## Exploring information needs and information behaviour in oncology contexts: the importance of tasks, roles and organisational settings

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#### **Abstract**

In healthcare contexts successful task fulfilment, teaching, professional development, and patient education may to a large extent depend on information. The increasing number of cancer patients world-wide, the life-threatening aspects of cancer, and the growing number of better informed patients mean that healthcare professionals in oncology are seemingly under increasing pressure to keep up-to-date with information. Studies conducted in The Netherlands and South Africa offer insight into the dynamics of information needs and information behaviour, which is important and relevant for both healthcare professionals and library and information (LIS) professionals serving in this context.

Oncology healthcare professionals (e.g. oncology nurses, nurse practitioners, social workers, physiotherapists) are influenced by their role and task, the care model accepted, organisational/institutional policy, and the healthcare policy in general. The results indicate that there are many different roles and tasks and that information needs and needs for library and information services (LIS) vary extensively between the different user groups and countries. Day-to-day patient care, using practice & clinical guidelines and treatment protocols, may seem to imply a lesser need for information than for healthcare professionals who is involved in training and education or in research. Perceptions on the responsibility to note the latest developments (e.g. between nurses and physicians or oncologists, but also between educators, team leaders and team members) will also be noted.

#### 1 INTRODUCTION

In healthcare contexts successful task fulfilment, teaching, professional development, and patient education may to a large extent depend on information. The increasing number of cancer patients world-wide, the life-threatening aspects of cancer, and the growing number of better informed patients mean that healthcare professionals in oncology (also known as cancer) are seemingly under increasing pressure to keep upto-date with information. Libraries and information services (LIS) can play an important role in this regard. Considering the increasing growth in literature on information behaviour, which includes information needs, information seeking, information searching, information communication and information use (1), it seems as if LIS should not merely improve their services on a continuing basis, but they

should also take note of theoretical findings that may influence their services and convert these to actions with a practical impact.

The intention of this paper is not to report in detail on insights gained form the subject literature and small-scale scale exploratory surveys, but to contribute to a practical framework to:

- Explore information needs and information behaviour in oncology contexts with a special focus on tasks, roles and organisational settings
- Contribute to developing information services in oncology contexts with a special focus on tasks, roles and organisational settings.

The intention with a "practical framework" is that it should be feasible for busy library and information (LIS) professionals to employ it to improve their services on an ongoing and evolving basis.

This paper will therefore briefly address the following:

- Interpretation of information needs and information behaviour
- Need to consult the subject literature
- Need for small scale exploratory surveys
- Preliminary insight on tasks and roles in oncology contexts
- Preliminary insight into organisational settings in oncology contexts, care models and healthcare policies
- Selected suggestions for improving LIS and continuing with data collection

Against this background we started by working from a cycle for information gathering, reflection and service development and improvement as depicted in Figure 1. This cycle is adapted in Figure 2, following the analysis of results from the exploratory surveys.

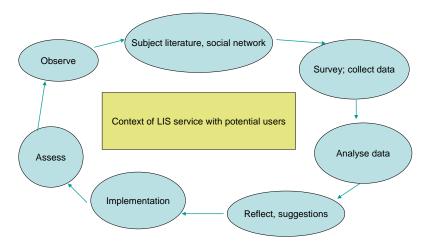


Figure 1: Cycle for improving LIS services on an ongoing and evolving basis

#### 2 INFORMATION BEHAVIOUR AND INFORMATION NEEDS

Information seeking follows when an information need is experienced and acted on. This is when a gap (ASK — Anomolous State of Knowledge) is noted between what a person knows and what he/she should know e.g. when needing to complete a task. When such a gap is noted, there is often an effort to make sense of a situation and to bridge the gap. One way of doing this, is through information seeking (2). It may also happen that even though recognising an information need a person may decide not to seek information, or that an information need is not recognised at all, or that it is recognised but not expressed e.g. because it is assumed that the LIS will not be able to provide in the information need(s). Figure 2 depicts a "gap" approach to information needs. It builds on amongst others the work of Dervin (2), but in addition explicitly indicates that although a gap may be experienced it is not always experienced as an information need.

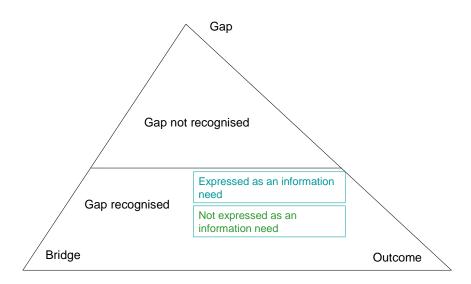


Figure 2: Information needs depicted as a gap requiring action such as information seeking to bridge the gap

Recognising information needs, acting on information needs through information seeking and information searching, browsing for information, passive information seeking (i.e. receiving information without making an intentional effort), intentionally deciding not to act on an information need, intentionally avoiding information, as well as not recognising a need for information (i.e. dormant or latent information needs) all forms part of information behaviour (3). Understanding information needs and information behaviour, in-spite of all its complexities, seems essential for LIS to move forward in providing dynamic services that can enable healthcare professionals to contribute to a challenging, ever-changing healthcare environment as sketched in the introduction. This is also true for oncology healthcare contexts facing increasing numbers of cancer patients (4).

For LIS professionals intending to improve their services a first step when exploring information needs and information behaviour in oncology healthcare contexts would therefore be to recognise and acknowledge that not all information needs are realised, expressed or acted upon. The use of questionnaires, interviews (individual and focus group), analysis of queries and observation would therefore not be sufficient to fully explore all information needs and potential information needs. A variety of methods to collect data on information needs therefore need to be explored.

## 3 UNDERSTANDING INFORMATION NEEDS AND INFORMATION BEHAVIOUR IN ONCOLOGY HEALTHCARE CONTEXTS

Not much has been published on information needs and information behaviour in oncology healthcare contexts. To gain insight into what might be learned in this regard, literature from a number of focus areas can be consulted. In addition there is literature from the wider context of information behaviour (1, 5):

- Library and information services e.g. current awareness services (CAS)
- Information behaviour & information needs (including information seeking, information searching, literature searching, use of the Internet, use of discussion lists, use of Web2.0 technology)
- Information literacy & information skills
- Information use
- Information behaviour of cancer patients (this may stress the importance for healthcare professionals to use information).

In addition to literature studies, surveys can be used to explore issues of importance. The intention of this paper is not to report on such exploratory surveys, but to take a few issues of importance that were noted and to develop these, in conjunction with what can be learned from the subject literature into a framework to promote the improvement of LIS services ensuring user-involvement. Either one or both the authors were involved in the exploratory surveys reported by Fourie and Claasen-Veldsman (6) and Fourie and Bakker (7). Fourie and Bakker also conducted an exploratory project in September 2008 in The Netherlands and Fourie in February 2009 in South Africa; the results of these projects have not yet been reported, and the February 2009 results still need to be analysed. These are individual exploratory surveys conducted for different reasons such as promoting the use of CAS or evaluating the LIS service. The settings, methods for data collection and research foci were different and therefore they cannot quite be used for purposes of comparison. They, however, proof valuable in developing a practical framework for exploring information needs and information behaviour. The settings and methodology for the projects are sketched in Table 1 as background to the paper.

Researchers &	Country	Setting	Participants	Methods
survey period Study 1: Fourie & Claasen-Veldsman (2005 – 2006). Reported by Fourie & Claasen-Veldsman (6)	South Africa	Private medical oncology clinic, private oncology hospital wards	Oncology nurses, social workers, oncologist <sup>1</sup>	Questionnaire (print), focus group interview, individual interviews
Study 2: Fourie & Bakker (February 2008). Reported by Fourie & Bakker (7)	South Africa <sup>2</sup> , The Netherlands <sup>3</sup>	Private medical oncology clinic (SA), private oncology hospital wards (SA), private oncology hospital (NL)	Oncology nurses, psycho-oncology and epidemiology research staff (senior and PhD students)	Questionnaire (electronic, print)
Study 3: Fourie & Bakker (September 2008)	The Netherlands	Private oncology hospital	Nurse practitioners, students, secretary, head of subsection, project leader, specialised nurse practitioners (e.g. urology, psychology), physiotherapist, human resource development coordinator	Focus group interviews
Study 4: Fourie (February 2009)	South Africa	Private medical oncology clinic	Oncology nurses, social workers, oncologists, radiographers	Questionnaire (print), individual interviews

Table 1: Exploratory surveys on information needs and information behaviour in oncology contexts

# 4 TASKS AND CONTEXT AS INFLUENCING FACTORS IN INFORMATION BEHAVIOUR

An increasing number of reports are appearing on the importance of tasks in information behaviour, e.g. Vakkari (8). It has been noted that relevance assessment of retrieved information depends on expertise, experience and/or educational background. It has also been found that prior knowledge changes when receiving and using information, and that information needs and topics of interest may therefore also constantly change.

<sup>&</sup>lt;sup>1</sup> Oncologists were questioned on the importance for healthcare professionals other than doctors to use information

<sup>&</sup>lt;sup>2</sup> South Africa = SA

 $<sup>^{3}</sup>$  The Netherlands = NL

Many reasons why healthcare professionals do not use LIS services, databases, the Internet or CAS have been reported including lack of time, lack of access, lack of skills, as well as the fact that information is not considered relevant to the tasks at hand. Fourie and Claasen-Veldsman (6) and Fourie and Bakker (7) report on some of these barriers. During the interviews Fourie and Bakker had in The Netherlands in September 2008, it was noted that the language of publications is a problem for some staff members. They also often read only the abstract and the introduction and then have no knowledge of the methods and finer intricacies of a research report. In this context a need was noted for publications spelling out the practical implications of research projects.

The relevance of information to tasks and people's interest is especially important when improving LIS services based on an interpretation of tasks and roles, and will therefore be addressed in the following section if participants remarked on the relevance of the information or LIS services. Some of the participants explained that they did not use the CAS offered by the LIS, since they preferred to set up their own CAS, and some monitored additional sources to stay abreast since they prefer to look at general information on cancer as well and since they preferred to look wider than their own interest: "nice to see what everybody is doing...". "I hope I am not missing anything". They would therefore appreciate alerts on the most important general medical journals. There were some comments that people might focus too narrowly on a single topic: "But what I see is people are so focused on one topic... we should also look at general things". Some participants indicated that they also look at publications outside the cancer field, and that they have a problem with the large amount of publications reporting applied research "... which is not always very interesting". They are also not only interested in scientific journals, but also in the opinion of people. Networking with other people e.g. through professional organisations is therefore important.

Although there are big differences in the tasks and research interests of participants, some information might be of interest to an institution as a whole, or to a specific department.

## 4.1 What can be learned from exploratory surveys on the impact of roles and tasks?

The results from the surveys mentioned in Table 1 indicate that there are many different roles and tasks in oncology healthcare contexts and that information needs and needs for LIS services vary extensively between the different user groups, as well as countries. Tasks may also consist of sub-tasks; although we refer to "sub-task" we are not attempting to draw a clean-cut distinction for purposes of this paper. A variety of tasks were noted from the three studies. These can help to identify the topics on which e.g. a CAS can focus, the databases to which LIS needs to subscribe and other services required. Following a qualitative approach, comments with regard to the value of information or participants' own information practices are included where applicable. Such comments are mostly based on the interviews (individual or focus group). The questionnaires were useful to get a "checklist" of tasks. The tasks listed here are not intended as a comprehensive representation of oncology healthcare contexts; merely an indication of what can be learned through the methods followed.

#### (1) Day-to-day patient care

Sub-tasks mentioned include: administrating treatment such as chemotherapy; assisting patients with hygiene, wound-care and injections; monitoring and observation of patients with appropriate and regular feedback to the treating oncologists; administrative tasks; doctors rounds; information sessions at shift takeover; and nursing interventions.

Fourie and Claasen-Veldsman (6) noted frequent mentioning that the administration of treatment is based on prescription and instruction of the oncologists. "For me it is not that important... for the doctors it is very important. I usually do what the doctors prescribe". Their participants, including an oncologist, felt it is the doctor's responsibility to keep up with new information concerning treatment. One of the nurses noted that when working with children, it is different, and that she needs more information for which she strongly relied on the pediatric oncologist: "Pediatric oncology ... completely different". In contrast to the study by Fourie and Claasen-Veldsman (6), Fourie and Bakker (7) noted some nurses showing interest in information on managing treatment side effects. During their interviews of September 2008 a trainer of oncology nurses noted that it is important to understand treatment and nursing interventions such as advising patients to rinse their mouth with salt when receiving chemotherapy. "I expect people to take a critical look on the way these things are done; not only during training, but also in practice."

#### (2) Clinical guidelines and treatment protocols

Sub-tasks mentioned include: using practice and clinical guidelines as well as treatment protocols, clinical practice, doing presentations and clinical cases.

### (3) Patient education and councelling

Sub-tasks mentioned include: support to caregivers and emotional support. Although seen as a very important task, the study by Fourie and Claasen-Veldsman (6) did not found that it is specifically linked to the need to use information: "Our patients need a lot of emotional support, because they are very ill". Participants in their study mentioned frustrations with patients searching the Internet and knowing more than them: "One feels stupid if patients know more than you do because they went onto the Internet". They did, however, not explicitly express a need for information sources. In contrast the participants in the focus group interviews by Fourie and Bakker in September 2008 reported a strong need for information for patients, as well as information patients may note through the general media such as TV, newspapers and radio broadcast. They stressed the importance of knowing what is published for patients. They need to know what patients are getting alarmed about.

## (4) Training and education e.g. of colleagues

Sub-tasks mentioned include: incorporation of quality management into the oncology nursing teaching programme, teaching in oncology nursing and oncology physiotherapy, everything related to learning and education in oncology (nursing) in

the NKI-AVL<sup>4</sup> as well as in other hospitals in the region and country, coordination of research protocol in practice, and teaching.

Considering the reports by Fourie and Bakker (7) and their observations from the September 2008 focus group interviews it seems as if there is a greater need for information from those interested in oncology nursing education. The institution (Netherlands Cancer Institute) is extensively involved in specialised training e.g. for oncology nursing (also offered to nurses from other hospitals or institutions). Participants involved in such training therefore look for good examples for presentations e.g. websites.

#### (5) Staff management

Fulfilling a leadership role was indicated as a sub-task.

#### (6) Research

A variety of research topics (discussed in the next section), and publication was mentioned. Some participants indicated that they are responsible for writing reviews, while others explained that they only start searching actively when writing a paper.

Some of the participants were also involved in post-graduate studies e.g. for a PhD. Participants involved in research showed a strong interest in information, although not all considered the LIS services and the databases e.g. PubMed relevant to their research focus. "Could be useful... but not useful yet" — she rather searched the Internet, since her research topic falls outside the clinical medical field, i.e. Health Technology Assessment and Organization and Management.

### (7) Quality management

Sub-tasks mentioned include: development of practice guidelines and development of Dutch guidelines in oncology, development of standards for oncology institutes, development of practice guidelines in services provision, hereditary cancer and sexology, being a member of national clinical working groups, and incorporation of quality management into the oncology nursing teaching programme. (Participants work with groups, including groups outside the institution, on the development of guidelines.). They indicated that information on clinical guidelines from other countries would also be useful.

Perceptions were noted that the LIS service did not really cater for information on quality management: "Don't get what I look for... I often use other databases" (not available through the LIS). The participants had a need for examples of how others are doing things with regard to good business practices. In The Netherlands there is e.g. a database with good examples in health care, namely http://www.cbo.nl/misc/info\_cbo/folder20090212162916/snellerbeter/Goede%20Voorbeelden%20Sneller%20Beterdef.pdf. These "good examples" are the result of a

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<sup>&</sup>lt;sup>4</sup> This applies to The Netherlands

project named "Sneller Beter" supported by the Ministry of Health and several other stakeholders in health care.

#### (8) Other

Other tasks mentioned include: being a dietician (nutritionist) at another hospital and studying psychology. With regard to information needs concerning their tasks, participants also mentioned statistical support, organisational development, changes in the organisation, publishing, and research. It was not clear whether "research" referred to the participant's research project(s) or to a need for information on the research process *per se*. Considering comments during the interviews Fourie conducted in 2009 in South Africa where several participants mentioned a lack of research skills and experience as an inhibiting factor, it might be worthwhile for LIS services to provide information and support on research methods and practices relevant to the specific oncology sub-disciplines.

Some participants noted an interest in general information rather than research articles. They prefer magazines or popular journals explaining how things are done elsewhere. Some expressed a need for background information for which they will mostly search the Internet.

The study by Fourie and Bakker (7) also noted interest for information on dealing with burnout and emotional issues, while the study by Fourie and Bakker in September 2008 noted interest in literature searching and database management.

One of the respondents remarked that the use of information is a cultural thing (i.e. a work culture). Some nurses do not even belong to a professional association, and if they belong they do not even read their own journal: "Some just look at the pictures... and there it goes [they throw the journal away]".

Roles noted during these surveys that might be of relevance when further exploring information needs and information behaviour in oncology healthcare contexts, and improving LIS services, include:

- Management and supervisor role
- Educator role (healthcare professionals involved in training and education felt that healthcare professionals functioning on an operational level should after completion of their studies, continue to consult the literature on a regular bases).
- Researcher role
- Student role

• Gatekeeper role: "If I find something that is interesting, I hand it to people... if in English people are however not always interested. I try to find examples in Dutch". The participants in The Netherlands referred to the "Harry's" — those colleagues with a passion for information and information seeking, even willing to set up a "library" for the nurses in a ward. One participant from The Netherlands remarked that lists of references from CAS "give me the

<sup>&</sup>lt;sup>5</sup> http://www.minvws.nl/dossiers/kwaliteit\_van\_de\_zorg/voor-zorgprofessionals/kwaliteitsprogrammas/http://www.cbo.nl/misc/info\_cbo/folder20090212162916/snellerbeter/default\_view

opportunity to alert others that are not particularly interested in receiving the CAS themselves. I really see value of having broader lists".

Specialisation in specific roles such as an oncology nurse specialising in psychiatry, and being the only one to fill the role in the institution was also noted.

## 4.2 A strong link between research interests and information needs

Not surprisingly, a strong link can be noted between research interests and the need for information and LIS services. People may also work on a variety of topics at once such as disease, cognition, and strokes. The research interests especially featured strongly in The Netherlands, and include the following:

### (1) Quality management, business process

Participants mentioned applying business approaches to oncology to improve efficiency and patient flow e.g. logistics, operations research, lean management<sup>6</sup>, quality management and standards for oncology institutes, as well as infection control. LIS services and especially PubMed were not considered relevant for research on quality management. The participant rather searched the Internet or databases to which she had access through the institution where she is doing her studies. She considers her work to be of a practical nature, and not clinical. One participant noted that she needs to know what has been published before she comments on articles received for refereeing or review.

#### (2) Breast cancer

Participants mentioned Phase I research in breast cancer, heredity breast cancer and lifestyle environmental factors, genetic epidemiology of breast cancer, breast cancer etiology, gene-environment interactions in BRCA1/2 families and carriers, nipple banking, sexuology, preventive operations (e.g. amputations), and breast reconstruction.

## (3) Psycho-oncology services

Participants mentioned hereditary cancer, sexuology, preventive operations (e.g. amputations), breast reconstruction, and psychometrics.

## (4) Effects of cancer treatment

Participants mentioned late side effects, effects of hormonal therapy on cognitive functioning, cancer risk after ovary stimulation for in-vitro fertilization, and morbidity after lympadenectomy.

### (5) Genetics and heredity

Participants mentioned gene-environment interactions in BRCA1/2 families and carriers, as well as hereditary cancer and second primary tumors after retinoblastoma.

<sup>&</sup>lt;sup>6</sup> see also: lean manufacturing: http://en.wikipedia.org/wiki/Lean\_management

#### (6) Other

Other research interests mentioned include: moral support (e.g. in the context of the secretariate and office management), molecular biology, genetics epidemiology, clinical research, cognitive dysfunction, oncology nursing teaching, education in nursing and human resource development, ear-nose-throat diseases, rehabilitation, cognition, quality of life, and oncology rehabilitation. Participants also noted that research may change: "*Not my speciality anymore*...". They may, however, continue to monitor the literature in their earlier research field.

# 4.3 Methods to deepen understanding about information needs and information behaviour in oncology healthcare contexts

It seems as if the exploration of information needs and information behaviour requires a variety of methods for data collection, used in a complimentary manner. These can include the following:

- Questionnaires (print or electronic e.g. through SurveyMonkey).
- Individual interviews.
- Focus group interviews. In explaining the rationale for having a focus group interview over lunch and providing snacks, a participant note that it should be "een aantrekkelijk moment" (a pleasant moment).
- Literature reviews and audits of reported information needs.
- Observation and participatory observation.
- Task analysis (various forms of task analysis can be used).
- Opportunities for suggestions.
- In-house material e.g. minutes of meetings, sitting in at meetings, in-house reports, titles of presentations and publications of staff.

Methods for data collection need to be chosen according to the participants' circumstances. In the case of nurses working in South African oncology wards, an oncologist remarked "If you get two of them together at the same time you are lucky". This would rule out focus group interviews (From the study by Fourie & Claasen Veldsman – Study 1). According to Kim, Bartlett and Lehmann (9) vignettes may help to identify dormant and unexpressed information needs.

## 5 IMPACT OF CARE MODELS, ORGANISATIONAL/INSTITUTIONAL POLICY AND HEALTHCARE POLICY IN GENERAL

Fourie and Claasen-Veldsman (6) noted the importance of autonomy, financing, infrastructure, staff situation, patients, external pressures and external interaction on the access oncology nurses may have to information resources, and to some extent on their opportunities to use information. Some differences between the healthcare policies of the two countries were noted in passing. It seems as if the tasks and responsibilities assigned to healthcare professionals in The Netherland may better position them to do research, and as if there is more pressure on them to be involved in research. This is, however, only a preliminary observation that needs to be further verified. During the February 2009 interviews held by Fourie in South Africa, there e.g. was a much stronger research interest as well as use of information than during

the earlier study reported by Fourie and Claasen-Veldsman (6). The 2009 interviews were held at different branches of a private medical oncology clinic in a different setting.

The importance of institutional policies was touched on by participants from The Netherlands, e.g. the institutional policy on the use of alternative treatment or alternative medicine in treating cancer. They e.g. noted there seems to be a strong aversion among doctors to address the issue of alternative or complimentary medicine. They felt the need for a more integrative approach, even though some of the alternative medicines or treatment may seem ridiculous. "At least we should know about more or less reliable sources on this subject in order to discuss this with patients". It may happen that research later might show some value: "We need to be up-to-date with such research that seems to contradict what seems ridiculous". The respondents felt that their patients are interested in alternative methods and medicine and that they need information to help them. Such information should come from the healthcare professionals.

Institutional policies in financing the membership of staff to professional organisations, as well as on what is expected from staff in terms of keeping up with their field, can also have an important impact on access and needs for information. It was noted that the institution in The Netherlands has decided that all nurses should belong to their professional society and that the institution will pay the membership fees. The nurses would be expected to show proof that they are keeping up in their field. It is important to note the institution's policy and attitude towards evidence-based medicine, and whether it is adopted by the doctors as well.

In the South African context it was noted that there is scant emphasis on further academic development and research by the nurses (6). This does, however, not apply to all contexts. In a more recent survey still to be analysed and reported, Fourie noted several remarks by social workers furthering their qualifications and research.

#### 6 DISCUSSION AND SUGGESTIONS

Some information needs are difficult to collect through questionnaires. Participants would respond to options indicated and perhaps add a few extras, but they would not expand much on their information needs. Focus group interviews are very useful in stimulating discussion, but it may be difficult to arrange due to participants other responsibilities. If LIS professionals want to improve their services, they thus need to gain insight into the task-related information needs and needs and expectancies for services from various resources. It should be noted that not all information needs are expressed; some may be implied by the task and expectations to complete it successfully, and some may be implied by the care model followed by the institution, the institutional policy or the country healthcare policy. To address task-related information needs from various points of view, the following can be considered:

- Explicitly expressed information needs e.g. as reported by research publications, during surveys, queries to LIS, and informal networking.
- Information needs implied by care models. A systematic study of care models accepted in the institution or country may help to explore potential information needs e.g. in providing patients with information.

- Information needs implied by institutional policy e.g. encouraging or expecting staff to keep track of new developments, to participate in research, to publish, etc.
- Information needs implied by the healthcare policy of the country.
- Information needs implied by specific task-related subject literature.
- Information needs identified by means of task analysis, through observation, and participant observation.

Although interesting examples of information needs have been noted by the exploratory surveys, there is still much more to learn. Some participants seemed unable to relate their tasks and information needs to the sources available through the LIS: "I don't have a real starting point that gives me information that is perfectly adjusted to what I am looking for". They do not know how they can benefit form the LIS services, and they will not necessarily contact the library if they think that it does not cater for their information needs. The LIS services also need to cater for the needs of marginal groups where their tasks fall outside the field of clinical medicine. A variety of types of publications seems to be relevant for the tasks mentioned e.g. books, journal articles, popular media, newspaper clippings, protocols, guidelines, standard and theses. It seems as if newspaper clippings are very important especially with regard to what patients will be seeing. Some participants seemed to rely very heavily on personal contact as method to stay abreast and find answers.

In order to continue in exploring information needs in oncology healthcare contexts, the model we started with need to be adapted.

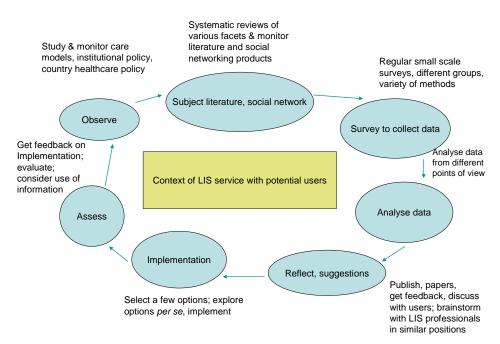


Figure 2: Expanded model - cycle for improving LIS services on an ongoing and evolving basis

#### 7 CONCLUSION

Although knowledge of the tasks and roles of oncology healthcare professionals in specific context are very important, it is also necessary to explore other influencing factors, such as the language of publications, the media in which it is available, and other factors such as knowledge to search and interpret information. Physical barriers to access information are only a minor part of the many barriers that inhibit actual use of information sources. External and contextual factors play a major (supportive or inhibitive) role, maybe an even larger role than personal characteristics (intellectual capacity, cognition, experience, training and skills). The study of tasks, roles and organisational settings of end-users is therefore of utmost importance to librarians and information professionals to interpret the observed information behaviour and expressed information needs. Tailored information services will by definition only fit the right person, and will never fit all.

In addition it is important to explore unexpressed information needs and information needs related to tasks that are not recognised. Ways also need to be found to study and monitor the care models, institutional policies and the countries specific healthcare policy.

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