Development of Resource-Use and Expenditure Questionnaires for Use in Rheumatology Research

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ABSTRACT. ***Objective.*** To develop a self-completion and postal resource-use and expenditure questionnaire for use in economic studies of early inflammatory polyarthritis (IP).

Methods. Identification of cost-generating events associated with early IP through a literature review and focus groups of IP patients and their partners. The information obtained was used to inform the development of self-completion postal resource-use and expenditure data collection instruments/questionnaires in terms of structure and content. Finally, the developed questionnaire was pilot-tested and validated in populations in 2 geographically different areas.

Results. The main cost categories identified through the focus groups, and used in the development of the questionnaires, included forgone leisure time and activities, reliance on other people, life events, emotions, help with everyday chores, travel, and over-the-counter medication. Pilot-testing the questionnaires resulted in high unit and item response rates, and high acceptability and ease of completion by respondents, as well as generalizability to different geographical settings. Where possible, collected data were validated against alternative data sources, and agreement was good.

Conclusion. Overall, resource-use and expenditure questionnaires developed in this study were shown to be highly acceptable to respondents, easy to complete, and generalizable to different geographical settings within the UK. (J Rheumatol 2003;30:2485–91)

Key Indexing Terms:
INFLAMMATORY POLYARTHRITIS COSTS QUESTIONNAIRES
PILOT-TESTING VALIDATION RESOURCE USE

The rapid increase in health care expenditure and survival rates in all countries has led to increased interest in the economic impact of individual diseases and disease categories (including rheumatology). Evidence is needed on the relative value for money of new, often expensive, health care programs and treatments (e.g., cyclooxygenase-2 inhibitors[1,2] and biologic agents). Until recently, most health care interventions or services have not been evaluated from an economic perspective. The few existing economic evaluations have used economic data that have been collected retrospectively or otherwise independently of the effectiveness evaluation, and usually in different patient populations. Estimates derived using this type of approach are often not based on actual sampling of costs, and include no informtion about the typical distribution of costs among patients.

It is a challenge to collect data on costs relevant to patients taking part within a clinical trial and, hence, allow the cost-effectiveness of new health technologies to be assessed at the experimental stage. Some relevant data may be collected routinely as part of the clinical trial but more information is normally required (e.g., non-health service resource-use and expenditure data, which are important to represent the part of total resources society devotes to health care)[3]. In making decisions about optimal allocation of health care resources it is important to consider the economic effect from all perspectives (e.g., health service, patient, employer). The best way of obtaining this additional information is from patients themselves through the administration of a patient-based resource-use and expenditure questionnaire. It has been shown that there is strong agreement between patient self-report and medical records for conditions and surgical procedures[4]. Such questionnaires gather structured information on all aspects of health and social care resource-use (e.g., general practitioner visits, physiotherapy, home care visits, etc.), including information on out-of-pocket expenses incurred by the patient and other agencies (e.g., informal care givers, employers, etc.). Existing questionnaires (e.g., Client Service Receipt Inventory[5], Health and Labor Questionnaire[6]) have been developed for disease or client groups. That is, they cover particular patient groups, or particular aspects of resource-

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use such as travel costs. There is no established resource-use and expenditure questionnaire for use in arthritis research, although a generic cost-questionnaire, designed as a resource for investigators throughout the UK to develop questionnaires for administration to patients for the collection of health care costs, has recently been developed by the UK Working Party on Patient Costs[7].

It is important to note that there is no gold standard for the measurement of resource-use and expenditure. An alternative to the primary data collection method described above is to extract health service resource-use information from health records and/or administrative databases using a data extraction form. However, such data may not include all relevant information for research purposes and may be coded and difficult to extract[8].

There is a need for a standardized resource-use and expenditure questionnaire specific to rheumatology, accessible "off-the-shelf" and for completion by patients for use in economic studies (either stand-alone or alongside a clinical trial). The aim of this study was to develop a self-completion postal resource-use and expenditure questionnaire for use in economic studies of inflammatory polyarthritis (IP) in the early years after diagnosis[9]. Self-completion postal questionnaires are considered to be the most efficient and cost-effective way of collecting resource-use and expenditure information simultaneously from a large number of people (Campanelli P, Thomas R, Lynn P. Short course: Design and administration of postal and self-completion surveys. Centre for Applied Social Surveys, 1998 unpublished). The 3 stages in the development of the questionnaire were: (1) Identification of cost-generating events through a review of the literature and focus groups; (2) development of resource-use and expenditure questionnaires; and (3) pilot testing and validation. It is believed that the resulting data collection instruments will be useful not only for economic studies of IP but also for rheumatology studies in general.

MATERIALS AND METHODS

Identification of cost-generating events. Two focus groups were conducted to identify and analyze the "costs" people with IP have to bear as a direct consequence of their illness. "Cost" was defined as "the value of that which has to be given up to acquire or achieve something."[10] The participants were people with IP recruited from the Norfolk Arthritis Register (NOAR) and Rheumatoid Arthritis Support, Care and Love, a patient support group for all ages based in Norwich. A "question route" was developed prior to the focus groups, using themes extracted from the literature, to help the facilitator stimulate discussion about the topics of interest and to ensure all relevant issues were covered. The main objective of these group discussions was to inform quantitative research by assisting in the development and design of self-completion postal questionnaires for use in IP economic studies.

Development of resource-use and expenditure questionnaires. The resource-use and expenditure questionnaires were based on cost-generating events identified in the literature and by the focus groups. Such events were divided into the conventional cost categories of *health care resource use* (e.g., health professional visits, prescribed medications) and *non-health care resource* use (e.g., patient's travel and time, informal care). Two questionnaires were developed — a baseline questionnaire and a 3-month followup questionnaire — to gather structured information on health and social care resource-use as well as out-of-pocket expenses incurred by people with IP and other agencies (e.g., informal care givers, employers, etc.). For completeness, the EuroQol (a generic health status instrument) was also included in the questionnaires to record information on the overall health-related quality of life of individuals[11]. A diary, containing the same sections as the questionnaires, was developed to be distributed with the baseline questionnaire to act as an optional memory device for completing the followup questionnaire at 3 months[12], and was not collected from the participants. Diaries are a very valuable resource that allow people to record events close to when they occur and provide the opportunity to trace events over a continuous time period[13]. The diary was presented in a ledger format with separate pages for each different cost-generating event.

Pilot-testing. The completed questionnaires were pilot-tested on 2 cohorts (Norfolk-based and Cheshire-based) of individuals with early IP (< 5 years) to test the suitability of the questions as well as the survey procedure. Participants recruited to the pilot study were individuals who either incurred an annual NOAR followup visit or attended the local rheumatology clinic at the time the pilot study was being conducted. The approach used was a mail-out/mail-back test (Campanelli P, et al; unpublished; see above). Once the pilot survey had been completed, participants were sent a page of debriefing questions asking about their views on the questionnaire (e.g., ease of completion and interpretation, acceptability, length of time to complete, etc.). An important part of the pilot process is to validate the data collected from individuals against alternative and independent sources of information, where available, to examine accuracy of reporting. Use of second-line agents and patient characteristics were validated with information from other data systems such as the NOAR data, inpatient stays, and outpatient visits against the Hospital Information System (HIS), and distance and time spent travelling to health providers against AutoRoute Plus computer software[14].

Values were assigned to the collected resource-use data by multiplying it by the corresponding unit cost, as shown in the general costing equation:

$$\text{Total cost} = \sum_{i=1}^{n}\sum_{j=1}^{m} (\text{frequency})_{ij} \times (\text{unit cost})_{j}$$

where i = ith individual (i = 1,.....n), j = jth service received or resources used (j = 1,....m). Sources of unit costs are listed in Table 1.

RESULTS

Prior to the focus groups, a literature review of cost-generating events for arthritis was undertaken to inform the content of the "question route" (Table 2) and thus the relevant discussion areas. The 2 focus groups consisted of 10 individuals with IP and 2 of their spouses. Participants were primarily female, aged between 37 and 75 years old, age of onset between 23 and 68 years old, and roughly half were currently in paid employment.

Data extracted from the transcripts of the 2 group discussions are reported under each question of the "question route." These cost-generating categories were then used to inform the content and structure of the resource-use and expenditure questionnaires [available from http://www.prw.le.ac.uk/epidemio/personal/njc21/ (Cited June 13, 2003)], together with additional information on health service usage. Patients are reported to be a reliable source of information about their resource-use of services provided by other agencies such as the health service[4]. That is, patients are able to provide accurate information on the number of

Table 1. Cost categories and sources of unit costs.

Cost Categories	Source of unit cost	Baseline Questionnaire	Followup Questionnaire
Costs to health care service			
Primary and community health care	Personal Social Services Research Unit (PSSRU)[25]		Sections 2 (Q4), 3 (Q7)
Secondary health care (outpatient visits, day unit visit and inpatient stays, by profession)	Local provider prices or Department of Health[26]		Sections 3 (Q7), 5
Medication	Monthly Index of Medical Specialties (MIMS)[27] or British National Formulary (BNF)[28]		Section 6 (Q12)
Costs to individual with RA			
Travel	Motorweb news or respondent	Sections 3, 4, 5	
Aids and modifications	British Red Cross[3] or respondent	Section 6	Section 7
Over-the-counter medication	Respondent		Section 6 (Q13)
Prescription charges	Department of Health	Section 8	
Alternative medical care	Respondent		Section 4
Formal care	Personal Social Services Research Unit[25] or respondent	Section 7	Section 8
Forgone time (leisure, work)	Annual Abstracts of Statistics[31] or Department of Transport[32]	Sections 3 (Q8), 4 (Q14), 5 (Q19c)	Section 2 (Q5, 6), 3 (Q8, 9)
Costs to other agent (e.g., family, friends, employer)			
Forgone time	Annual Abstracts of Statistics[31] or Department of Transport[32]	Sections 3 (Q8), 4 (Q14)	Sections 1, 2 (Q5, 6), 3 (Q8, 9)
Informal care	Netten, *et al* [25]	Section 7	Section 8

visits to health professionals, prescribed medications, and inpatient stays. Emotions and life events, although identified as important cost-categories by participants, were not measured by the questionnaires developed. Such costs are known as intangible costs, and are considered differently in the comparisons of costs and outcomes depending on the form of evaluation being considered[15]. These intangible costs are not only difficult to measure but also difficult to assign meaningful monetary values (unit costs) and thus translate into economic costs. Patient characteristic data (such as age, sex, household income, and employment status) were collected to identify any cost differences that may exist across groups of individuals. Respondents were also provided with an opportunity to include additional resource-use and expenditures not covered by the structured survey questions. As discussed above, a semistructured diary containing all sections of the questionnaire was also developed to act as a memory aid for trial participants (available on request from corresponding author). Table 1 shows the contribution of each section of the questionnaires to the different cost-categories together with the sources of unit cost information.

Twenty-four individuals were recruited to pilot test the questionnaires (12 from Norfolk and 12 from Cheshire) (Table 3). The *unit response rate* (i.e., the percentage of people who return the questionnaire)[16] for the Norfolk-based and Cheshire-based cohorts were 100% and 92%, respectively. The *item response rate* (i.e., percentage of people who completed each question)[16] ranged from 67% to 100%. The most frequently unanswered question, as is often the case in such exercises, asked respondents about their household monthly income.

Seventeen out of 23 (74%) study participants completed and returned the feedback questionnaire. The majority of participants were happy to complete the questionnaires, found the questions easy to answer, and considered the diary to be a useful memory aid (Table 4). The average completion times of the initial and followup questionnaires were 19 minutes and 16 minutes, respectively.

Figure 1 displays the results of the pilot study in terms of the average (per person) 3-month costs for both the NOAR and Cheshire cohorts split by costs to the individual, the health service, and other agencies (i.e., friends, relatives, employer). The costing methodology has been reported[17]. The NOAR cohort encountered higher costs to the individual than the Cheshire cohort, but roughly the same for costs to the health service and other agencies. One explanation for the difference in costs to the individual is that people from the Norfolk-based cohort tended to have to travel further to health professionals, incurring greater transport and time costs. This reflects the rural and urban characteristics of the cohorts. There were also differences in the cost of lost leisure time. Informal care was the largest component of total cost for both the NOAR and Cheshire cohorts, accounting for 37% and 45%, respectively.

Table 5 presents the mean 3-month costs for the 2 pilot cohorts combined, and suggests higher costs may be associated with individuals with the following characteristics: female, age $\geq$ 65 years, living in a village or farm, presently in employment, and with low quality of life (EuroQol score < 0.69). However, due to the small sample size the uncertainty around the mean estimate (represented by the stan-

Table 2. 'Questions route' or 'interview guide' and results of the focus groups.

1. How would you spend your time differently if you did not have arthritis?
Travel; hobbies (embroidery, sewing, singing, gardening); work — have a job; sport (walking, cycling, swimming, physical exercise); socialise more

2. What would you say was the most significant consequence of your arthritis?
Frustration; having to accept it; anger; continuously explaining, justifying; loss of independence; self-conscious (e.g. wearing splints, etc.); reliability on others; restriction of your usual role (e.g. as a mother, housewife, etc.); whole encompassing; not being able to live a normal life free from restriction

3. How has your lifestyle changed to accommodate your arthritis?
Cut in work hours; give up things / put off things (e.g. sport, extra planning; socialising, hobbies, etc.); give up work altogether; total restriction on outdoor activities; slower pace of life; dependence on others (i.e. rely on children and (e.g. physically tired / fatigue) spouse to do the housework, cooking, look after the children, etc.); more careful; unable to look after the grandchildren

4. Tell me about the aids you have and modifications you have had done to help you around the home:
Lever taps; alter bathroom (e.g. shower, bath hoist); light-weight kettle; work surfaces, cupboards and furniture heightened; non-slip flooring; stair lift; surgical shoes; special long handled cutlery
.....What about outside the home?
Emergency call; rails on steps and slopes; change type of car (e.g. automatic, ramps; power steering, more comfortable); walking sticks

5. Have you become more reliant on other people (e.g. friends, neighbours, social services, relatives) since the onset of your arthritis?
Yes
(a) If so, who.....

Unpaid	***Paid***
Colleagues, friends, family, support groups, church groups, strangers	Childminders, house cleaners, ironers, gardener, decorators, nursing home (to recover after operation)

(b)... And how do they help (i) you, (ii) your children, and (iii) other dependants?
Assist with garden; assist with shopping (e.g. loading the car, etc.); assist with housework; 'odd-jobs' around the house (e.g. change light bulbs); cooking; assist with travel (e.g. rail); someone to talk to — relieve tension

6. How do you cope with everyday chores such as shopping and housework?
Help to have a bath; with help (e.g. supermarket workers; family; friends); shopping — little and often (more expensive); great difficulty without help

7. Has your ip had an impact — both positive and negative — on important events in your life?
Provides a more positive outlook on life (e.g. want to make the most of what you've got)
(a) .....Changing pattern of work/job: Give up work; change to a more manageable job; take early retirement; change to part-time
(b) .....Family relationships:
Can affect relationships with partner (withdrawal, hurts to be touched); either strengthens or crumbles (e.g. partners may not be able to cope with someone being totally dependent on them)
(c) .....Accommodation:
Walk-in shower installed; may have to move to a bungalow

8. Can you describe how your arthritis has affected you emotionally?
Depression; withdrawal; stress; nervous; frustration; pain

9. Have your family, relatives and / or friends incurred any additional costs as a result of your arthritis?
Bought a mobile phone in case of emergency; employment of cleaner, ironer, gardener, etc.; time off work to take to appointments; car with all 'mod-cons' essential; employ people to do his work (i.e. self-employed and needed to look after patient)

10. In keeping with the discussion that has just occurred, are there any other forms of costs that you think should be considered?
Difficult to get grants for modifications to home; over-the-counter drugs and special diets; prescription drugs (exemption 60 years old; season ticket £87, pay in full); child care; travel costs (more mileage as can't walk far, parking fees at hospital); disability living allowance (but only if qualify); need for greater public wareness.

dard error) is large, and therefore these observed differences are nonsignificant. Predictors of costs in individuals with early IP have been described[17].

Where possible, resource-use and expenditure data were validated against information from alternative sources. This is often difficult, especially for resources such as travel time to health professional appointments, lost leisure time, and hours of informal care. Distances travelled (in miles) to attend health professional appointments self-reported by participants were compared with estimates using the

Table 3. Characteristics of patients in pilot study.

	NOAR (95% CI)	Cheshire (95% CI)
Mean age, yrs	64 (55–72)	60 (49–71)
Proportion female	7/12	9/11
Mean disease duration, yrs	2.7 (1.7–3.8)	3.5 (1.2–4.4)
Mean income, £	1639 (546–1642)	860 (534–1187)
Proportion working	3/12	3/11
Mean Euro Qol score, scored on a scale 0 (worse possible health) to 1 (best possible health)	0.64 (0.57–0.70)	0.72 (0.64–0.80)

Table 4a. Results of the feedback questionnaire for the 17 out of 23 participants who completed it.

Time to complete	
Initial	Mean = 19 minutes
3 month followup	Mean = 16 minutes
Do you think the costs of arthritis are an important area to investigate?	17 out of 17
Did you find the diary useful as a memory aid for completing the followup questionnaire?	11 out of 14 (3 missing)

Table 4b. Please indicate how happy you were filling out the questionnaires on a scale of 1 (very unhappy) to 5 (very happy).

1 Very Unhappy	2 Unhappy	3 Okay	4 Happy	5 Very Happy
1	1	3	6	6

Table 4c. Please indicate how you found answering the questions on a scale of 1 (very easy) to 5 (very difficult).

1 Very easy	2 Easy	3 Okay	4 Difficult	5 Very Difficult
6	3	8	0	0

computer software AutoRoute Plus. The mean difference (in miles) and its standard deviation between the 2 sources of information were –1.3 miles and 3.0, respectively. The 95% limit of agreement[18] ranged from –7.3 miles to 4.8 miles.

The reported number of inpatient stays and outpatient visits for the NOAR cohort only were validated against information from the HIS for the National Health Service Trust providing the majority of hospital care to the NOAR population. For inpatient stays there was perfect agreement. The kappa statistic of agreement for categorical data between the self-reported and HIS recorded number of outpatient visits per person was 0.58 (based on a total of 8 outpatient visits during the 3-month followup period incurred by 5 of the study participants). This indicates "moderate to good" agreement between the 2 methods[19].

DISCUSSION

The resource-use and expenditure questionnaires for use in IP research developed in this study were shown to be highly acceptable to the respondents and easy to complete. Comparisons with other data sources suggested that the data had been reported accurately. Despite the small sample sizes of the pilot study, the questionnaires did appear to be generalizable to different geographical settings within the UK (i.e., mainly rural Norfolk and mainly urban Cheshire). Any differences in the results of the 2 cohorts appeared to reflect the rural and urban settings and were therefore genuine differences, not spurious (i.e., arising from poor data quality). The questionnaires developed here may not be as generalizable to populations outside the UK due to variations in health care systems. All these questionnaires were designed and validated in a UK context only, but one would expect the basic structure to be broadly similar, although more research and pilot-testing would be required.

The questionnaires were developed for use in longitudinal data collection (such as alongside a clinical trial), but the same questions would be relevant to a cross-sectional study. However, the investigators would have to be aware of the length of reliable recall of respondents, especially as a memory-aid diary would no longer be relevant. For health related questions the length of reliable recall period varies from 6 months for remembering a hospitalization[20] to 5 months for days of sick leave[21], to one month for a general practitioner consultation[21], to one week for purchase of a prescription[20].

Postal questionnaires were chosen as the main method of data collection rather than interviews as they are less labor intensive (i.e., do not require interviewers to be recruited, trained, managed, and paid) and face no geographical restrictions; however, they do rely on participants being fully literate. Diaries could have been used as the main source of data collection, but problems include conditioning effects in the form of sensitization (initial enthusiasm) and fatigue (tired and less thorough as time passes)[22] and complexity of data collection and analysis if participants are allowed to provide open responses[12]. Instead, diaries were

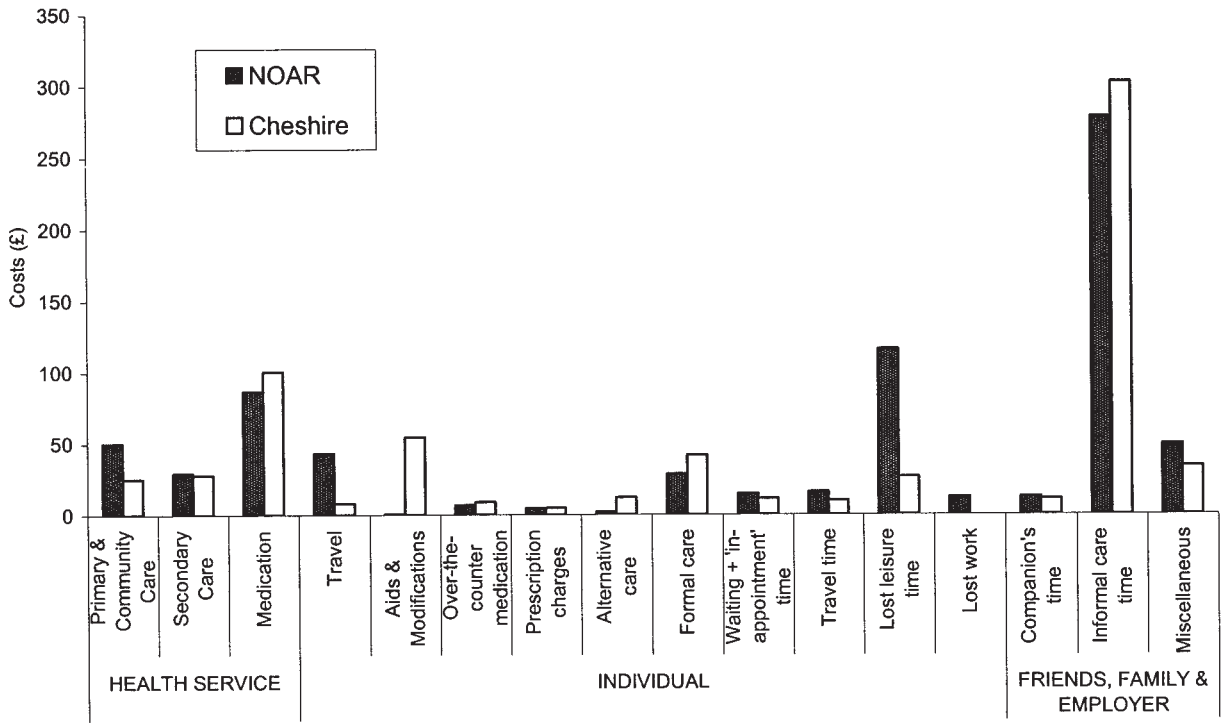

Figure 1. Cost comparison between 2 pilot centers split into cost components.

used to improve recall of events and resource-use in the followup questionnaire.

All the resources included in an economic study need to reflect the perspective chosen for the analysis. The relevant perspective, and thus the identification of the relevant resources and how they should be measured, can be chosen by asking, "When the choices about the broad allocation of health resources are considered, who is affected?" and "On whose behalf are decisions made?"[23] Possible perspectives include the health service, decision-maker, patient, clinician, or purchaser[8]. The questionnaires in this study were developed from a societal perspective, which meant that all the resources used were counted regardless of who experienced them (e.g., patient, family, friend, employer, or health service). This viewpoint is the widest and preferred approach, as it considers the value of all the resources consumed during the illness/intervention. Without an assessment of those resource costs incurred by the patients, economic analyses would be incomplete[3].

Table 5. Mean (SE) 3 month costs split by demographic factors. All amounts given in UK pounds.

	Mean Cost (SE) [median (interquartile range)]
Sex	
Male	334 (80) [285 (141 to 611)]
Female	818 (304) [553 (228 to 972)]
Age, yrs	
< 65	519 (103) [492 (250 to 670)]
≥ 65	807 (430) [258 (140 to 806)]
Where live	
City or town	439 (90) [592 (241 to 277)]
Village or farm	1091 (592) [611 (241 to 1277)]
In employment	
Yes	729 (288) [318 (188 to 649)]
No	476 (144) [492 (168 to 775)]
EuroQol score	
< 0.69	937 (466) [330 (193 to 1078)]
≥ 0.69	446 (99) [405 (166 to 639)]

The questionnaires have been used successfully to collect resource-use and expenditure data in a study of the economic impact of IP in the first 5 years following symptom onset in an adult population (mean age 57 yrs, range 27–85)[17]. Further work is required to assess the flexibility/applicability of the questionnaires designed in this study to capture all relevant resource-use and expenditure as changes in clinical practice occur (e.g., the introduction of day units).

Although the questionnaires were developed for use in early IP research, it is hoped that they will be useful tools to study the economic element of more established disease, where the main cost-generating events are likely to include: longterm care in residential or nursing home accommodation; surgery (especially total knee or total hip arthroplasty), postoperative infections, and other surgical complaints;

increased lost work and leisure time; and greater dependence on formal and/or informal social care[24]. These questionnaires could also have a more general application to other conditions entailing functional limitations, but more research and pilot-testing would be required.

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