentially be captured. It is important to maintain a comprehensive survey by including a wide variety of questions. However, to minimise the burden on the respondents and reduce the possibility of too many incomplete responses, it was necessary to restrict the number of cost elements to a more manageable level.

One particular aspect related to cost is the reporting period. The practice has great variation

and ranges from requesting cost data relating to the last month, quarter or year. For this survey, we chose the last year as the time frame. We considered this to be relevant and easy to analyse, and the engagement with co-designers and pilot testers suggested that a full year would be possible and the most appropriate time frame. The relatively long time perspective increases the risk of recall bias. Some respondents may have forgotten some resource use and could have mixed up the timing of such use. However, this did not seem to be a particular problem among respondents. In contrast, it was clear that many respondents readily understood the time frame and had no problem remembering their various personal costs over this period.

Despite undergoing co-designing and pilot testing, the questionnaire had several limitations. The chosen categories for education level were not sufficient in capturing the full range of educational qualifications. This resulted in many respondents not being able to correctly specify their most appropriate level of education, and instead, being limited to choosing the 'other education' option.

Another challenge was related to the non-use of different resources. Initially, we had considered including additional options where respondents could indicate if they had used a specific resource or not, and additionally could indicate the frequency and duration of use. However, during the co-design phase, it was agreed that this would further add to the already long questionnaire. Alternatively, we considered asking respondents to identify whether they had used a resource zero times. Similarly, this solution would require the respondents to actively answer more questions. In the end, we simply asked respondents to report the number of visits they had made to a healthcare provider, if they had more than one visit. Respondents were also asked to report their average time and personal expenses, ensuring that their responses would more accurately reflect their perspectives. However, the limited number of responses to all of the cost questions is a challenge in itself. As indicated earlier less than 70% of those who started the questionnaire provided completed answers. For the analysis it was important to be clear if some respondents had attempted to answer some of these questions, in which case a non-response may be representative of zero resource use rather than having no response at all. Errors in these assumptions may have serious implications for the estimates of means and confidence intervals.

Additionally, the expenses estimated pertain to the day-to-day healthcare costs for individuals. This differs from the more commonly collected costs, which are typically viewed from the healthcare system's perspective.

Some of the responses had to be excluded from the cost analysis because respondents provided varied answers which were invalid. Therefore, the estimated costs do not include some information that was initially provided by respondents.

5.3 Strengths and weaknesses

This is the first time the personal expenses for individuals living with arthritis in Ireland have been reported. This information was captured using a standardised and co-designed online survey, which made it easy for participants to provide responses on a computer or a mobile device.

The survey tool was developed in collaboration with people with personal experience of arthritis and their expenses related to the disease. This co-design process meant that we applied a tailor made, comprehensive questionnaire that includes many facets of living with the disease not only in terms of financial expenses but also the impact of the arthritis on other aspects of life. We included an extensive pilot testing of the questionnaire which helped ensure the comprehensiveness and appropriate wording of the questionnaire. The pilot phase also addressed the technical aspects, ensuring respondents could complete the questionnaire using a laptop, tablet, or mobile device.

However, since the survey was only shared online, it is possible that some people who wanted to complete the survey were excluded. For example, people who do not wish to use or are not familiar with online applications may have been excluded from taking part in the survey.

In addition, some people who started the survey did not complete the full survey. This may have been due to the survey's length, as well as respondents' reluctance to share confidential information about their private arthritis-related expenses.

One of the principle weaknesses of this survey is that it is unknown to what extent the survey represents the general population with rheumatic and musculoskeletal diseases. This of course depends on how these diseases are defined. It has been suggested that one in four to one in five of the general population has one of these diseases[1]. If this is the case, then there could be up to 1 million people in Ireland living with these conditions. However, the Healthy Ireland Survey includes a section on self-reported diseases, and this report suggests a considerably lower number of people with self-reported arthritis. It would therefore appear that it is difficult to establish an accurate definition and representation of the population with rheumatic and musculoskeletal diseases. It is important to be aware of these difficulties when interpreting the results in this report. We aimed to extrapolate personal expenses to the national level, but without consensus on the number of people with the disease, such calculations were not possible.

5.4 Perspectives

The cost information reported in this report has many possible uses. For example, the results can provide a reference point to understand the private costs associated with arthritis, which can be compared to the entire Irish population living with arthritis.

Additionally, these results can be used in combination with other data sources, for example Irish survival data, from which outcomes such as lifetime costs, life expectancy, and quality-adjusted life expectancy can be estimated.

Additionally, the information from this survey can be used to inform future clinical trials of new treatments for arthritis, as well as inform the healthcare system and other stakeholders of the financial burden that people living with arthritis face.

[1] Versus Arthritis. THE STATE OF MUSCULOSKELETAL HEALTH 2024. Arthritis and other musculoskeletal conditions in numbers, 2024. & Scottish Government. The Scottish Health Survey 2022

A Appendix

A.1 Acknowledgement

We wish to thank all of the respondents for spending their time and energy completing the long and detailed online questionnaire.

A.2 Ethical approval

The study was approved by the RCSI Research Ethics Committee (REC 202304014).

A.3 Funding

Arthritis Ireland provided financial contribution to the RCSI School of Population Health to conduct this research.

A.4 Authors' role in the project

Jan Sorensen, Professor of Health Economics, RCSI School of Population Health. Took part in negotiating the financial support from Arthritis Ireland, the initial design of the study and planning the data collection process, co-design of a tool for data capture, ongoing monitoring of data collection, data management and analysis, drafting and editing of the report.

Gintare Valentelyte, Postdoctoral researcher of Health Economics, RCSI School of Population Health. Took part in planning the data collection process, design of the tool for data capture, ongoing monitoring of data collection, data management and analysis, drafting and editing of the report.

Una Rósa Birgisdóttir, Research assistant, RCSI School of Population Health. Took part in data management and analysis.

Laura Hammond, Research Officer, RCSI School of Population Health. Took part in planning the data collection process, design of the tool for data capture, ongoing monitoring of data collection, data management.

Claire Kinneavy lives with rheumatoid arthritis and Sjögrens syndrome and was involved in the co-design of the survey, providing feedback, editing and reviewing drafts of the report.

Tim O'Sullivan is Chairman of Arthritis Ireland and lives with rheumatoid arthritis and psoriatic arthritis. Tim was involved in co-designing the survey.

Peter Boyd lives with rheumatoid arthritis and osteoarthritis. Peter works as Services Support Officer at Arthritis Ireland and manages the organisation's helpline. Peter was involved in the co-design of the survey, providing feedback, editing and reviewing drafts of the report.

Tara Regan is Communications and Advocacy Manager at Arthritis Ireland. Tara oversaw the design of the survey, coordinated its promotion to the Arthritis Ireland network, provided feedback and edited and reviewed drafts of the report.

Gráinne O'Leary is Chief Executive of Arthritis Ireland. Gráinne was involved in co-developing the survey, providing feedback, editing and reviewing drafts of the report.

A.5 Online questionnaire



Costs associated with accessing healthcare related to a diagnosis of arthritis - E

1. Introduction and Consent

You are invited to take part in a research study being carried out across Ireland, through this voluntary and anonymous questionnaire. The purpose of the questionnaire is to understand the individual costs related to arthritis amongst a sample of adults with the condition. This may include Arthritis Ireland members, service users, as well as others who engage with the charity.
The voluntary and anonymous questionnaire asks questions about you, your arthritis diagnosis and your quality of life. It asks about your use of and payments made for health services, help received in your home, work status, and transport relating to appointments, over the last 12 months.
You do not have to participate in the study. If you decide not to take part in the questionnaire, or not to continue once you've started, you don't have to give a reason. The quality of treatment you receive in future will not be impacted by your decision to participate, or not.

Why is this study being done?
This study seeks to understand the individual costs related to arthritis amongst a sample of adults with the condition.

Who is it for?
The questionnaire is for adults (18 years +) with an arthritis diagnosis.

What are the risks?
There are no obvious risks to you taking part in the study. There will be a demand on your time, which may be an inconvenience. You may feel tired after completing the questionnaire; if this is the case, you can save and come back to complete the questionnaire at a time that suits you. You may feel upset when answering questions about your diagnosis.

What are the benefits?
The questionnaire aims to better understand the costs and quality of life for people with an arthritis diagnosis. The resulting report will aim to better inform researchers, service providers and policy makers. There may not be any direct benefits for you in that you will not receive any additional treatment by taking part in the study.

Is the study confidential?
This questionnaire is voluntary and anonymous. Your identify will not be known by the research team. Members of the research team will be bound by professional codes of confidentiality. Any breach of this is against RCSI regulations and will result in disciplinary action, and your data will not be used for any other purpose other than described above. It will be destroyed 5 years after the study is complete.

Results
The findings of the study will be published in a descriptive report. There will not be information which will enable identification of participants.

Who is organising and funding the research study?
This research study is being conducted by researchers in the Health Outcomes Research Centre at the RCSI (Royal College of Surgeons Ireland). It is funded by Arthritis Ireland.

Data Controllers
Professor Jan Sorensen, Director of the Health Outcomes Research Centre, is the data controller. If you have any questions about this study, contact HORC@rcsi.com.

Completing the questionnaire
This questionnaire will take approximately 15 minutes to complete.
Where a question is followed by an asterisk (*), this question requires an answer before progressing.
To progress through the questionnaire, click 'Next Page'. If you cannot complete the questionnaire at this moment, click 'Save and Continue Later'. Your responses will be saved, and you will be prompted to input your email in order to receive a unique link to continue at a later time. This process maintains your anonymity and your email will not be visible to the research team.
Remember to click 'Finish Survey' once you have completed the questionnaire to ensure your responses are submitted. If you change your mind about completing the questionnaire once you have started, you can close the web browser, and the questions that you've answered so far will not be submitted.

1. I have read the above information, understand the purpose of the research, and consent to my anonymous data being processed as part of this research study.

- [ ] Yes

2. About You

2. In what year were you born? Please note this survey is for adults 18 or over.

3. What is your gender?

- [ ] Male
- [ ] Female
- [ ] Non binary
- [ ] Prefer not to say
- [ ] Prefer to self describe (please specify):

4. What are the first three letters/numbers of your postcode?

5. What is the level of education or training you have completed?

- [ ] No formal education or training
- [ ] Primary education
- [ ] Secondary education
- [ ] University education
- [ ] Other (please specify):

3. Your Diagnosis

6. In what year did you receive your first arthritis diagnosis?

7. Which rheumatoid or musculoskeletal disorder have you been diagnosed with?

- [ ] Gout
- [ ] Rheumatoid arthritis (RA)
- [ ] Osteoarthritis (OA)
- [ ] Psoriatic arthritis (PsA)
- [ ] Juvenile idiopathic arthritis (JIA)
- [ ] Sjögren's syndrome
- [ ] Ankylosing spondylitis/axial spondyloarthritis (AS/axSpA)
- [ ] Fibromyalgia
- [ ] Polymyalgia rheumatica
- [ ] Raynaud’s
- [ ] Lupus (SLE)
- [ ] Scleroderma
- [ ] Down syndrome associated arthritis (DA)
- [ ] Other (please specify):

8. In addition to your arthritis, do you have any other conditions?

- [ ] Diabetes
- [ ] Lung, e.g. Asthma, COPD
- [ ] Cancer
- [ ] Hypertension
- [ ] Cardiovascular, e.g. Coronary Heart Disease, Heart Failure, TIA
- [ ] Stroke
- [ ] Neurological, e.g. Parkinson's, Alzheimer's
- [ ] Mental Health
- [ ] Other (please specify):

4. Your General Health and Wellbeing

Under each heading, please tick the one box that best describes your health in general, in relation to your condition.

9. Mobility

- [ ] I have no problems in walking
- [ ] I have slight problems in walking
- [ ] I have moderate problems in walking
- [ ] I have severe problems in walking
- [ ] I am unable to walk

10. Self-care

- [ ] I have no problems in washing and dressing myself
- [ ] I have slight problems in washing and dressing myself
- [ ] I have moderate problems in washing and dressing myself
- [ ] I have severe problems washing or dressing myself
- [ ] I am unable to wash or dress myself

11. Usual activities, e.g. Work, study, housework, family or leisure

- [ ] I have no problems doing my usual activities
- [ ] I have slight problems doing my usual activities
- [ ] I have moderate problems doing my usual activities
- [ ] I have severe problems doing my usual activities
- [ ] I am unable to do my usual activities

12. Pain/discomfort

- [ ] I have no pain or discomfort
- [ ] I have slight pain or discomfort
- [ ] I have moderate pain or discomfort
- [ ] I have severe pain or discomfort
- [ ] I have extreme pain or discomfort

13. Anxiety/depression

- [ ] I am not anxious or depressed
- [ ] I am slightly anxious or depressed
- [ ] I am moderately anxious or depressed
- [ ] I am severely anxious or depressed
- [ ] I am extremely anxious or depressed

14. Sleep

- [ ] My sleep is not interrupted
- [ ] My sleep is slightly interrupted
- [ ] My sleep is often interrupted
- [ ] My sleep is significantly interrupted
- [ ] I am unable to sleep

15. In general, compared to other people your age, would you say your health is:

- [ ] Poor
- [ ] Fair
- [ ] Good
- [ ] Very good
- [ ] Excellent

5. Health Services

16. In this question, we would like to learn about your use of health services relating to your arthritis during the last 12 months.

In 'Number of visits', please indicate how many visits you made to the service.

In 'Approx. time spent per visit', please indicate approximately how much time you spent per visit, from arrival to departure, in minutes. Include waiting time, but do not include time spent in transit.

In 'Payment made in the last 12 months', please indicate how much you paid for the service over the last 12 months, in Euros. If you have private health insurance, include the amount that health insurance has reimbursed. Do not include the cost of transport.

	Number of visits	Approx. time spent per visit (Minutes)	Payment made in the last 12 months (Euros)
GP service			
Out of hours GP service			
Hospital Outpatient Appointment with Consultant			
Hospital Accident and Emergency (No admission)			
Private consultant appointment e.g. rheumatologist, dermatologist			
Surgeon Appointment			
Blood Tests			
X-Ray/MRI			
Public Health Nurse			
Physiotherapy Services			
Occupational Therapy			
Speech and Language Therapy			
Orthotist/Prosthetists			
Dietician Services			
Optician Services			
Dental Services			
Chiropody Services			
Psychological/Counselling			
Day Care Centre			
Rehab/Respite Care			

Chiropractor			
Alternative Therapies/Complementary Practitioner (Acupuncturist, Reflexology, Chinese Medicine, or other)			
Pharmacy Consultation (Not including collecting a prescription)			

17. In this question, we would like to learn about your use of overnight health services relating to your arthritis during the last 12 months.

In 'Number of admissions', please indicate how many times you were admitted to the service.

In 'Total number of overnight stays', please indicate the approximate total number of overnight stays you had in the service.

In 'Payment made in the last 12 months', please indicate how much you paid for the service over the last 12 months, in Euros. If you have private health insurance, include the amount that health insurance has reimbursed. Do not include the cost of transport.

	Number of admissions	Total number of overnight stays	Payment made in the last 12 months (Euros)
Hospital Scheduled (Planned) Inpatient overnight stay			
Hospital Accident and Emergency with overnight stay			
Rehab/Respite Care			

18. Do you have a GP Card?

- [ ] Yes
- [ ] No

19. Do you have a Medical Card?

- [ ] Yes
- [ ] No

20. Do you have private health insurance that covers some of the cost of healthcare?

- [ ] Yes
- [ ] No

21. In the last 12 months, how much have you paid for your private health insurance? (Euros)

22. In the last 12 months, how much have you received in reimbursement from your private health insurance? (Euros)

23. How important is your private health insurance to you, given your condition?

- [ ] Very important
- [ ] Important
- [ ] Slightly important
- [ ] Not important
- [ ] I do not have health insurance

24. How much have you paid for medication relating to your condition over the last 12 months? (Euros)

Prescription medicine	
Over the counter medication	
Supplements	
Other	

25. How much have you paid for other products relating to your condition over the last 12 months? (Euros)

Sexual health	
Personal grooming	
Other	

26. Are you registered with the Drugs Payment Scheme?

- [ ] Yes
- [ ] No

27. Do you have life insurance or assurance?

- [ ] Yes
- [ ] No, because I do not wish to purchase
- [ ] No, because I was not approved when I tried to purchase
- [ ] Other (please specify):

28. If you have purchased life insurance or assurance, are you aware if your premium was increased due to your arthritis diagnosis?

- [ ] Yes
- [ ] No
- [ ] Other (please specify):

29. Have you made use of any of the below to assist with your arthritis in the last 12 months? If you have, please advise if it was provided by state or local authority grant and/or self-funded. If you know the amount covered by the state or local authority grant, please include this amount. If self-funded, please include this cost. (Euros)

	Amount funded by state or local authority grant (Euros)	Amount self-funded (Euros)
Bathroom adaptations		
Kitchen adaptations		
Bedroom adaptations (E.g. mattresses)		
Appliances		
New clothing or alterations		
New footwear or alterations		
Wheelchairs		
Walker or roller frame		
Wheelchair ramp		
Additional home heating or cooling		
Other		

6. Help in the home

30. Have you received help at home relating to your arthritis in the last 12 months? (If no, skip to Q35)

- [ ] Yes
- [ ] No

31. If you have received help in the home relating to your arthritis, how many hours did you receive over the last 12 months?

	Number of hours over the last 12 months
State or local authority grant	
Private (Paid for by yourself or family/relatives)	

32. If you are receiving paid help in the home, how much did you pay for this service over the last 12 months? (Euros)

33. If you have received unpaid help relating to your arthritis from any of the following people over the last 12 months, for approximately how many hours?

	Number of hours over the last 12 months
Spouse or partner	
Your children	
Other relative	
Friend or neighbour	

34. In the last 12 months, did you receive any paid or unpaid help relating to your arthritis with the following activities?

	Paid Home Help	Spouse or partner	Your children	Other relative	Friend or neighbour	Other
Walking	☐	☐	☐	☐	☐	☐
Getting dressed	☐	☐	☐	☐	☐	☐
Bathing	☐	☐	☐	☐	☐	☐
Eating	☐	☐	☐	☐	☐	☐
Getting in and out of bed	☐	☐	☐	☐	☐	☐
Going to the toilet	☐	☐	☐	☐	☐	☐
Preparing meals	☐	☐	☐	☐	☐	☐
Doing household chores	☐	☐	☐	☐	☐	☐
Gardening	☐	☐	☐	☐	☐	☐
Shopping for groceries	☐	☐	☐	☐	☐	☐
Childminding	☐	☐	☐	☐	☐	☐
Getting to or from appointments	☐	☐	☐	☐	☐	☐
Making telephone calls	☐	☐	☐	☐	☐	☐
Taking medication	☐	☐	☐	☐	☐	☐
Managing your money	☐	☐	☐	☐	☐	☐

7. Ability to Work

35. Please select the status which best defines your current situation with regard to work.

- [ ] Full time employment
- [ ] Part time employment by choice
- [ ] Part time employment due to arthritis
- [ ] Job seeking
- [ ] Unemployed
- [ ] Student
- [ ] Caregiver within the home
- [ ] Volunteer
- [ ] Retired by choice
- [ ] Retired early due to arthritis
- [ ] Unable to work due to arthritis
- [ ] Other (please specify):

36. If in paid employment, how many hours are you scheduled to work per week?

- [ ] 0 - 10 hours
- [ ] 10 - 20 hours
- [ ] 20 - 30 hours
- [ ] 30 - 40 hours
- [ ] 40+ hours
- [ ] Not in paid employment

37. In the last 12 months, how much loss in income have you had due to your arthritis? E.g. Reduced working hours due to pain, or missing work due to arthritis flare-ups. (Euros)

38. If in paid employment, how much did your arthritis affect your productivity while you were working over the last 12 months?

Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.

- [ ] Health issue had no effect on my work
- [ ] Health issue had some effect on my work
- [ ] Health issue had a significant effect on my work
- [ ] Health issue completely prevented me from working

39. Over the past 12 months, how much did your arthritis affect your ability to do your regular daily activities, other than work at a job?

By regular activities, we mean the usual activities you do, such as work around the house, shopping, childcare, exercising, studying, etc. Think about times you were limited in the amount or kind of activities you could do and times you accomplished less than you would like.

- [ ] Health issue had no effect on my regular daily activities
- [ ] Health issue had some effect on my regular daily activities
- [ ] Health issue had a significant effect on my regular daily activities
- [ ] Health issue completely prevented me from my regular daily activities

40. During the past 12 months, have you needed to change jobs due to your arthritis?

- [ ] Yes
- [ ] No
- [ ] Other (please specify):

41. What has been your source of income over the last 12 months?

- [ ] Employment
- [ ] Partner's income
- [ ] Family income
- [ ] State or local authority grant
- [ ] State pension
- [ ] Personal savings
- [ ] Other (please specify):

42. If you are currently working, what is your annual income?

- [ ] Less than €25,000
- [ ] €25,000 to €50,000
- [ ] €51,000 to €75,000
- [ ] €76,000 to €100,000
- [ ] More than €100,000
- [ ] Prefer not to say

8. Your Transport

43. How are you usually transported to and from the following treatment centres and how long in total does it take? (Minutes)

	Walking or biking	Bus, train or Luas	Hospital transport	Taxi	Private car	Ambulance
Outpatient Clinic with Consultant						
Other outpatient clinic (E.g. Physio, OT)						
GP service						
Consultant Appointment						
Hospital Admission						
Emergency Department						

9. Thank you and final comments

Thank you for completing the survey. We greatly appreciate your time and advice.
Click on 'Finish survey' to submit your answers. As this survey is anonymous, once you have submitted your answers, it will not be possible to identify and/or delete them.

If there are other costs related to your arthritis over the last 12 months not yet recorded in the survey, please include these below.

44. If you have any other comments about the survey, please include these here.

A.6 Responses to open-ended cost question

Question: If there are other costs related to your arthritis over the last 12 months not yet recorded in the survey, please include these below.

- "My mental health has completely suffered. I am lucky to have carers three times per week, but they are doing the bare minimum. I have lost all dignity and feel that sometimes the pain is so much that I am better off not here. The current treatment is working but means monthly visits to the hospital and little or no follow-up during the week."
- "Tests, MRI, X-rays, scans: Approx €700"
- "I pay €630 a year in a gym that I only use pool for exercising and water aerobics for seniors and walking in the water. It has helped me so much. Prior to joining the pool, I spent a lot of money with physio as my knees were giving up. Thank God for the pool."
- "I have hand controls in my car, and I have a primary medical cert."
- "Had a hip replacement and also a stoma operation in the last year. Walk very bad and in pain all the time."
- "I am also looking after my 44 year-old son who is awaiting lung transplant. He is my main worry."
- "Cane: €40"
- "Day to day costs are increasing."
- "Orthotics: €250"
- "Hire of private mobility scooter wheelchairs."
- "Yes: (1) additional dental hygiene appointments because hand arthritis means I can't properly brush my teeth; (2) hand and toenail appointments for the same reason."
- "I need to make an appointment with a private OT as there is a 2-year waiting list. The cost is approx. €250."
- "Buggy for golf: €30 a week."
- "I can't afford counselling as on pension. I need it as arthritis has made me fearful, isolated, anxious. I'm on a biologic and it can cause illness as I'm immune suppressed. I'm alone and my back, knees, wrists, neck get so painful. I find the GP's shuttle me through and I'm on GP Card for 6 months but with my health insurance I at least get to see consultants and it pays half for X-rays, MRI, Scans etc."
- "Made adaptations to my home 14 years ago and paid for them myself"
- "Paying people to do garden work , outdoor cleaning and decorating which I would previously have done myself: €600"
- "Reimbursing drivers for diesel and meals: €300 "
- "Private dental insurance: €422.15"
- "I have purchased various knee, back and wrist supports."
- "Fuel for car."
- "I was diagnosed with idiopathic pulmonary fibrosis in the last 12 months, which is RA related and which has now become an added expense for consultant visits, extra related tests etc. which need to be claimed back (50
- "Just the cost of knee supports, gels, and prescription charges and our private health insurance which we may have to give up next year."
- "Buying takeaway food, shop bought cakes and bread."
- "Transport, cost of petrol, parking etc. Most hospitals cost a fortune to use their car parks."
- "I use more home heating as the cold effects my arthritis."

- "House cleaning and Pilates."
- "I had to retire early which meant loss of income and friends etc. Working helps you stay mobile. I'm much better now but see so many specialists. It's a pain but I'm much better."
- "I have now been told l need treatment on my gums which will cost €150 for consultation fee. No appointments until September 2024."
- "I have Sjögrens syndrome and am on immunosuppressants, so I need to wear factor 50 cream every day. The approximate annual cost is €80. I also need foot creams and antiseptic balm (Gehwol cream €15 Bepanthen €12) and bandages for foot pads €12."
- "Car parking fees in hospitals."
- "Due to mobility issues and inability to drive, transport costs are enormous especially if pain is too bad to use public transport with several changes, walking and waiting times. Also, technical devices had to be adapted, and prices have doubled for specific items; heating and electricity costs increased significantly due to extra support items."
- "Cost of taxis to and from hospital and GP appointments."
- "Holidays. I need to book places with accessibility. Costs more. Concerts. I must pay to be seated."
- "A lifter for bowling €26. Hand massage machine €300."
- "Extra heating oil to keep my home heated is expensive with the increased cost of living. Also electricity is expensive despite the government assistance which was appreciated."
- "I pay a cleaning service occasionally as I can't do all the household tasks myself."
- "Only hospital and medicine."
- "Small aids to help open jars and lids."
- "Intolerance/ allergies to medications, including penicillin and others."
- "Chiropodist €500."
- "Due surgery on my foot I will have to buy a knee scooter. Toilet surrounds."
- "My biggest expense and worry is getting to Belfast to see my orthopaedic surgeon (I am on a treatment purchase scheme) and to my rheumatology team in Manorhamilton. And of course my reduced income having given up work due to a bad episode two years ago."
- "I cannot work so I have no income myself and I am completely reliant on my state pension and my husband. I always worked myself and always had my own money, so I am struggling. €237 for the state pension is an insult and I can't afford physio on that."
- "Food and supplement costs are huge for me as I also had a gastric bypass, so vitamins and minerals are required and glucosamine for arthritis! All these products have been recommended that I take from my bariatric consultant and my rheumatologist."
- "€1200 for membership of a swimming pool as regular swimming helps my mobility and relieves my pain. An interesting cost, which is hard to quantify is the cost of tickets to concerts or events like "Bloom" garden festival, where you plan to go and due to sudden fatigue (worst part of arthritis) or maybe unexpected strep throat infections, you cannot attend the event, so you end up giving away the tickets."
- "Arthritis affects my ability to apply for a higher paid job. Silent suffering of pain and stiffness cannot have a financial cost applied to it"
- "As a result of increased tiredness, I get through my workday but have no energy left for home life or housework. I often must nap before I can have dinner. If my husband is going out and I am due to make dinner I may order takeaway if I have no energy to cook. I order online and pay for deliveries instead of visiting stores. I have bought an automatic car to have no gear changes when my hands hurt from arthritis. I buy things in local shops instead of travelling to a major supermarket so pay a higher price. On mortgage protection insurance I am loaded with a fifty per cent increase. "

- "Knee support €60. Regularly changing pillow €100."
- "Massage gun €40. Heat pads €25."
- "Changed car to automatic."
- "Buying new clothes due to weight gain from low mobility."
- "Working hand splints support: €100."
- "I put in the amount that I paid for various supports for joints. Also, not this year but I previously purchased a walking stick."
- "Podiatrist costs €40 per visit every 2 months and is not available on medical card."
- "Expenditure on items such as shoulder heating pads, foot accessories due to sausage toes because of my condition, estimated at €200 per year."
- "Your survey doesn't consider many things that would help with our disease but are not within our means. For example, an OT recommended a particular type of chair but it isn't covered by the medical card, and I cannot afford it. Also, many of us are waiting on appointments for OT etc."
- "Ten's machine €60. Support bandages €120."
- "Mental health. So down somedays because I must work to pay the bills despite the pain."
- "Pilates classes €150."
- "I have bought kitchen appliances which specifically help with my poor use of hands. Also try not to buy shoes/trainers with laces etc."
- "Online courses."
- "I spend a lot of money online when I see online ideas/diets to help pain. Over the year €200."
- "Opportunity cost of not being able to go for a promotion worth circa €9k gross."
- "Not financial but emotional, familial, social."
- "Yes definitely other costs, plus zero help from anybody!"
- "Having to put the heating on more than other households because the cold really affects me."
- "Other activities that would help my condition, but not possible to take up on account of costs e.g. Yoga, pilates or swimming."
- "Knee support €14, gloves for hands €30."
- "Petrol for transport to appointments, toll bridge charges, parking fees."
- "Had to buy a small secondhand car as the walk to and from the train station is too much for me, that was €8,300."
- "€180."
- "Eating a healthy diet is very important but as with everything else the cost of food has significantly increased recently."
- "Cost of personal time required to recover from activities both work and leisure- I need to take time to let my body rest after strenuous or prolonged activities. Cost of massages to relieve pain €500 approx. p a."
- "Voltarol 2
- "Having to use extra electricity to dry clothes that I can't hang on clothes line. Having to buy ready meals."
- "Gosh there's so much. Every penny I have goes on looking after my health in a roundabout way. Currently putting loads of costs for visits, blood tests, procedures, etc. on my credit card, which means I'm paying 23
- "Food, changes to diet and fresh fruit and vegetables very expensive."

- "I visit my family in Mayo once or twice a year. I must stay over in Athlone on both the outgoing and return trip as it's too painful to complete the full journey in one trip. This costs about €250-€280 per visit."
- "Eye drops, emollients, replacement shoes, dry mouth gel/ mouthwash, toothpaste. Need someone to cut toenails! Swimming as I can't walk far"
- "Going to see GPs and private consultants is not covered under my health insurance. Because of the high costs I am now attending Cappagh Hospital which are way better than any medical treatment I have received privately."
- "Household gadgets, splints, supports for feet hands in bed. Compression socks and gloves. Lowering cupboards."
- "The cost that is unquantifiable is that of your loss of self. With chronic pain, fatigue, poor concentration and inability to do simple tasks like kneeling down to pick something up or get on the floor, priceless."
- "Because I'm in my early 50's I'm not entitled to a carer to help me around my house and I'm not able to manage it alone. I do my best but it's a work for 10 minutes sit for an hour type thing!"
- "Three tolls from where I live to get to hospital and three back home again. In for infusion every six weeks So fuel costs are all adding up."
- "Aids to help with housework approx. €200."
- "I've already noted that I relocated to a warmer house in a central location for services. The cost of swimming, which is vital for my movement, is unaffordable for me at the moment. My spouse drives me to all appointments that are more than 30 minutes away which is 99
- "Approx €100 on compression supports."
- "Exercise costs to maintain health. That would be gym membership and paying for yoga."
- "Requirement for automatic car, unable to drive manual, an extra 5k to 10k depending on car. Cost of gym with coach to maintain muscle strength and mobility, yoga and swimming. All of these are not optional for pleasure but necessary for trying to manage my condition. It's €2000 min per annum."
- "It effects my husband working hours. He loses hours driving me to appointments. Also had 3 major surgeries in the last 12 months. Had a spinal fusion recently and had a major spinal procedure three days ago in Dublin. We live in Waterford."
- "Online classes for flexibility strength €35 per month."
- "Yes - while I am a family carer it eats into my husband's time when I am unwell. The value of my work while not paid incurs a cost in lost hours to my husband and his job. Please value the purple economy!!"
- "I feel that my answers are a bit skewed as I have not had sufficient income in the last 12 months to care for myself as much as I would like to. (e.g. physio, supplements)"
- "Not over the last 12 months but after my diagnosis I took a period of unpaid leave and then a year (unpaid) career break in order to determine what medication would work to manage my symptoms and whether I could continue to work. That had a big financial impact. On return to work I needed to purchase new equipment to improve my homework station. Costs €1000."
- "I travel for work, and it is challenging in the extreme when colleagues expect I take public transport to overseas locations, I need to get taxis as have bags/laptops etc. to carry and while my feet are generally unaffected, I can be sore for days from carrying anything! Hands, shoulders, neck, sides and back areas. I also need to book parking close to airport or other areas at my own cost as once again carrying, pulling, lifting is a major issue with days of recovery after, which I can't have as work must go on."
- "For the past two years I have had frozen shoulders (both sides). Have had additional steroid injections from my rheumatologist but think next step is surgery. The frozen shoulders are triggering flare ups - particularly in my arms which can become quite useless. I work a desk job and even with this limited use of my arms, by the end of a working day (even a nice short 8 hour one working from home) I

would have difficulty undressing, and washing my face, etc. at least one or two days a week. I work for lawyers and can regularly work up to 15 - 20 hours a day but am cutting back on that now as these long days, result in up to a week of additional pain and weekends in bed (and I am not always paid for overtime - grrrrr)."

- "Gym so I can use the pool for hydrotherapy. Cost €700 per year."
- "I don't have home help, but I need a lot of help from my husband with all household jobs as there are days, I just can't do them. That has a huge emotional cost for us. Parking costs at hospitals make waiting in queues at appts more stressful. Parking should be free with a Blue Badge"
- "I got a pedal-assist bike instead of a regular one. This cost approx. €600."
- "I can no longer drive so must rely on taxis or my spouse to take time off work to take me to appointments. Other costs include GP charging to renew drug prescriptions as rheumatology won't provide repeat prescriptions for some items, they previously prescribed. Over the counter medication to relieve side effects of prescription drugs. Working time lost to scheduling appointments, chasing up results, sorting out prescriptions (E.g. renewal of high-tech drug prescriptions), constant trips to pharmacy, etc. I'm self-employed!"
- "I received knee injections with hyaluronic acid. My VHI covered most of the cost apart from the excess of €75 paid x 6 visits. I didn't see an option to record this type of information in the survey."
- "I feel more should be done for reduced prescription costs. Other diseases, e.g. diabetes receive free medication. €80 x 12 months is a huge cost."
- "Splints bandages heat packs/pads, cold packs support, cooling/heating gels pillows."
- "I have to buy certain soaps, deodorant and lotions as well as having to pay for some medication as suppliers don't have gms available but have them for sale, for example fybrogel."
- "I pay €100 a month for semi personal training sessions and Pilates to help my joints."
- "Cost of travelling to appointment: Kilkenny to St James hospital."
- "Cost of private Pilates: €1,800 "
- "I got no help from anyone for anything. I work 4 days a week and am a single parent trying to survive with no help from anyone."
- "Problems sleeping due to pain. Using hot baths for pain relief."
- "Quality of life as energy used on working and everyday activities, cleaning bathing cooking etc."
- "Gloves, socks, Epsom salts."
- "Help keeping my garden under control."
- "€500 a year for membership to a health club for access to a heated pool."
- "Buying splints supports and sunscreen all year round."
- "Sometimes my husband must take time off work to take me to appointments resulting in loss of earnings."
- "Because I'm immunosuppressed there's also a cost factor for sunscreen year-round of €60. Also have to purchase dressings and saline for wounds €150."
- "The loss of my job as a nurse has been a huge loss financially."
- "Cost of buying pre-cut veg fruit for convenience. Delivery costs for groceries etc. when flaring."
- "I was experiencing a lot of costs. Just recently got a medical card which is helping with the costs a lot."
- "Taxis to from school for my kids when I couldn't drive approx. €500. Loss of spouses' earnings due to needing to take unplanned days off as I was unable to get down the stairs look after my kids at all. Also taking time off to take me to appointments in Dublin Cork incurring significant travel associated costs on top of consultant fees etc. It's a huge financial burden on my family."

- "Splints €40, knee supports €20, electric blanket €100."
- "I feel that I have spent a lot of money on over-the-counter medication due to the continuous cancelling of my rheumatology appointments for no reason. My appointments are usually yearly but appointment due in September 2023 was cancelled twice and not scheduled for June 2024. This is unacceptable as I cannot look for adjustment in medications as GP is reluctant and leaves it to rheumatologist."
- "Cost to and from hospital an hour away. I also need childcare for this, and my husband takes time off work for this. Cost off additional heating, to home, as cold effects arthritis."
- "Included personal training that my consultant said I should do to improve my muscles for my future."
- "Intangible cost - Significant impact on mental health and general wellbeing over the last 12 months due to severe flare up, resulting in changes to my biologic injection and inability to work (which in turn affects pay and stress levels). Stress is a major trigger for flare ups, as such it can be a vicious cycle."
- "If you can't walk much and the bus doesn't run exactly where you need it to, you must get a taxi. You have to buy grabber, special can and jar openers, special things to help you put on your socks, hand rails, slip mats, electric blankets, heat pads, ice packs, migraine glasses, pads, eye masks, special things to help you tip the kettle, you eat a lot more convenience food, because you can't stand long enough to cook, you buy rails for your bed, you try 100 different types of pillows and cushions, you buy supplements, CBD oil, this root, that plant, this book that your third cousin recommended, you pay for extra physio as you have run out of your allowance, you try acupuncture, acupressure, massage, Reiki, yoga, this healer and that, you pay for a private scan or doctor appointment to try and get an answer. And it all costs money."
- "Had to pay a cleaner as physically unable to wash floors or reach with rib/sternum pain."
- "Cleaner! I was so limited at times in terms of mobility, I get a deep clean done in my house during key times like Christmas etc. €500 approx. in last year."
- "I pay a monthly fee for the gym - this is really important as it plays such a key role in managing my arthritis. This cost is just under €2K per annum."
- "Non appointment sick certs €20 each time, €80 total in the last 12 months. New clothes due to putting on weight due to an inability to exercise €500. Not being able to use my gym membership due to flare ups €420."
- "My arthritis is well controlled at the minute due to medication. Before I was on this medication I would have spent more on physios, GP and over the counter medication etc."
- "Taxis when I'm not able to get the bus and can't drive somewhere because there is no parking, and I don't have a disabled sticker on my car. Food is delivered when I can't walk so can't cook. Dog walker when I can't walk my dog."
- "I visited a kinesiologist 3 times which cost €200."
- "There are so many hidden costs such as orthotics, vaccinations recommended by your rheumatologist, travel to and from all the appointments, parking at hospital, anti-inflammatory gels, over-the-counter pain relief, specific footwear, etc."
- "Being able to be there more for my son who has ADHD , being able to support him more in all ways especially cooking for him he has taken the brunt of that. Also, his grant sometimes is mostly spent on taxis to train station as I'm not able to drive him when so tired."
- "Buying supports for ankles, wrists. Buying eye drops for dry eyes. (Unsure which category these should fit into)."
- "Because of my condition - Psoriatic Arthritis - I was refused income protection. I spoke to my consultant who understood my frustration given that my condition does not limit me in any way, nor does he expect it to shorten my life span. I found this to be really unfair. People who have no conditions (that they know of) can avail of income protection but I cannot. My opinion is that I am in a better position than some people my age as I get bloods taken regularly and keep on top of my health and wellness. Other 40-year-olds with bad habits and who haven't been to a doctor in years have income protection in place and I have been refused. Seems so unfair to me."

- "Income Ability to pick up casual work is gone since diagnosis. This was a big supplement to my income, especially during summer. Physical nature of work and medication side effects make it impossible."
- "Added heating cost due to feeling cold more. Supports for work i.e. chair, keyboard to alleviate pain etc."
- "When I have had surgery, I use buses which can sometimes amass to €10 per day for daily activities."
- "Apart from long waiting lists for an appointment with facial surgeon, I am concerned that by the time I get one my issue in my jaw will be way worse (not money related) but life related."
- "Change of car to an automatic due to issues when driving: €26,000"
- "Gym classes supplements are both expenses related to my diagnosis. €500 per year for the gym where I can do low impact training (I used to run but had to give it up as directed by consultant). Supplements of €40 per month."
- "Adaptive aids for work - ergonomic mouse, office chair."
- "Costs of purchasing take away/ convenience food if unable to cook some days, cost of delivery service for grocery shopping if unable to carry heavy loads of shopping, costs of hiring a dog walker for days that pain/ fatigue are heightened, cost of taxi service if unable to walk the distance/ stand on public transport."
- "I have a strict diet and exercise routine in order to maintain my pain levels at a manageable level. As a result, I spend a considerable amount extra on groceries and/or exercise services, gear and equipment."
- "€720 swimming pool membership."
- "Delivery costs. I have to get all of my groceries delivered, which costs around €40/month, not including the cost of the wasted food that shows up rotten or otherwise inedible because I can't choose it in the shop myself (this happens very often). I also have to get a lot more takeaways than I'd like, for example on days when I don't have the energy to prepare food, which can get very expensive. Nearly all of my other purchases come from online websites as I cannot visit the stores in person, meaning I don't get access to the reduced prices for items in-store and also have to pay shipping and delivery costs for most orders. It can be very time and energy consuming to manage all of one's purchases online, shopping around for the lowest prices and trying to find shops that offer free delivery, when I could otherwise just go to a shop and find everything I need quickly. It's also extremely time and energy consuming just to manage all the different doctor's appointments, blood tests, etc., which means I have less time and energy for other things, like paid work. There have been many times when I've had to opt for a more expensive purchase simply because it is more convenient and I no longer have the ability to choose the more budget-friendly option, despite having a much lower income due to my inability to work. Also, I had to purchase an ebike to get around (approx. €2100) because I am no longer able to reliably use a standard bike."
- "Additional childcare costs for emergency situations e.g. doctor appointments, AE admissions etc."
- "Yes, the cost of needing to hire people to do works around the house and garden that I used to be able to easily myself. I was trained from young age to do larger scale DIY jobs, but now cannot do these anymore."
- "I was doing manual driving lessons but couldn't continue due to my arthritis. Need to start automatic lessons but as there is such a demand the prices have gone from €50 to 65 an hour."
- "Not all my appointments are with the same hospital which means I have longer drives to clinics for ophthalmic care and rely on a relative to bring me as you cannot drive to those. This is a huge burden, and I have not yet been referred to my main clinic for this. This journey is 100km each way."
- "Convenience purchases other than usual to support arthritis - buying chopped vegetables/fruits, readymade meals."
- "Rollator to assist in walking cost €6000."
- "There are other facilities, hydrotherapy pool and yoga classes that I could do but everything is too expensive. I have to pay for everything."

- "Hydrotherapy €40 a week and exercise classes €7 a week."
- "Had to purchase very light shoes as I trip a lot. Difficult to do housework and gardening. I am a widow."
- "Child minding to help with kids when I'm exhausted."
- "I have purchased a knee support and Wellknee patches which both help."
- "I pay for sports massage to loosen tight neck muscles once a month."
- "It was necessary to purchase an automatic car due to difficulties in changing gear. Also had to replace lawn mower and other garden equipment to lighter battery-operated equipment."
- "I get pain management 4 times a year which my health insurance company pays for it (approx. 675.00 for each treatment)"
- "€10 per day to go to town shopping."
- "Extra tank of oil required to keep home comfortable: €1150."
- "Most additional costs relate to purchasing OTC supplements for wellness purposes."
- "I also suffer from osteoporosis."
- "Walking stick €150. Have plantar fasciitis in my left heel. Shoes €160, inserts €400, scan €60 this year. Between everything I find myself in debt of €950. Podiatrist €55 every 6 weeks. I have been seen three times free of charge but will not see me for another four months so I will need to pay for more private visits. I am 70 years of age."
- "Change car for one more easily accessible."
- "Diet is expensive to keep up eating properly."
- "I have to use shoe horn and an aid to put my socks on."
- "Can't get past interview stage due to stooping. I'm now exploring self-employment options by designing a job I can do with AS in a sage location."
- "I lost my job due to arthritis."
- "Due to my long-term Type 1 diabetes, arthritis health services are very, very poor for me."
- "Alternative therapies- naturopath €600, osteopath €600, hypnosis €1000."
- "Lack of testing on my condition. No written diagnosis. Little or no support."
- "Payment in the form of meals and gift certificates to friends for helping. Which all cost money."
- "No, not that I am aware of."
- "Gym / pool costs. "
- "Exercise classes €300."
- "I'm going through a divorce."
- "Medical marijuana."
- "Trying to get away to the heat during the winter if possible."
- "Not able to maintain upkeep of a rental property. Loss of €2000 per year. Not able to referee matches anymore. Loss of €2000 per year. Not able to exercise well anymore."
- "Cost to mental health with never having enough money with large heating and electric bills."
- "Total outlay on medical costs for the year was over €7,000. VHI repaid circa €2,200 so overall outlay was over €4k. The medical card was taken off me two years ago due to my income being above the threshold. Despite my severe arthritis I am willing and trying to work yet get punished for working hard and ensuring I have a good job."

- "I have invested in a better workstation - ergonomic chair, standing desk, mat etc. Also, I've bought heat pads, massage equipment and other general items to help ease my pain and increase my mobility. Some are used often and others only when experiencing extreme pain and a flare. I'd say these items have cost roughly €1k in the last year."
- "Not that I can think of."
- "I've entered them under 'Other'–gym fees €35 per month."
- "Food waste when my illness prevents me from eating food in the fridge, incalculable. The cost of getting take away food when in too much pain to prepare food, incalculable (min €30 per week). The cost of grocery delivery services, retailers have minimum spend to allow for delivery and add a service charge to the overall price €10 per delivery, twice per week. Extra charge to get assistance spots for concerts from Ticketmaster, as GP charges for letters. Cost of missing ticketed events that were paid for but not attended due to arthritis conditions."

A.7 Other comments about the survey

Question: If you have any other comments about the survey, please include these below.

- "Excellent survey. I have a medical card from the EU because I worked in the UK. The only time used is for medicine."
- "We wish we had a medical card as our ages are 83 and 87. We are marginally over the limit, but have constant medical problems including my husband, outside of this survey."
- "It was interesting to fill in. Makes me see that I'm lucky with my general health."
- "I have been waiting 10 years to see a consultant. The consultant said that he was going to diffuse my ankle, but I haven't heard from him. I also have arthritis in my wrist. I had to stop riding my motorbike 6 years ago on account of arthritis. I didn't have enough power in my wrist to accelerate."
- "I have had to go several times to GP, hospital appointment, out-of-hours GP, hospital emergency, but as you asked for 'arthritis-related' I did not include them. The biggest monetary cost for me has been my wheelchair (still paying CU loan), wheelchair ramp, and disabled aids bought before the last twelve months."
- "I try to make do. I cannot go to seminars when run by Arthritis Ireland. I am not aware of all services available"
- "A booklet on entitlements would be helpful. Not everyone owns a computer Visits to dentists need to be looked at it's too expensive for pensioners and others. I have not been to a dentist in years."
- "Arthritis Ireland is a wonderful source of support and help. Local meetings are very good and the courses they offer are excellent. More government funds to support this important and vital service. Thank you."
- "Please could I have a printed copy of the newsletter and further updates delivered as I don't have internet access. I used my grandson's email just to create an account."
- "Like all surveys, it has its shortcomings and on a few occasions I've needed to include approx. figures."
- "You didn't name Physical Therapist specifically and I have found that hands on help the most beneficial."
- "I need to use taxis at least 3 times per week as I find public transport makes the pain from my arthritis worse - back, shoulder, hips."
- "Questions in arthritis related surveys often focus on the pain aspect of the illness. Due to very effective biologic and DMARD medication, my pain is well controlled. However, I have constant issues with fatigue which can have a significant effect on my day-to-day energy levels. I also get regular 'flares' of the malaise type which although they don't cause pain, leave me exhausted and feeling fluey. These flares can be very debilitating and can mean having to suspend normal activities sometimes for several days."
- "I do a lot of exercise which greatly helps my osteoarthritis in my knees. 3 classes a week plus walking. I got an injection into one knee 9 months ago which is a huge benefit to me."
- "I need 2 new hips and 2 new knees, and I have been told I will be waiting 9 months to a year to see a consultant."
- "Interesting"
- "I have to say that my cost estimates are approximate."
- "At 70 I should get more than 20
- "It was fine, did my best to do the questions."
- "The overall annual cost figure to me is shocking, not calculated before!"

- "It's a blight on the health service and consultants that you have to make different appointments depending in what area of your body you have arthritis. I pay €70 every three weeks to see a private medical physical therapist who deals with me as a whole person and works on whatever part of my body is giving me pain at that time. This therapist has suggested exercises that have given me a whole new perspective on my arthritis. I have cut back on walking which exacerbates the condition in my feet and thanks to her advice I now swim 4/5 times a week. Being treated as a whole person with this condition has been life changing for me. Traditional medicine in this country needs a rethink about how patients are treated."
- "My arthritis is very mild at present."
- "I did it rather late at night so it took me longer to do it !!!!"
- "Had hip replacement last year due to arthritis. Much improvement."
- "I'm in early stages of arthritis hence why some questions left unanswered."
- "Too boxed and not enough choice for answers."
- "Thank you for doing this survey. Both my husband and I have similar conditions. Our consultant is retiring soon, and we have been transferred to another consultant who is charging almost double and a whooping €250 each for an initial consultation. Thanks again."
- "I have arthritis as has my hubby. I am also a cancer patient. Life is hard for us, but we cope at the moment."
- "I find it very hard/difficult to get more than one appointment a year with my consultant especially when the pain gets worse"
- "The cost for facet rhizotomy seems exorbitant. €2000 to the consultant and €2000 to the hospital. Maybe that's why private health insurance costs are what they are. A day procedure over in minutes and a production line of people waiting for their turn. Crazy."
- "Very difficult to be sure of the amount of time over a year."
- "Having a chronic condition is costly if I couldn't afford to pay for membership of a leisure centre my quality of life would suffer significantly as would my mobility especially in the winter months."
- "My osteoarthritis has been put down to wear and tear and largely ignored. I would love someone to touch base with and keep me in a loop when a flare up happens. I would like advice on how to help myself, how best to slow deterioration and not have to live on medication. Tips to keep mobile and tips on diet etc."
- "It's very difficult to find what treatments are the best for you. I was told ten years ago to replace both knees and my hip. I still have my knees and hips. I can walk and drive well enough. I can swim. I cannot not run. My quality of life is better in the last few months. I had stem cell therapy. It's working."
- "Last 12 months, my health has been rather good."
- "Just waiting on knee replacement. My mobility is bad with chronic pain sometimes. I hope to see a surgeon in June. I had X-rays and have severe arthritis. Knee deformed going inwards"
- "I am not entitled to a state pension or fuel and electricity allowance despite being on a small teacher's disability pension. I had to retire very early from work and feel that I have spent a big portion of my income historically on my arthritis and adapting my house and buying gadgets, shoes orthotics and medications etc. The survey only asks what I spent on house adaptations etc. over the past 12 months. I feel I cannot afford to go to theatres or musical events and special holidays. I feel extremely lucky and grateful to have qualified for a medical card and am being well looked after in the public health system. The spiraling cost of electricity, fuel and commodities is very worrying with my health condition and I am worried about my future as I age."
- "I have never been seen in the public sector for my condition, other than my GP for pain relief when I'm really bad."
- "Hopefully someday arthritis will be recognised with LTI card coming from this survey."

- "I've had to retire early from the workforce due to my arthritis. I exist on a Widows pension. I do not qualify for Household Benefit extra payments as I am not yet 66."
- "Many people with arthritis are not diagnosed. We are in denial for ages. It was when I was on day 3 of covid. Still viral. I said to my husband, "I'm feeling much better. Just like on an auto immune day". I normally never complain. But I was able to feel it that day. I'm recovering. But this is exactly how I feel on an arthritis low day."
- "Grateful for state DPS scheme capping costs at €80 as using high tech drugs which are very expensive. I would not otherwise be able to afford them."
- "It is important to do a survey like this to enable research."
- "This survey is probably not for me, but I do have arthritis in my hands and my back. I am reasonably fit, walk a lot (two/three hour walks at weekend). My main issue is with my hands. I have had to give up sewing and any fine work with my hands but have taken up Ukulele as I can manage to play this instrument (not very well) but it's fun. (and good for my mental health). Medication wise, I occasionally take some ibuprofen for pain in my hands. My doctor did offer me Difene but I try to avoid it unless absolutely necessary."
- "Had arthritis for a long time, doesn't help getting cancer in the middle of it."
- "I personally would like to be able to afford treatments such as massage, hydrotherapy treatments, alternative treatments to augment healthier habits to improve my daily quality of life but these are not available and are expensive. Tablets and medicines play a big part in Rheumatoid treatment but it is being able to access other treatments and amenities that prevent further damage."
- "Depressed due to isolation because of illness."
- "Thank you for your great work."
- "Add self-employment."
- "We never received any financial help adapting our house to make life a little easier."
- "As I am not diagnosed with arthritis, I could not complete a large portion of the form. I have however pain in my wrists and fingers lock in my right hand in past two months. Have been attending 6 week exercise programme recently."
- "What is not factored here in survey is what is not done, the bare minimum is all that is done because I cannot do a lot of chores myself - this is depressing as you sit in the melee of untidiness - a personal assistant is what is needed - my family and friends have enough going on in their own lives to be helping me all the time. As for personal grooming - you touched on this but I cannot afford to spend money here! I can't cut my toenails but can't afford a chiropodist- I get maybe physiotherapy sessions on health service, but I really need dry needling done but that is €80. I also have fibromyalgia and I treated myself to some massage therapy for my birthday but I can't afford this in ongoing time it's too expensive"
- "Survey was pretty good, covered most areas. I would like a question about the effect of "fatigue" alone on daily life and the cost implications e. g. not being able to travel to weddings at short notice, having to cancel hair and nail appointments as a result, which means you pay half the cost as it is cancelled within 24 hours of appointment date!! Of course, then you don't wear the outfit or shoes you bought for the event! It's hard to plan! My social life has definitely been affected hugely by my RA. I used to sing in a choir. Singing is like a light switch, it forces you to focus on the music and the words, to forget yourself and your worries. Most choirs hold practice from 8pm onwards, too late for me with my fatigue. I would love Corus. i.e. to facilitate a choir for people with arthritis in the morning or afternoon, via zoom, an online choir. It would be fabulous."
- "No comment but retired from a physical job my joints constant pain."
- "Survey was an opportunity to think about effect, impact and cost implications of arthritis in our lives and also how to go about managing our condition. Thank you."
- "GP and hospitals don't care or follow up and waited 18 months for physio appointment."

- "I am finding work difficult at present and finding it difficult to get information on entitlements when I have to finish."
- "Online services from Arthritis Ireland have been extremely helpful"
- "My rheumatologist recommended that I get the shingles vaccine because of my condition. This led to the €465 approximate consultation with the pharmacist who administered the two shots."
- "I am at the early stages."
- "This is very detailed survey and a prewarning to have items to hand like receipts from pharmacy/ annual medical list etc. would have been useful."
- "My hands, knees and shoulders cause me pain. I'm working in an office and manage there, but trying to do manual work at home is very difficult. I do what I can and ger very frustrated with what I can't get done. I do not want to go on medication if at all possible."
- "I'm sure I've forgotten something! Newly diagnosed."
- "The struggle to live day to day but not have support is overwhelming sometimes."
- "No problem, I didn't realise that there was help available. Trying to do as much as I can to stay as mobile as possible ??"
- "I often drop and break items due to poor coordination and weakness in my hands. This costs me also. I had to purchase an automatic car due to the pain in my left foot. I struggle to afford the car which I really need."
- "In the last 4 years I have been lucky in that I was granted a medical card. This has been a huge help with the cost of my treatment for R.A. Before this I worked full time, and it cost me €150 per month. Sometimes I skipped my high tech injection as I could not afford to pay for it."
- "I have an infusion every 6 weeks but do not know the cost of same as it is fully covered by my private health insurance."
- "The pension does not cover my prescription with the cost of electricity, food etc."
- "As I have two chronic medical conditions it is difficult to differentiate between some of the impacts and costs, and to ascribe same exclusively to arthritis. It is also difficult to differentiate between work my spouse does around the house because I am unable to do it, and what he would do anyway as part of a shared responsibility."
- "I also availed of two Be active with Arthritis courses run by Arthritis Ireland over the past year. These are 'free' to attend but I made a donation to Arthritis Ireland to help cover costs."
- "Some tests/exams requested by my consultant have not been covered under my health insurance."
- "I am still waiting on a public appointment to see the orthopaedic consultant for nearly 18 months and the haematologist for close to 2 years."
- "I've never considered the economic cost of condition- thank you for bringing it to mind. My concern with having fibromyalgia is the lack of doctor's knowledge and support, along with the suggestion that this is a misdiagnosis of a menopausal impact on my body."
- "I had to go private as the waiting lists were so long and my hands and feet were swollen. My private health insurance package ran out as I developed this just after renewing and have been out of pocket for the last few months and will be till September- something needs to be done to support when out of work and the statuary sick pay is a disgrace!"
- "I have had very little help from my doctors. I try to manage my condition myself."
- "My pain has ruined my ability to be financially independent. This brings huge stress and worry for the future."
- "This cost is ok because I work but with retirement coming, I will have to reduce costs, this is a worry as the condition is slowly getting worse, this was a good year cost-wise. In the past these cost have been multiples of it."

- "Mental cost of not being able to live your life because you are waiting for doctors' appointments . . . "
- "This was very useful and I hope the survey findings will go a long way to highlighting the need for all people with arthritis to be awarded the dignity of having a medical card without having to complete an exhausting process."
- "Very difficult to isolate the PsA from other issues. For a number of years, I suspected that I had PsA attended prior to scope which confirmed it. Consultant indicated to me he thought I was lying. I am autistic find it hard to deal with medical professionals. Also in my case, I am now having to go job sharing as a teacher due to the multiple conditions I have. This will cost me €12k net a year!"
- "Phone consultations/ do people agree or disagree? How often do you get to see your consultant. Can you contact anyone at the hospital / clinic by phone when in a flare or needing advice or earlier appointment? "
- "Getting a correct diagnosis is hell as every time I go to a hospital appointment, I am told something else is the problem!! No help with pain or how to manage exercise."
- "I'm unable to let my condition prevent me from going to work due the money! Therefore, I use painkillers when possible!"
- "How do I find out what I can get from the state to assist me."
- "Told to go and pay myself for private physiotherapist as waiting list with HSE for outpatient appointment is currently 2 to 3 years waiting list."
- "The importance of movement and exercises. Promote the online HSE yoga/ Pilates and the online Arthritis Ireland programmes. This has helped me greatly. Best of luck with the survey."
- "In 2018 after a knee arthroscopy to trim a torn meniscus in my left knee my consultant said he was surprised to see so much arthritis in someone so young. My masseuse says I have arthritis in both knees."
- "I really think that sticking to 12 months throughout doesn't give a clear picture of what the real cost is to people. It most definitely isn't so cut and dried. There are more variables to costs. Just because something didn't happen in the last 12 months doesn't mean you are not paying for it now. I hope you understand."
- "I have all but given up looking for help from a GP."
- "I think this survey is a fantastic idea as so many people in Ireland have arthritis which is a disability but like myself are not registered as disabled."
- "A non means tested medical card or GP should be considered. The long-term chronic disease list needs to be updated to include arthritis/inflammatory conditions that are life altering conditions. In Ireland the waiting lists for public consultants is much too long, therefore private health insurance is essential but not everyone can afford the premium in order to get prompt medical care."
- "As above."
- "I am self-employed and often have to 'push through' pain, fatigue flares as if I'm not working I'm not earning, and practically all of my health care is self-funded. The cost of my healthcare affects my ability to do things like go on holidays or take time off as the costs are prohibitive. I don't know how I'd manage if I were unable to work. The financial burden often contributes to stress which then has a detrimental knock-on effect. That being said, I'm lucky to have an excellent team around me, GP, consultants, pain management etc."
- "When I relocated to new area no GP's were taking new patients. I was without one for 3 months before finding a private only GP. My partner earns a good but moderate income but means I don't qualify for medical card and due to my own back history I don't qualify for any benefit. So while it's great and we have a great marriage I am now dependent on their salary. Last year was so expensive. Health insurance is so important, but we don't travel abroad, no holidays unless a few days here and there with day trips. Little eating out etc. the above are impacted by my health but really, we are seriously financially pinned to the collar by lack of any support. The lack of awareness from health professionals on the huge variety of symptoms re myelopathy is staggering and very difficult to deal with. The injury

to my spinal cord means the symptoms overlap hugely with MS for example, trigeminal neuralgia, mobility, allodynia, neuropathic pain, spasticity, painful numbness in the body, fatigue, balance issues on and on yet no awareness or support for myelopathy. It was a great survey. Hope it Informs policy."

- "If I was physically able to work full time I would, however it is not possible as I need to ensure rest time is factored into my daily schedule. For me fatigue is the most debilitating part of my diagnosis, the pain I can manage, but would rather not to have to live with pain daily despite my RA being in clinical remission. Thanks for taking the time to understand the consequences and financial costs of living with arthritis."
- "Fatigue with arthritis is affecting how much exercise I do. It's frustrating if you have been used to doing more. Also, fatigue affects my eating. I also spend more on vitamins/supplements and food to help arthritis."
- "Please advocate for free medicine. I have no disposable income, everything goes toward medicines, physio, consultants, doctors. We do not get free anything to support us. It is means tested and if just above the threshold all costs have to be covered. For some that leaves nothing and negatively impacts standard of living, less income for good quality nutritional food, heating, house adaptation, etc. Please make it a recognised condition to qualify for assistance. Thank you for all the work you do."
- "This effects everything."
- "I would love if I could access online physical health workouts for strength and flexibility. Ideally live for motivation. A group would be a great way to help me manage my arthritis as I find exercise so important but when it flares it's a catch 22 trying to get the energy, overcome pain and discomfort, and get moving. But the results are undeniable. I do sign up every now and again... but my stiffness means it's hard to keep up with the pace!"
- "There is never any reference to my primary diagnosis which is palindromic rheumatism."
- "I was diagnosed by a private consultant and on waiting list for public care. During the first year of diagnosis I had thousands in medical costs for GP and consultant visits, blood tests, x-rays, MRI etc. Two years later got into public clinic so costs majorly reduced. Also, my health insurance changed as my husband changed jobs and his new company covered better premium. So, my costs over last 12 months are not comparable to my costs in the previous 2 years."
- "The main comment I need to make is that disability badges for drivers are for those who have 'walking' issues only. I feel that this is very un-inclusive for many who have equal mobility issues carrying, pulling, lifting and these people are not taken into consideration in any way. I get upset that there are adequate empty disability spaces in most shopping centres, airports, hotels and other establishments that have to be ignored while struggling from spaces far away to reach required destination. Blue badges need to become more inclusive or perhaps an alternative colour to indicate other equally disabling mobility issues for people who are trying to continue to work, care and live as normally as possible daily. Thank you for forwarding this survey and the very best wishes with the results and outcomes."
- "I wish I could work less hours and rest more but I have bills."
- "I'm not sure how much I pay for health insurance - work contributes some and not sure how much I got back (website down), sorry I couldn't answer but I get €25 back on each GP visit (which is €65) / €70 back on every consultant visit (which is €170). I also got the shingles vaccine in 2023 (I have had shingles twice since 2020) which cost an additional €600 for the prescription plus GP fees to administer. My last MRI was in 2023 (for frozen shoulders) and I think was fully paid for by my insurance."
- "Prior to 16 months ago - I wasn't able to work for 6 years due to my fibromyalgia and inability to walk and stress aggravating my condition. It took that long break for some relief for my body and pain continues but not to the same extent as I now work part-time because of my fibromyalgia."
- "Due to arthritis I had total knee replacement 6 weeks ago. There is virtually no support that I can find in relation to my recovery. The surgery was done privately as it would have taken too long publicly. This is an extremely difficult surgery to recover from. Even the possibility of disabled parking on a temporary basis is a minefield. Life with arthritis is very difficult."

- "Survey has prompted me to keep better records of costs. I receive no state contribution/payment despite being on rollover Illness Benefit for the past few years with no actual payment and being told I don't qualify for any other illness related payment as either my illnesses don't qualify, or because my husband earns more than minimum wage. Our outgoings such as family living expenses and substantially increased mortgage payments aren't considered against qualifying for illness support payments. Very frustrating. I often put off medical appointments based on high cost."
- "Availability of on street parking being lost due to Active travel plans across the whole of Dublin impedes my independence freedom. Arthritis Ireland should look at the costs psychological problems caused by having access to areas blocked."
- "My big costs are the hairdressers (once a week) as I cannot wash and dry my hair myself, and then also the physio classes to help me stay mobile. My prescription is also expensive as not all items are covered in the monthly payment. I would really like to work less hours, but it is not possible with my financial responsibilities and then the additional costs of the conditions add to this. This survey did not cover fatigue. This is possibly my biggest limitation and the symptom that most affects my quality of life. It also drives costs indirectly as I end up paying for things I could otherwise do myself."
- "The biosimilar medication I am currently on is brilliant. I have had no flare-ups in more than a year and am fit and well. The previous one worked well but the delivery system (pen) left significant bruising. I spoke to a consultant, and they switched my meds and it's working great."
- "As arthritis is a long term illness I/we should have or be entitled to a long term illness card."
- "Diagnosis has had huge impact on trajectory of my career earning potential. I work at a level well below my qualifications experience earn a much lower salary rate due to illness. Was unable to work at all for 2-3 years. Have never been asked by any doctor about the impact of my illness on my livelihood! (Or to be honest, the impact on any other aspect of my day-to-day life)."
- "I was a lucky high earner until I became unable to work about 7 yrs ago. Despite being lucky and having centralised company income protection (I could never get as an individual), the system wouldn't actually let me enter the true amount of my yearly loss in earnings."
- "I would always have praised the service received in x until covid. To say I have been so disappointed with their lack of care is an understatement and from speaking to others I know I'm not alone in that opinion. Haven't seen a consultant in 4 years. My last appointment was 2 years ago. Consultant covering was late in and didn't come in to me. Left the appointment crying and in pain and basically feeling it was all in my head. A lot of time will just get on with pain etc. as no point contacting service. Have been put on new medication but no follow up. Had to go to GP who said really x should be dealing with me."
- "I am on a biological drug for Rheumatoid Arthritis for the past 12 years - I will be taking this or another for the rest of my life - having to pay €80 (was €125) per month on the DPS is so unfair - it's a lifelong condition and there should be an entitlement to free medication for this type of illness! To date I have paid approx. €17,000 for this medication - it's not right!"
- "My life changed completely with rheumatoid arthritis, I became dependent on others help."
- "I rely heavily on my sister and my friend without them I probably would have died long ago."
- "There is zero help and support for people like me struggling. It's just extremely hard to live with the cost-of-living crisis. We need to be supported better."
- "Every time I go into the office standing on public transport for 40/50mins where there are no seats available, which aggravates my arthritis in my knees. I do not wear a mobility badge as there is no point."
- "I am acutely aware how lucky I am to have an extremely supportive partner, children and employer. My employment income has not been affected, to date, by my illness, which means I can afford private health insurance, and certain outpatient services (e.g. physiotherapy). Physiotherapy is essential for my medical condition, and if I did not have the financial means to avail of private physiotherapy and was reliant solely on the public health system, I don't believe I would receive the necessary services to enable me to live an independent, abled life."

- "No."
- "It us a very difficult condition to live with as to the outside world I look fine and so there is a lack of understanding of the challenges. I find this especially from employer."
- "It is very restrictive and does alter your mental health especially of someone only in their 40s."
- "I used to work in festivals, and events, and music concerts/ gigs - the pandemic stopped that industry for a while, and then I had to find another job due to my hip pain - your question relates to the last 12 months and it was slightly longer, but it has affected what I love to do."
- "I had to give my job up this year and had to stop driving also, I am unable to do the housework or gardening, I cannot walk far and the hospital appointment waiting list is between 1 to 2 years. I am still awaiting the pain management team and none of the medication is working for me."
- "I have to pay €185 for a rheumatology consultant as I have been 2 years waiting for public one and was told it will be at least another 2 years. €180 for pain management consultant. I cannot afford to give up my job as have to pay for all my medicines, consultant and everything. No support available as you can't get onto the public consultant list. I was referred to physio by my doctor but was costing €100 per visit every few weeks and then gym membership. I had to give it up as couldn't afford it."
- "I can't access my bath due to the height of it , I have a shower but it is in the bath. I can't afford to take the bath out. People are wanting from €3,500 to €9,000 to take out my bath and install a shower tray. More support is needed to people like me."
- "Not eligible for help because have savings which I need to help pay off mortgage if I can't work in the morning /college fund for kids."
- "I've used up my unpaid leave so if I have to go out sick again I will only be on state payment."
- "Difficult to calculate the loss of income as I feel the loss of income / not being able to work has a knock on affect within the family - Very lucky to have medical card (after an appeal) otherwise arthritis would have a very different financial impact."
- "My medical card was recently taken from me after having it since my diagnosis. This is a lifelong diagnosis so on lots of medication to which now I have the further worry of costs of medication on top of everything else. Unnecessary stress in my opinion."
- "Biologic medication and healthy lifestyle changes to my diet, exercise, sleep, and social life have made a huge difference to my quality of life, and I feel very well now."
- "Fatigue is a massive symptom of arthritis that has more of an impact on my day to day activities than pain/ mobility issues etc. from arthritis."
- "More education on psoriatic arthritis would be good, like an employer pack to show how they can help an employee and also one for families as it can be hard when you may look ok from the outside but you are struggling in pain daily. Some sort of card to carry with you."
- "Fatigue due to methotrexate and RA needs to be highlighted."
- "I cannot put into words the effect my condition has not just on me but my family. I dread the idea of going on holiday even, as can't manage stairs/steps. You cannot put a price on quality of life. I have had ten years of being refused care, surgery. We have a mortgage that is hard to maintain and a car on the road. I do not have a blue badge yet. My spouse is also going to need care soon as he is unwell. No help even with little things, unless you pay someone."
- "I think a medical card should be provided- it is a long-term illness and it is very costly and it is affecting my work ability"
- "Not enough financial support for long term illness or not recognised as such an illness. More info and help needed."
- "Long term illness should be recognised there is no cure yet. All applications are means tested. I don't have the same quality of life with income. I work hard on my health versus my peers who can enjoy their money in other ways ... all long-term illnesses should get prescription and bloods covered at minimum."

- "My husband is self-employed so much harder to allow myself get benefits as he will be assessed and is nearly always just on it so does not make it easier on either of us. So don't claim things then to be constantly rejected. I will only get worse so that doesn't help in the long run."
- "Importance of exercise and movement and perhaps asking the costs factored in with this."
- "Thank you for highlighting the financial side of chronic illness. It is hugely forgotten and adds an enormous amount of stress to an already stressful time. I think there is a huge lack of assistance for those who can work but not able to work full time- I feel stuck between paying bills and mortgage and no access to any help because you can work, or when sick leave runs out you literally have no options for assistance, so I am left with no alternative but to attempt to work which can sometimes be impossible, my work suffers and makes me feel awful as others have to make up the difference."
- "I'm not aware of any grants or assistance that I can get and I have no family to help. My income doesn't qualify me for a medical card, but a huge amount of my income is spent on costs associated with my chronic conditions. Please, if there are assistance or supports available, publicise how to access these."
- "One of the most frustrating side effects along with pain is extreme fatigue. When I wake up after sleeping 7 hours, it feels like I haven't slept at all. I also suffer with dry eyes."
- "Loss of income due to low energy, pain and flares."
- "The waiting list to get an appointment with a consultant in the hospital are over a year. I had to fly to my home country to get my first diagnosis."
- "Thank you."
- "Loss of friendships, loss of social inclusion due to fatigue."
- "Arthritis is a chronic condition. I will never be able to discontinue my medication. I have months whereby money is tighter, particularly if my husband doesn't have work. Some months I have to try and stretch out my time between my injections (Cosentyx) as I haven't got the money for the drugs payment scheme. I think conditions such as arthritis and the medication (such as high-tech prescriptions as mentioned above) should be free for patients."
- "My condition has resulted me in taking a step back at work and will make me reluctant to go for promotion therefore reducing my current and future earning potential. I have made this decision myself for the sake of my long-term health but this of course impacts on sense of self and fulfilment which is another hidden cost of living with arthritis. I count myself incredibly fortunate that I could afford the cost of private consultant/tests/physio/acupuncture etc. I dread to think where I would be if reliant on the public health for these services."
- "Doesn't take into consideration exercise, type, duration and if your condition has influenced training etc. Similar more in-depth question perhaps on mental health struggles during condition if it flares more etc."
- "In the UK I was eligible for disability allowance regardless of my income. Thankfully, as I claimed before 1990, I am still in receipt, but this money is important to fund additional needs I have such as needing a car (not a choice) and other healthcare. I feel privileged to have this, something which many in Ireland do not."
- "I would love to see arthritis recognised as a long-term illness like diabetes, €80 a month is tough at times."
- "My employer is very helpful and supportive, so I have the flexibility to change shifts and hours due to my health. I can work extra when in good health and bank my hours to use when I need them. This is not the case for many. I would not be working as much if I was in an unsupportive job."
- "I've just been diagnosed with arthritis this year in both feet, knees and both hands. The pain isn't bad as yet and hasn't really changed my life with the exception of running, which I loved and have had to give up. This meant I had to pay for gym classes, which is an additional expense. Not being part of my running group also affects my mental health as I loved running, it was my thing and overnight it was gone. It was very important to me physically and socially. I was devastated by my diagnosis."

- "Application for medical card or GP card denied because I apparently earn too much working 30 hours on minimum wage. Can't afford to go to the doctor as often as needed. But I have to work this much to afford to be able to go to a doctor at all."
- "My pain flares up irregularly. When my pain is minimal or non-existent, I am not restricted in my activities whatsoever. However, when the pain increases, there are times I am incapable of doing even the most basic functions and rely entirely on my partner and my mother."
- "I was waiting 2 years for my diagnosis. I was finally diagnosed 5 months after having my first baby, only because I went private. I spent the majority of my maternity leave sick and unable to enjoy it and care for my baby on my own at times."
- "None."
- "The government is taking away my disability allowance because they deem me not disabled enough."
- "Thank you for bringing awareness to this subject. The hidden costs are a strain to me and my family. It is a struggle."
- "I don't understand why no one advocates for parking discs for people with inflammatory arthritis and it is never mentioned in a survey. There are outings we miss out on because of inadequate parking."
- "Appreciate survey but hope a map of services is considered to identify gaps."
- "Arthritis affects your life in so many ways. You learn to live with it, but it changes your physical and mental health so much you are not the same person."
- "Was pleased to do survey waiting to see x in x hospital as my mobility is bad. I am hoping for a knee replacement as my knee is in chronic pain. I fell on the bus and stairs a few times and have difficulty getting off the bus."
- "GP visit card should be considered. RA should be considered a chronic illness"
- "Wish they bring out treatment for fibromyalgia besides taking pain relief and antidepressants."
- "Loss of contact with friends. Being able to shop. Independence and freedom taken away."
- "Little or no communication between public services related to this condition. Consultant indicates that orthopaedic shoes and physio required but almost no follow up."
- "I had back surgery in January 2023 and a hip replacement on the 28th. November 2023. I received a medical card last October which was a great help in saving money. After the back surgery in January 2023 I qualified for home help in April last year which amounts to two visits per week, lasting less than 1 hour ."
- "There is no button to allow me to stop and save while I look up information, even though it was stated that facility was there in the introduction."
- "Some aspects of the survey does not question additional medical conditions, i.e. epilepsy hypothyroidism, cardiac rehabilitation, or gender specific conditions for the arthritic patient."
- "My arthritis only flares up now and again and can last for some weeks at a time."
- "Arthritis mainly affects my hands and gout in toes. Thus the need to drive an automatic car and use lighter battery operated garden equipment"
- "I suffer with spondyloarthropathy and find a significant amount of your monthly news does not apply."
- "Very comprehensive."
- "I have had both hips replaced in the last 3 years."
- "Death worries me but I will remain strong come what may."
- "Although suffering from Sjögren's for over 30 years it is not classified as a long term illness for medical card."
- "General mobility is not great."

- "Due to my long term Type 1 diabetes, sadly there is no long-term medication available in Ireland to really help me. Which means that I am suffering more with my arthritis fibromyalgia."
- "Biggest cost due to arthritis so far occurred in 2022. Consultant fee and Arthrosamid knee injection costing €2500. No health insurance help available for this procedure."
- "I am living in my mother's house while she is in a nursing home with dementia. When she passes, the Fair Deal Scheme will evict me and my family and sell my family home. I will then be homeless and at the mercy of a Local Authority housing needs list."
- "I think the organisation should look into deeper the financial implications and the options a person has when suffering with arthritis in one of their courses."
- "Improve Arthritis health services and more allowances for arthritis medicines."
- "With lupus I have had to stop everything outside of work in order to keep working."
- "No thank you"
- "I think public pools/gym should be free or significantly reduced for people with medical needs to use them. Or at least some kind of a grant for them. Also, although I can walk well some days there are days when I find it very difficult to move and a disabled parking pass would be beneficial."
- "You didn't ask about sports hobby impacts. I can't run anymore due to my knee."
- "Types of clothing to wear especially in the winter. Regarding warmth."
- "Go raibh maith agat as ucht as Ceistlann."
- "I find my memory is very poor lack of focus brain fog."
- "Hard to find the right combination to control my pain."
- "Good survey."
- "I think the government hate disabled people."
- "My application to the HSE for the Long-Term Illness Card (LTI) was rejected due to arthritis not being a recognised illness/disability under the scheme. I challenged the HSE using representation from area Fianna Fail politician. We recently received a letter stating that the criteria and list of illnesses have not been updated on the LTI since 1975, nearly 50 years. We have decided to challenge the Minister of health directly on this on the basis that surely the scheme should be at least at a par with modern medicine. Surely the LTI scheme should match the statistics of disability in Ireland instead of being ignored for nearly 50 years and not updated."
- "Why are prescription costs not covered by long term illness scheme, a medical card or a GP card etc.?"
- "I'm in the early stages but having a lot of pain from time to time."
- "The survey does not ask the opinion of treatment or different treatments time medication etc. between public or private care."
- "I think you should have collected other info related to work i.e. If you are not working due to arthritis when was the last time you did work. How much did you earn when you did work. I say this because my husband is a high earner we are continually discriminated against regarding getting state help. Disabled should mean disabled. Is it not bad enough that I am disabled and discriminated left right and centre by having a disability in society. I paid taxes all my life until I couldn't. My husband is taxed to the hilt. We are thousands of Euro out of pocket each year. No health insurance or tax rebate will compensate us fairly, plus we pay for the health insurance! Don't get me wrong, I know a two-tiered system is wrong in the healthcare system but it's not my doing. Neither are my disabilities my doing. I had to almost degrade myself to get Invalidity Pension. Having it gets us nothing else because it's all means tested. Why is my husband made to support me and others with his taxes. I'm me, not him. No matter how much he earns it is one bloody wage into a household. How do we ever get ahead with all that goes out on me. Please lobby for a Swedish model system. Disability is disability. I should be treated the same as others."
- "Much of my totals are estimated and probably lower than the actual amount, as I am inclined to minimise the real amount of time, cost and help I require. I appreciate the lost earnings is more important, but it might be worth considering the cost of "fun" events (concerts, flights, etc.) that are missed due to arthritis conditions."