Improving data collection processes for routine evaluation of treatment cost-effectiveness

Sari Monto, Riku Penttilä, Timo Kärri, Kari Puolakka, Antti Valpas and Anna-Maria Talonpoika

Abstract
The healthcare system in Finland has begun routine collection of health-related quality of life (HRQoL) information for patients in hospitals to support more systematic cost-effectiveness analysis (CEA). This article describes the systematic collection of HRQoL survey data, and addresses challenges in the implementation of patient surveys and acquisition of cost data in the case hospital. Challenges include problems with incomplete data and undefined management processes. In order to support CEA of hospital treatments, improvements are sought from the process management literature and in the observation of healthcare professionals. The article has been written from an information system and process management perspective, concluding that process ownership, automation of data collection and better staff training are keys to generating more reliable data.

Keywords (MeSH): Cost-effectiveness; Healthcare; Data Collection; Databases as Topic; Quality of Life; Value of Life; Cost-Effectiveness Analysis; Cost-Benefit Analysis; Costs and Cost Analysis; Hospitals; Finland.

Introduction
The purpose of the paper
This paper discusses the systematic collection of health-related quality of life (HRQoL) data for cost-effectiveness analysis (CEA) and challenges to the implementation of this collection in South Karelia Central Hospital, Finland. The research approach is a pragmatic one and we are looking for answers to the following research questions:

- What are the problems associated with the systematic cost-effectiveness data collection process in practice?
- What should be done in the future to improve the quality of routinely collected data to create reliable and relevant cost-effectiveness information for hospital level managers?

The paper is organised as follows. First, we give a short introduction to CEA and 15D, which is an instrument for collecting HRQoL data. The CEA process in the case hospital is then described, concentrating on the data collection process and implementation challenges. The challenges of the data collection process are assessed in the context of the business process management literature of healthcare organisations in order to develop strategies that can be used to improve data collection.

What is CEA?
Cost-effectiveness analysis (CEA) compares the costs and health effects of medical interventions to assess the extent to which a treatment can be regarded as providing value for money (Weinstein & Stason 1977; Russell et al. 1996; Drummond et al. 2005). CEA has been used in healthcare evaluations from the late 1970s, and guidelines for CEA have been developed by the US Public Health Service (Russell et al. 1996) and by the World Health Organization (Murray et al. 2000; World Health Organization 2003).

CEA compares costs with health outcomes that are generally measured as natural one-dimensional units (effects), for example as cardiovascular events prevented or life years gained. However, in addition to length, life also has a quality dimension. This is taken into account in cost-utility analysis (CUA), which combines measures of change in both patient survival and quality of life. Health-related quality of life (HRQoL) is expressed as an index number, in most cases between 0.00 and 1.00. When patients are surveyed about whether and how much their HRQoL has improved, the utility gained is multiplied by life years gained to calculate the combined measure of the number quality-adjusted life years (QALYs) gained. This can be regarded as a general measure of health benefits produced by any treatment or intervention and can be compared between disease conditions.

Systematically collected effectiveness and cost data are valuable tools to produce relevant information for decision makers in healthcare systems and organisations (Räsänen 2006). The majority of CEA/ CUA studies are context-specific (Murray et al. 2000) and few studies address the problem of applying these methods within healthcare organisations. For example, Prenger et al. (2013) point out that some interventions have delayed effects not detected in effectiveness analysis with short follow-up. In addition, the results
of CEA/CUA vary according to geographical areas, healthcare technologies compared, effectiveness measures chosen, or medical conditions under study (Barrios et al. 2012).

**15D – an instrument for CEA**

15D is a health-related quality of life (HRQoL) instrument that measures quality of life in 15 dimensions (Sintonen 2001). The dimensions (e.g. mobility, sleeping) and questionnaire are presented in the Appendix. Each patient questionnaire produces an index between 0.00 and 1.00. For a specific condition or intervention, these are averaged to enable the calculation of QALYs. 15D has been studied and validated in multiple conditions and healthcare settings. There are currently over 500 studies concerning 15D as a HRQoL instrument, but only a few studies include cost information to estimate the cost-effectiveness of interventions (e.g. Räsänen et al. 2012, Seppälä, Häkkinen & Pekurinen 2008).

Hawthorne et al. (2011) compared five different HRQoL instruments and found that 15D systematically generates higher utilities than the other instruments. Saarni et al. (2006) compared the 15D and EQ5D instruments in a generic study of Finnish patients with different chronic conditions and found that EQ5D is less sensitive in identifying relationships between conditions and health related quality of life than 15D. The 15D scores have also been found to reflect time-tradeoff values, as measured by surveys of the survival time patients would sacrifice to gain increased quality of life (Honkalampi & Sintonen 2010).

**Cost-effectiveness analysis in the case hospital**

**CEA data collection process**

The South Karelia Central Hospital (SKCH) is a secondary level acute hospital and a part of the South-Karelia Social and Health Care District (EKSOTE). EKSOTE is a federation of nine municipalities in southeast Finland. Population in the area is about 133,000. EKSOTE’s services include outpatient care, specialised hospital care as well as family services, adult social services, disability services, and services for elderly people.

Since 2008, EKSOTE has systematically collected information about the effectiveness of treatments, and documented the cost of treatments in order to allow for cost-effectiveness considerations to influence hospital and clinical policy. Effectiveness is measured as the average change in 15D for a given treatment or patient group 15D was chosen for the HRQoL instrument as it was developed and has been validated in Finland (Sintonen 2001).

The routine collection of 15D data has been implemented in other hospitals in Finland. Helsinki University Hospital is the largest hospital in Finland and started the systematic collection of HRQoL data using 15D from the start of 2002. Räsänen (2006) studied the results of cost-effectiveness analysis conducted after a systematic collection of 15D data in Helsinki University Hospital and found it to be useful when combined with other performance measures of

![Figure 1: The CEA data collection process in SKCH](image-url)
the hospital. The data collection processes are similar in all hospitals.

In practice, the collection and storage of effectiveness data in EKSOTE is done electronically by a software program developed as a joint venture between EKSOTE and an online service firm. At the moment, the database contains information from nearly 8,000 patients. Figure 1 shows the CEA data collection process.

When a patient visits the hospital for the first time, his/her personal information is logged into the 15D software (name, social security number, date of birth, sex and date of the visit). The patient fills in the 15D questionnaire either electronically at the hospital’s computer or manually on a paper form, which is the most common way to complete the questionnaire. Nurses enter the data to the database or the papers are posted to an online service firm for data entry and storage. The 15D software calculates the 15D index score for each patient in the database.

The patient is asked to complete a second 15D questionnaire approximately six months later. The patient can choose how to complete this second questionnaire: by email, mail, or phone. After the second 15D questionnaire, data is stored into the software and it calculates the difference between the first and the second 15D index score with QALYs gained (or lost) as the result of that hospital admission.

In EKSOTE, patient costs are estimated using standard unit prices for outpatient visits, Diagnosis Related Group (DRG) -treatment periods, etc. These are determined each year by the district board of directors. The unit prices are linked to referrals and when the patient’s visit is entered into the 15D software, the software automatically enters the price of the visit or admission. After the second 15D questionnaire, the system calculates QALYs, sums the prices of the patient’s visits over the six month period and finally generates a cost per QALY for the patient.

Implementation challenges of the CEA data collection process

Implementation of the CEA data collection process in South Karelia Central Hospital has encountered two related challenges. The HRQoL data and the cost data are incomplete, and hospital staff members are not committed to collecting the data, since there have not been defined changes to management processes. These challenges are apparent from the 2008-2012 data in eight medical units of South Karelia Central Hospital, summarised in Table 1.

Rates of HRQoL data completion range from 32% to 58%, with a mean of just over half of all patients with two completed survey forms. When missing cost/price data is considered, rates of completed cost per QALY range from 22% to 43%, with 35% complete overall. These rates varied between clinical units, but have not improved over the five-year period of this study. With only a third of all episodes fully documented, reliable analysis of the cost-effectiveness of treatments, and any consequent decisions at the hospital level may be based on biased information.

Hospital staff are not acquainted with the data collection process, which in part has led to low response rates. There are no guidelines for or audit of the collection process and therefore the process varies according to the medical unit. What is apparent is that the data collection process is not a priority of the current administration, and this reduces the commitment of the personnel who are responsible for data collection. Räsänen (2006) reported that the response rate for the second questionnaire at Helsinki University Hospital was 80%. She argues that the data collection process is reliable when the process is well managed and the staff have a positive attitude towards

<table>
<thead>
<tr>
<th>MEDICAL UNIT</th>
<th>n ALL PATIENTS</th>
<th>n 15D CHANGE</th>
<th>n COST/QALY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orthopedics</td>
<td>1981</td>
<td>1078</td>
<td>716</td>
</tr>
<tr>
<td>Day surgery</td>
<td>1666</td>
<td>891</td>
<td>513</td>
</tr>
<tr>
<td>Gynecological Department</td>
<td>1332</td>
<td>776</td>
<td>526</td>
</tr>
<tr>
<td>Physical and Rehabilitation Medicine Outpatient Clinic</td>
<td>499</td>
<td>228</td>
<td>205</td>
</tr>
<tr>
<td>Pain Outpatient Clinic</td>
<td>450</td>
<td>142</td>
<td>98</td>
</tr>
<tr>
<td>Rheumatic Diseases Outpatient Clinic</td>
<td>279</td>
<td>138</td>
<td>120</td>
</tr>
<tr>
<td>Rehabilitation Outpatient Clinic</td>
<td>203</td>
<td>97</td>
<td>80</td>
</tr>
<tr>
<td>Respiratory Medicine Outpatient Clinic</td>
<td>67</td>
<td>33</td>
<td>26</td>
</tr>
<tr>
<td>Total</td>
<td>6477</td>
<td>3383</td>
<td>2284</td>
</tr>
</tbody>
</table>

n = number of observations in the dataset

**Table 1: Number of valid observations (and percentage from all observations) for CEA measures**
it, in spite of the fact that it increases the nursing workloads.

**Improving the CEA data collection process**

In this article, we concentrate on the deficiencies in the data collection process that have resulted in invalid cost-effectiveness data. Table 2 summarises the challenges and improvement suggestions from the business process management literature perspective, which are discussed further below.

The business process management literature traditionally argues that efficiency of processes is achieved through process and/or task automation, standardisation, elimination of non-value-adding tasks, automated coordination, role reassignments (Hammer 2010). Process management requires alignment to corporate objectives, adequate governance and employees’ customer focus, and involves a cross-functional viewpoint, strategy, operations, techniques and people (Rosemann & de Bruin 2005).

In terms of task automation, the cost of interventions should be automatically transferred into the CEA software; this is currently not the case. The effectiveness data should also be collected electronically and patients should fill both questionnaires themselves using a client interface, for example touch screens in receptions. The added automation would decrease typing errors and incomplete questionnaires.

Efficient and successful process management requires the implementation of a process performance measurement system as well as the concept of process ownership; that is, a person responsible for the process (Hammer 2007a; Hammer 2007b; Kohlbacher & Gruenwald 2011; Reijers 2006; Siemieniuch & Sinclair 2002). A process owner has to have leadership experience (Hammer 2007b) as well as the authority to coordinate, improve and allocate resources to the business process (Hinterhuber 1995; Nenadal 2008).

Marjanovic (2012, 2013) has conducted exploratory case studies regarding process management in healthcare organisations. He argues that these organisations need to go beyond the traditional process management techniques and use so called human-driven process approaches. Leggat (2009) highlights the importance of transformational leadership and collaborative skills that Health Information Managers (HIMs) should possess to be able to create, generating enthusiasm around organisational objectives. Process management needs to be based on experiential contextual knowledge held by process participants and small-scale innovations (Marjanovic 2012, 2013). A process owner, such as a HIM, can be very different from the traditional approach of a higher-level manager as a process owner. It can be created by a process participant and based on ‘grass-roots’ leadership and role reassignment.

The commitment of the personnel is a key element to ensure satisfactory response rates. This also requires resource allocation to software development, and training in the use of the software. Users should be educated on how to use the software properly: how to fill the 15D questionnaires; how to register the answers from the questionnaires properly into the system; and how to check that all the other data (e.g. patient’s personal information, diagnoses, procedures) are also being registered properly. Patients should be also made aware of how important it is to answer both

<table>
<thead>
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<th>Table 2: Challenges in the CEA data collection process and process improvements</th>
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<tbody>
<tr>
<td><strong>PROBLEM OF CEA DATA</strong></td>
</tr>
<tr>
<td>Lack of cost information</td>
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<tr>
<td>Unreliable effectiveness data</td>
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<tr>
<td>Second questionnaire is missing</td>
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<tr>
<td>The comparability of medical units</td>
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<tr>
<td>Various procedures to collect effectiveness data</td>
</tr>
</tbody>
</table>
of the questionnaires. In practical terms, a specific person should be given responsibility for the CEA data collection process. This person should take the responsibility for improving and checking the validity of the data as often as necessary. The person in charge should also train and instruct the software users on data entry.

Healthcare organisations face unique challenges when aiming to combine the efficiency needs of process management derived from administration and high-quality patient care carried out by medical staff (Gouberman & Mintzberg 2001). Attention to process efficiency is still rare and incomplete in the field of healthcare (Marjanovic 2012). Healthcare organisations have a long way to go in process management as many are still struggling to automate their administrative processes. New kinds of process ownership are possible only in environments that support innovative thinking and shared value commitment.

Conclusions
Cost-effectiveness of care will play a key role in the future when allocating limited resources. The aim of this paper was to describe the systematic collection of health-related quality of life data for cost-effectiveness analysis, and the challenges in implementation of this data collection. We have presented a real life case experience from our hospital in Finland, and drew conclusions about the process improvements required of the data management system to achieve the benefits of applied cost-effectiveness analysis in our hospital.

Measures of changes in health-related quality of life are being systematically collected in hospitals in Finland, but the implementation of this collection usually includes some challenges in terms of data completeness and efficient management of the data collection process. The challenges can be considered to be related to the management of the process and the quality of data. We also suggest improvements to the process based on the business process management literature and the observations of professionals. These include introducing process ownership, automation of most data collection processes, improved software training, and patient education to increase response rates on quality of life outcomes of treatment.

Whether or not cost-effectiveness considerations can be integrated with other decision-making processes in hospitals remains to be tested. It might be reasonable to overcome the weaknesses of the data collection process and continue measurement aiming to provide useful information in the future.

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QUALITY OF LIFE QUESTIONNAIRE (15D©)

Please read through all the alternative responses to each question before placing a cross (x) against the alternative which best describes your present health status. Continue through all 15 questions in this manner, giving only one answer to each.

QUESTION 1. MOBILITY
1 ( ) I am able to walk normally (without difficulty) indoors, outdoors and on stairs.
2 ( ) I am able to walk without difficulty indoors, but outdoors and/or on stairs I have slight difficulties.
3 ( ) I am able to walk without help indoors (with or without an appliance), but outdoors and/or on stairs only with considerable difficulty or with help from others.
4 ( ) I am able to walk indoors only with help from others.
5 ( ) I am completely bed-ridden and unable to move about.

QUESTION 2. VISION
1 ( ) I see normally, i.e. I can read newspapers and TV text without difficulty (with or without glasses).
2 ( ) I can read papers and/or TV text with slight difficulty (with or without glasses).
3 ( ) I can read papers and/or TV text with considerable difficulty (with or without glasses).
4 ( ) I cannot read papers or TV text either with glasses or without, but I can see enough to walk about without guidance.
5 ( ) I cannot see enough to walk about without a guide, i.e. I am almost or completely blind.

QUESTION 3. HEARING
1 ( ) I can hear normally, i.e. normal speech (with or without a hearing aid).
2 ( ) I hear normal speech with a little difficulty.
3 ( ) I hear normal speech with considerable difficulty; in conversation I need voices to be louder than normal.
4 ( ) I hear even loud voices poorly; I am almost deaf.
5 ( ) I am completely deaf.

QUESTION 4. BREATHING
1 ( ) I am able to breathe normally, i.e. with no shortness of breath or other breathing difficulty.
2 ( ) I have shortness of breath during heavy work or sports, or when walking briskly on flat ground or slightly uphill.
3 ( ) I have shortness of breath when walking on flat ground at the same speed as others of my age.
4 ( ) I get shortness of breath even after light activity, e.g. washing or dressing myself.
5 ( ) I have breathing difficulties almost all the time, even when resting.

QUESTION 5. SLEEPING
1 ( ) I am able to sleep normally, i.e. I have no problems with sleeping.
2 ( ) I have slight problems with sleeping, e.g. difficulty in falling asleep, or sometimes waking at night.
3 ( ) I have moderate problems with sleeping, e.g. disturbed sleep, or feeling I have not slept enough.
4 ( ) I have great problems with sleeping, e.g. having to use sleeping pills often or routinely, or usually waking at night and/or too early in the morning.
5 ( ) I suffer severe sleeplessness, e.g. sleep is almost impossible even with full use of sleeping pills, or staying awake most of the night.

QUESTION 6. EATING
1 ( ) I am able to eat normally, i.e. with no help from others.
2 ( ) I am able to eat by myself with minor difficulty (e.g. slowly, clumsily, shakily, or with special appliances).
3 ( ) I need some help from another person in eating.
4 ( ) I am unable to eat by myself at all, so I must be fed by another person.
5 ( ) I am unable to eat at all, so I am fed either by tube or intravenously.

QUESTION 7. SPEECH
1 ( ) I am able to speak normally, i.e. clearly, audibly and fluently.
2 ( ) I have slight speech difficulties, e.g. occasional stumbling for words, mumbling, or changes of pitch.
3 ( ) I can make myself understood, but my speech is e.g. disjointed, faltering, stuttering or stammering.
4 ( ) Most people have great difficulty understanding my speech.
5 ( ) I can only make myself understood by gestures.

15D©: Harri Sintonen
QUESTION 8. ELIMINATION
1 ( ) My bladder and bowel work normally and without problems.
2 ( ) I have slight problems with my bladder and/or bowel function, e.g. difficulties with urination, or loose or hard bowls.
3 ( ) I have marked problems with my bladder and/or bowel function, e.g. occasional ‘accidents’, or severe constipation or diarrhea.
4 ( ) I have serious problems with my bladder and/or bowel function, e.g. routine ‘accidents’, or need of catheterization or enemas.
5 ( ) I have no control over my bladder and/or bowel function.

QUESTION 9. USUAL ACTIVITIES
1 ( ) I am able to perform my usual activities (e.g. employment, studying, housework, free-time activities) without difficulty.
2 ( ) I am able to perform my usual activities slightly less effectively or with minor difficulty.
3 ( ) I am able to perform my usual activities much less effectively, with considerable difficulty, or not completely.
4 ( ) I can only manage a small proportion of my previously usual activities.
5 ( ) I am unable to manage any of my previously usual activities.

QUESTION 10. MENTAL FUNCTION
1 ( ) I am able to think clearly and logically, and my memory functions well.
2 ( ) I have slight difficulties in thinking clearly and logically, or my memory sometimes fails me.
3 ( ) I have marked difficulties in thinking clearly and logically, or my memory is somewhat impaired.
4 ( ) I have great difficulties in thinking clearly and logically, or my memory is seriously impaired.
5 ( ) I am permanently confused and disoriented in place and time.

QUESTION 11. DISCOMFORT AND SYMPTOMS
1 ( ) I have no physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
2 ( ) I have mild physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
3 ( ) I have marked physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
4 ( ) I have severe physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.
5 ( ) I have unbearable physical discomfort or symptoms, e.g. pain, ache, nausea, itching etc.

QUESTION 12. DEPRESSION
1 ( ) I do not feel at all sad, melancholic or depressed.
2 ( ) I feel slightly sad, melancholic or depressed.
3 ( ) I feel moderately sad, melancholic or depressed.
4 ( ) I feel very sad, melancholic or depressed.
5 ( ) I feel extremely sad, melancholic or depressed.

QUESTION 13. DISTRESS
1 ( ) I do not feel at all anxious, stressed or nervous.
2 ( ) I feel slightly anxious, stressed or nervous.
3 ( ) I feel moderately anxious, stressed or nervous.
4 ( ) I feel very anxious, stressed or nervous.
5 ( ) I feel extremely anxious, stressed or nervous.

QUESTION 14. VITALITY
1 ( ) I feel healthy and energetic.
2 ( ) I feel slightly weary, tired or feeble.
3 ( ) I feel moderately weary, tired or feeble.
4 ( ) I feel very weary, tired or feeble, almost exhausted.
5 ( ) I feel extremely weary, tired or feeble, totally exhausted.

QUESTION 15. SEXUAL ACTIVITY
1 ( ) My state of health has no adverse effect on my sexual activity.
2 ( ) My state of health has a slight effect on my sexual activity.
3 ( ) My state of health has a considerable effect on my sexual activity.
4 ( ) My state of health makes sexual activity almost impossible.
5 ( ) My state of health makes sexual activity impossible.