BenchCan

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BENCH-CAN GOOD PRACTICES

TO IMPROVE QUALITY OF CANCER CARE

June 2016

These case studies have been prepared within the framework the BENCH-CAN project which received funding from the European Union, in the framework of the Health Programme.

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Introduction

Defining good practice

Good practice refers to systems and processes associated with operational management and the qualitative attainment of best clinical practice for patient experience[1]. One of the key deliverables of the BENCH-CAN project was to identify good practice examples of clinical practice (including patient experience) and operations management processes at pilot sites (OECI designated comprehensive cancer centres & interdisciplinary tumour services) as part of a benchmarking exercise and assess them in order to create a practical knowledge database.

Good Practice Framework

Implementing change that leads to good practice can be challenging for any types of organisations, especially in cancer care where cancer centres may be part of a larger hospital with complex organisational structures and multiple stakeholders. As the organisational structure and number of staff in the BENCH-CAN pilot cancer centres also varied, a common framework was selected that could be applied across a wide spectrum of organisations regardless of size, structure or regional differences in order to gain further insights into the selected good practices.[2]

During the benchmarking process one or several good practices have been identified at participating institutions based on the analysis of the submitted benchmarking data and site visits. Institutions provided detailed information about the case examples using the framework.

Why these good practice case examples are useful?

Providing more insights into leading good practices enables other cancer centres to implement them and raise the quality of care on a European scale, thus leading to increased benefits to patients. The developed BENCH-CAN good practices help foster knowledge exchange and collaboration between several European centres also committed to excellence and the improvement of their processes, clinical practice and patient experience. The BENCH-CAN good practice database is available at www.oeci.eu/Benchcan/ where you can read more about the project and also download a *Benchmarking Manual*. The Manual is incorporating benchmarking tools for cancer centres and cancer pathways and presents the necessary processes for carrying out an own benchmarking project giving practical help for health care organisations interested in participating in benchmarking.

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[1] Kay, Jay FL. Health Care Benchmarking. The Hong Kong Medical Diary. 2007 Feb;12:22–7.

2 The "8-Step Process for Leading Change" developed by Harvard Business School Professor John Kotter (http://www.kotterinternational.com/the-8-step-process-for-leading-change/) was identified to present the good practices in comprehensive cancer care in a way that they are potentially measurable, replicable and adaptable at other organizations. In 2014 Kotter updated his 1996 model and revised the steps to make them relevant to today's environment.

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BENCH-CAN Good practices 1

ESTABLISHMENT OF THE PATIENT EDUCATION AND EMPOWERMENT GROUP AND THE PATIENT LIBRARY

Institution: ***Centro di Riferimento Oncologico di Aviano (Italy)***

Contact person:

Background

The Patient Education & Empowerment Group (PEG) is an open, multi-professional, trans-disciplinary, non-hierarchical team, including doctors, nurses, health technicians, biologists, educators, librarians and, as essential components, patient representatives and volunteers. The PEG components are involved, as equal members, in the planning, doing, checking and acting of the Patient Education & Empowerment Programme (PEEP) and activities. The PEG and PEP are an application of some key points of the standards of practice set out by the Cancer Patient Education Network (CPEN), USA, for addressing the PEP at the cancer organizations.

Creation and introduction

A formal deliberation recognizing the PEG & PEP was made on December 2015. It represents the institutional commitment to the PE (patient Empowerment) activities: background, aims, method, activities, evaluation. There are different roles, responsibilities and degrees of involvement. The different activities of the programme are not separated and only spontaneous, but based on the results of previous surveys related to the unmet needs. Classes about health topics with patients and their relatives, i.e. 1hour long meetings are one of the key activities as doctors and how (health care workers) are both teachers and learners. CROinforma, a booklet series about health topics are –co-produced with the patients.

The PEEP arose from, and it is based on, the CRO Patient Library (PL), a section of the CRO Scientific & Patients Library. The PL was a pilot project in Italy in the cancer patient information field. It is working both as a Cancer & Drug Information service and as a Centre for leisure activities for patients.

The threats that triggered the establishment of the PL, in the pre-Internet 'explosion' era (1998), were the patients and their relatives' information requests about topics related to

cancer issues, in Italian language. At that time the problem was the lack of heath related materials for laymen in Italian.

The reasons for an institutional Patient Education Programme (2010) were: the fragmentation of spontaneous initiatives in the field of cancer information and education; the lack of a strategic vision joining the different activities; the collaboration with the Princess Margaret Cancer Centre, leader in the Patient Education field; the possibility to "use" the Library as a pivot around which the PEG and PEP could play. The needs of the patients measured by the staff of the Cancer & Drug Information Service; and the discussion within the PEG where patients representatives are able to give voice to patients priorities, lead the planning of the different PEP's. The expertise of key group members are both related to specific cancer topics and communication ability.

The objectives for the PL since 1998:

- to offer a "neutral space" within the Institute where patients and their relatives can feel free to ask supplementary information about any kind of cancer related issues
- to provide patients and their relatives with reliable quality information and documentation material
- to "give voice" to the unmet patients' needs and narrations
- to organize leisure activities in collaboration with the local Public library

The objectives for the PEP:

- to build a Patient Education frame where the different activities are recognized within a Programme lead by a multiprofessional Group etc…(the PEG)
- to improve the patients' competence about cancer related topics for helping them to make more informed decisions
- to find reliable tools for measuring the level of health literacy of Italian cancer patients about health topics
- to increase the how competence to adequately communicate with patients and their relatives
- to make able how and patients and caregivers and volunteers to collaborate as equal partners.

What is key for a well-functioning support service for patients and their families

For organizing and implementing the PL the required competencies are related to: information and documentation search ability, quality evaluation of health information for patients, health literacy, communication and dissemination, narration competence. At the CRO indexing and cataloguing and evaluating health information for consumers are used. The CRO Scientific & Patient Library' staff is the author and coordinator of a national project, CIGNOweb.it, a digital repository of patient information resources for Italian cancer patients. CIGNOweb is filling a gap in Italy in this field.

For organizing and implementing the PEP, the expertise required is: first, the authority and will and knowhow of the Scientific Director (in our case he is a MD). Second, the specific technical knowhow of the coordinator (in our case a biomedical librarian also consumer health information expert) and of his/her close collaborators in involving the healthcare workers and patients and volunteers. Last but not last, the expertise both in specific cancer topic and in communication with patients, writing in plain language. This experience gave many doctors and nurses and other how the opportunity to question themselves about critical issues and definitively, to learn from patients.

For the PEP, the consumer health librarian, some cancer patient association volunteer and a few doctors, nurses and biologist are leading the activities.

For implementing the PEP were crucial:

- An organizational environment, the new Scientific and patients library rooms.

- Some appropriate spaces, suitable for teaching patients and families

- Appropriate technical support, as well as print, graphic and audio-visual support

- a scientific library and reference

- a Patient library already available for patients, family members and caregivers.

- the PEP resources are granted by the "5x1000" to our Institute' budget, i.e. the percentage of the taxes everyone can donate to an organization (tax donation system in Italy).

The CAPHIS, USA documentation (Bull Med Lib Ass, 1996) was critical to the CRO PL which has two dimensions: Cancer Information Service (nowadays Cancer & Drug Information Service) and Leisure Library. The approval of the HealthCare staff 'Advisory Board and the collaboration with the Psychological service were important for launching this project as a

new complementary way to meet the information needs of the cancer patients, their relatives and citizens.

Risks and opportunities and success factors

Risks

The main barriers were related to the organizational structure. For example, we proposed an improvement of the Day hospital furniture and colours and some other changes related to some comfort aspects but it was not possible to make them a reality. The organization of some activities, such as the CAM consultations for patients based on the voluntary activity of a specialist, turned out to be an unsustainable effort.

Some needs, although identified remain unmet such as for example: the nutritional support represents a great urgency for patients and, after some years, it is still an unmet urgent need.

The identifiable risk factors are:

For the PL:

- The instability of the staff contracts
- The weakness of the SPL position in the CRO organizational structure

For the PEP

- PE activities are not still embedded in the planning of the everyday clinical and research activities
- the lack of recognition of the necessary time for these activities
- the change of top direction
- it is necessary to make stable some key points to warrant sustainability
- It is necessary to save the achievements of the innovations as some changes in the top of the organizational structure can be unaware to those innovations/change
- It is necessary to conduct research on this process and publish results
- Al these activities are time consuming and this fact has to be visible

Opportunities and success factors

The opportunities were the capability of our Library, a unit of the Scientific Directorate, to take up the information challenge and organize a sustainable project based on three key points: 1) adequate material (to be searched, evaluated and organized); 2) appropriate setting, within the Institute area, but not in a ward; 3) expertise of a trained librarian in information & communication. There was a "contagious effect" on the different how. Some of them over the years became really interested in taking part of some activities. Some of them really appreciated the power of the patients' participation.

The main success factors were:

For the PL:

- the quality of the offered service
- the quality and quantity and accessibility of its products: the booklet series, CIGNOweb.it, the patients' narrative books, the artistic-literary competition etc…

For the PEP:

- the positive feedback of the patients
- the doctors learning from the patients
- the PEG coordinator as catalyst of the PE process
- To turn weakness into strength was possible, i.e. to make the patient education approach a real institutional approach starting from the will of the direction and the efforts of a Patient Library

The CRO employees were involved and motivated in different ways:

- The PEP became an "On the Job Training Programme". Employees receive Continuing Education Credits for the patient education activities in which they are involved
- The authorship of some booklets of the CROinforma series has a very low but important recognition as every booklet is full-text accessible through the CIGNOweb.it database.
- Part of the involved doctors began to understand the power of meeting with patients about health topics, for instance.
- The formal deliberation of PEG and PEP constituted an important motivation

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BENCH-CAN Good practices 2

IMPLEMENTATION OF A TOUCHSCREEN SURVEY SYSTEM AT THE RADIOTHERAPY DEPARTMENT

Institution: ***Centro di Riferimento Oncologico di Aviano (Italy)***

Contact person:

Background

The customer satisfaction paper form was distributed by nurses and radiographers and subsequently collected and analysed by a psychologist. Distributing, collecting, analysing and recording data was a resources- and time-consuming process. We estimated that the operators spent about 5 min for each patient, just to explain the purpose and the procedure for filling in the form. In total, our skilled human resources were employed for over one hour a day to carry out this procedure. Besides, the amount of paper forms returned was small, and the analysed data feedback took too much time to be delivered to the managers, and be useful to foster the decision making process. We also found a bias in the data collected, influenced by the professional role of survey distributors. The touchscreen survey system dramatically increased the number of surveys collected (more than 5 times); with an average of 1 survey every 5 patients, without any human resource involved. The survey feedback was available in real time instead of after 2 months.

Creation and introduction

The strategic vision behind the creation of the touchscreen survey machines was:

- To relieve qualified resources from distributing and managing such type of data, and to integrate the "customer satisfaction quality indicators" in our Division's BPM framework (dashboard).
- To avoid bias and improve the data reliability
- To collect data continuously, instead of just 2 months per year

One project coordinator (engineer & quality manager) leaded the project which was supported by Head of department. The new machines were introduced to the staff via E-mail; we encouraged our staff to invite patients to "play with our customer satisfaction panel". The introduction was easy and smooth. This improvement was triggered by the staff,

who reported this inefficiency through our "Criticality report system". The solution (touchscreen survey machines) was identified during brainstorming sessions.

What is key for a well-functioning implementation of a touchscreen survey system at the radiotherapy department

The critical items included: Hardware's (we purchased two PC Panels and IT infrastructures (network connections).

In fact, it should be mentioned that this project was implemented both at CRO Radiotherapy Division and Pordenone general hospital Radiotherapy Division (managed by CRO), which is 15 km from Aviano.

Risks and opportunities and success factors

Risks

No big barriers were found. The head of Division actively supported the project and that helped to spread the interest and motivation for the initiative.

We realized that the data of the first two months were biased by the tests made by the staff members to try out the new machine. Although it caused a (small) loss of data and information, we consider the first period as a "testing phase" that allowed our staff to become familiar with the new tool and acquire the right knowledge to support patients and customer in general in this activity.

Opportunities and success factors

The main success factor was the fact that the goal was reached:

Increased quantity & quality of the customer satisfaction feedback; no human resource daily involved in distributing, managing and analysis of customer satisfaction survey. The digitalization and the automation of non-clinical processes helps to free qualified human resources who can be dedicated in primary (clinical) processes instead. Nowadays the use of the new IT tools helps to achieve low cost solutions, which are easier, free and user-friendly for the organization, avoiding the scouting of alternative solutions in the marketplace. Digital platforms and technology in general, could be considered as a primary key for the implementation of lean organization processes.

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BENCH-CAN Good practices 3

ESTABLISHMENT OF THE YOUTH AREA TO PROVIDE SPECIAL SUPPORT AND SERVICES FOR YOUNG CANCER PATIENTS

Institution: ***Centro di Riferimento Oncologico di Aviano (Italy)***

Contact person:

Background

Following the model of other international oncology units, a framework was developed to create a special unit for adolescents and young adults.

1. Patients: (a) a central role taken by patients in defining their personal care needs by participatory planning; (b) identification and implementation of effective communication systems between young people and adults; (c) promotion of a culture of informed consent; (d) activation of educational services; (e) fertility preservation; (f) patients' active participation in talking of their own experiences with healthy peers;

2. Multidisciplinary team: (a) identification of medical caregivers responsible for clinical-therapeutic decisions; (b) organization and educational program of the participating caregivers;

3. Spaces: (a) definition and development of: care spaces; educational, recreational, and socializing areas; (b) spaces for relaxation and introspection; (c) courtesy services and facilities for visitors; (d) in-patient rooms, both colourful and personalized;

4. Social interactions: (a) involvement of family and friends; (b) support of volunteer service associations and charities; (c) project promotion and patient advocacy;(d) philanthropic fund-raising; (e) school project.

Creation and introduction

Adolescent and young adult (AYA) patients seem to be in a sort of no-man's land, halfway between the two different worlds of paediatric and adult medical oncology and bearing the brunt, in terms of inclusion in clinical trials and quality of professional care, of the lack of integration between these two worlds. The vision behind the establishment of the Youth Area was to design the conceptual framework for AYA cancer care attentively from the beginning to achieve practical development goals and ensure increased satisfaction with

treatment by involving adolescents in the general quality elements of comprehensive and psychosocial care.

The main object of the Youth Area project is focused on the patient-centered assistance.

Our goal is to dedicate the same attention to AYA patients and their families as to paediatric patients, in a model of care in which not only specific protocols but rather age-appropriate services considering the entire individual are grounded, and in which patients themselves are active participants.

The Youth Area was officially established in November 13, 2006, with a specific dissemination event organized in the same date.

The activities of the Youth Area are continuously communicated and disseminated through the institutional trimestral magazine (CRO News), training courses, internal and external events. The Youth Area is a trans-departmental dimension recognized since 2008 by AIEOP (Italian Paediatric Haematology-Oncology Society) for the diagnosis and care of 14-24 year old adolescents and encompasses two Departments (Radiation Oncology & Diagnostic Imaging, Medical Oncology) and 6 Divisions (Paediatric Radiotherapy, Psychological Oncology, Pain Therapy & Palliative Care, Cell-based Therapy & High-Dose Chemotherapy, Leukaemia Unit, Scientific Library & Patients' Library). It represents a new modality of care in a multidisciplinary setting in which patients benefit from all specialized oncology clinicians but mainly from Paediatric Oncology, Medical Oncology and Radiation Oncology in the diagnosis, staging, and treatment of lymphomas and solid tumours (musculo-skeletal, cerebral, germinomas, melanomas, Head & Neck cancers, carcinomas and rare tumours). Clinical care is given as an inpatient or outpatient from diagnosis to therapy and follow-up; whereas Day Hospital and ambulatory services are reserved to patients receiving radiotherapy or laboratory testing only. Medical and nursing staff shares clinical records and reports that are integrated throughout all hospital units.

The head of Unit is graduated in Medicine, specializing Paediatric Oncology and Radiation Oncology and he is also the national coordinator for Hodgkin lymphoma in children.

He has been leading this implementation since the very beginning, and promoted a multidisciplinary approach to AYA patients, where all the key areas of expertise are represented and involved. At present the professional involved are: Paediatric oncologist, paediatrician, radiation oncologist, translational hematology oncologist, psychologist, educator/librarian, nurse coordinator, Data manager and partners: subspecialties who have particular interest in AYA patients

What is key for a well-functioning establishment of the Youth Area

The following Human Resources are needed:

- Paediatric oncologist 1
- Pediatrician 1/2
- Radiation oncologist 1
- Translational hematology oncologist 1/2
- Psychologist 1
- Educator/librarian 1
- Teachers 1/2
- Nurse coordinator, (part-time) 1/2
- Data manager 1
- Partners: subspecialties who have particular interest in AYA patients (part time) pain therapist, physiotherapist, bone marrow transplantation expert, social workers, IT staff

In term of Infrastructures: 4 rooms with 8 beds and a common space were developed in a separate zone within Medical Oncology that was functionally divided into a) Rubik's Cube: a dedicated space within the common area for comics, books, play station, foosball, web-access and miscellaneous materials for creating (painting, scrap-booking, drawing) and b) Room for Myself: donated by the Italian Association against Leukaemia (AIL), a second space with a more relaxed atmosphere that is good for meetings or taking time out to have deeper conversations with psychologists but even just studying and reading quietly; strategically designed to be cheerful but reassuring. Adjacent to the hospital is a courtesy guesthouse for patients or parents completely supported by volunteers.

Communication resources: To stimulate dialogue and support, an interactive communication system common to the age-group including e-mails, short message services, blogs, social networks (e.g., Facebook, www.areagiovanicro.it), and blank diaries for the personal expression of patients have been introduced. In addition, organizational resources provided to each patient when admitted consist of welcome packets and descriptive materials, e.g., Colora la tua Linfa (Color Your Lymph) and computer access help with the patients' needs during hospitalization.

Risks and opportunities and success factors

The implementation of the Youth Area faces the following barriers and risks:

Financial constraints: the initial strategy that allowed the Youth Area to start its activities, despite of the general austerity policy, was to demonstrate the lack of added cost by building the AYA unit from a rearrangement of current resources.

Another strategy to ensure the sustainability of the facility is to raise external discretionary funds. This is commonly done through philanthropy.

The lack of similar experiences in Italy: The CRO Youth area is the first in Italy. One difficulty was, therefore, the lack of benchmarks and of opportunities to learn from peers. On the other hand, the Youth area best practices have been of great interest for other Cancer Centre, in fact the project was subsequently developed in another Italian Cancer Institute in Milan.

Professional resistance to change/prejudice: the strategies adopted to remove this barrier were: information, training and education; the evidence of lack of recruiting in dedicated clinical trials; the discussion of cases, and the evidence of a lack of prognostic improvement in the last 25 years with the strategies adopted by oncologist for adults and applied to young patients.

Dedicated spaces/logistic: One difficult faced at the beginning of the process was the reorganization of the spaces. An analyses of the needs was performed, and the spaces where arranged accordingly, following the main criteria of the age uniformity.

Opportunities and Success factors

Patients have been directly involved in the creation and development of the program helping to indicate the underlying principles of the unit. Working together with the patients began even before opening the unit to help us define the colours and facilities to use, and again after to calibrate interventions and receive initial feedback for educational support. Several Social interactions have been developed: (a) involvement of family and friends; (b) support of volunteer service associations and charities; (c) project promotion and patient advocacy;(d) philanthropic fund-raising; (e) school project.

From this experience, we infer that medical interventions linked to quality psychosocial frameworks of care are more effective than usual care as measured by an increase in knowledge of patients/their families and an increase in provision of quality communication in this care model.

We believe this is even more important to help young patients live well despite illness and get back to normal life at the end of their treatment.

Even though it was the first experience in Italy, our model proved to be feasible and effective; as a matter of fact it was transferred in 2011 to another Italy cancer institute. The Youth Area is a place where a little bit of normalcy takes hold, and patients and hopes are allowed to survive.

The direct involvement of the young patient empowers them and allows them to gain more information about their treatment and the disease. We have observed that through writing or oral communication, they are able to reduce the risk of loneliness in a period of life in which is it easy to feel alone, to be left to one's own devices and to give up hope.

BENCH-CAN Good practices 4

ESTABLISHMENT, MANAGEMENT AND COORDINATION OF THE LOMBARDY REGIONAL ONCOLOGICAL NETWORK

Institution: ***Instituto Nazionale Tumori, Milan (Italy)***

Contact person:

Background

The "Lombardy Oncology Network" (ROL) is a regional platform that allows the sharing of clinical information to facilitate communication among physicians, hospitals, General Practitioners and care facilities to implement prevention and care for cancer patients. INT is the coordinator the network.

The aim of " ROL " is the integration of efforts and skills of health care services to improve cancer patients' care and to guarantee equal opportunities of access to treatment. Within the ROL, INT contributes to the Regional Electronic Patient Record as part of regional projects CRS-SISS social-healthcare network.

Creation and introduction

INT is part of the regional healthcare system, Lombardy Region launched the ROL project aimed to integrate the efforts and skills of healthcare services to improve patient care.

without moving paper-based clinical information and charts among regional hospitals. ROL is a system that allows hospitals to share clinical information at every step along the care process using a common tool (the ROL-Docs) that is implemented for every patient. The network will simplify the exchange of information and collaboration among healthcare providers. The key group members involved in the ROL are the Regional Healthcare Directorate, the coordinator of the project (INT) and the Management Board (one representative for each collaborating hospital). In INT the Scientific Directorate, the ICT Department and the Healthcare Directorate support and lead this change. The main goal of ROL is also the creation of a regional network aimed to reduce inequalities in the access to healthcare services. The use of the tool (ROL-Docs) helps employees in managing patients and in retrieving clinical information: every patient can be monitored "on line" because visits and exams are recorded and displayed in a specific platform available to all the participants of the network, irrespective of where the visit or exam has been performed.

What is key for a well-functioning establishment, management and coordination of the Lombardy regional oncological network

Within the ROL a common IT infrastructure is available to record and share clinical information: employees can login into the system using their personal account to implement clinical information. The Lombardy Region funded the ROL project to cover costs for the implementation of the IT infrastructure, personnel for the coordination of the network, meetings and training.

Risks and opportunities and success factors

Risks and barriers

It has been challenging to have a common vision within the network and in our institute mainly on:

- the subset of information to be collected and the semantic issues

- the most appropriate platform to be used based on the existing hospital platform already in place

To remove these barriers several consensus meeting were organized in order to have a common agreement. The main risk factor was the non-compliance of the employees filling in the clinical information in the platform.

Opportunities and success factors

The main success factor was the possibility for the employees to monitor the overview of the whole cancer care pathway of every patient included in the platform/network. The change should be hierarchically supported at “high level” in order to have a strong institutional commitment and receive an appropriate financial support.

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BENCH-CAN Good practices 5

PROVIDING SUPPORT FOR BOTH PATIENTS AND FAMILY MEMBERS DURING THE ENTIRE PATIENT PATHWAY

Institution: ***Institute of Oncology "Pr. Dr. Ion Chiricuta", Cluj (Romania)***

Contact person:

Background

During the years, the team at IOCN has noticed that the oncological patient and even the members of their families need psychological support. The reasons for implementing a change to psycho-oncological service were: Romanian research (Degi C.L., 2013: in search of the sixth vital sign: cancer care in Romania, Supportive Care in Cancer, vol. 21. Issue 5, pp 1273-1280) held between 2007-2014 showing the fact that clinical depression and anxiety symptoms remain very high (over 40% which means that 1 of 2 patients suffers of clinical depression situated at the maximum point accepted in the literature); research from the psycho-oncology field offered us the guidance for meeting psycho-social needs; subjective observations made during clinical practice in our Institute, which has created the sense of urgency for change. The IOCN view is that strategic vision should meet the needs of the patients and through creating guidelines, getting closer to the patients and centering the care paradigm around them though a holistic approach.

Creation and introduction

When the psychosocial support service was created people from different backgrounds and with different levels of expertise were involved. From the IOCN point of view, expertise is a fusion between the basic academic background (bachelor and master degree in Clinical Psychology, Psychological Counselling and Psychotherapy) and certificates in the psycho-oncology field, as well as participation to the Cancon Training School: Intervention studies in the field of Cancer and Work at the University Babe Bolyai of Cluj Napoca (Romania) - 18th-20th of February 2015.

Also, they organised 2 training programs: 1st) Communication Skills Training targeting mainly physicians treating cancer patients from the Institute and also from other relevant public hospitals in Romania- October 24-25, 2013 2nd) Psychosocial Oncology Care targeting professionals providing psychosocial care to cancer patients, mainly psychologists but also nurses and cancer physicians from the Institute, also from the main cancer hospitals in

Romania- November 18-20, 2013. The training was provided by the main specialists in psycho-oncology (Luzia Travado, Vice-President of IPOS, Luigi Grassi, Profesor of Psychiatry, Chair of IPOS Federation of National Psycho-Oncology Societies, Anja Menhert, IPOS Board Directors, Darius Razavi, IPOS Bernard Fox Award, MD, Professor of Psychosomatic and Psycho-Oncology, Maggie Watson, PhD, Honorary Professor of Clinical Psychology, University College and Royal Marsden Hospital).

The main goals were:

- Psychological counselling for patients and families who need intervention
- Building a thorough research base and disseminate the results in the academic community:

November 2013: Ranking of quality of life determinants by structural equation modelling in a population of women at childbearing age, treated for premalignant and malignant pathology of the uterine cervix, Journal of Cognitive and Behavioural Psychotherapies, Vol 13, no. 2, 605-620

September 2013: Identification and validation of quality life measures in a population of life measures of women with premalignant and malignant pathology at childbearing age in Journal of Cognitive and Journal of Cognitive and Behavioural Psychotherapies, Vol. 13, No. 2,

October 2014: Screening for distress: A qualitative Description of a Pilot Study in two Romanian Cancer Centers" Silvia Golita, Florina Pop, Lisbon, Portugal. Poster from International Psycho-Oncology Conference.

September 2015: The assessment of emotional distress, anxiety, cognitive coping strategies and health-related quality of life in Romanian breast cancer survivors of childbearing age, Journal of Evidence-Based Psychotherapies, vol 15., No. 2, pp 267-284.

- Providing psycho-educational materials through the translation of the "Coping with Cancer" Brochure (Dr. Maggie Watson & Dr. Charlotte White, 2009, a patient Guide) The new program was introduced to the organization through the website of the Institute and in the doctors' meetings by presenting psycho-social services available at the Institute level.

What is key for a well-functioning support service for patients and their families

- Assuring the necessary minimum conditions for creating an appropriate location for the psychological room
- Extra time offered by the psychologist for assuring the psycho-social assistance and research activity

Risks and opportunities and success factors

Risks

The main barrier for implementing the change was the limited number of psychologists available. This has prevented the implementation of psychological screening for emotional distress for each patient. Involving the volunteers from Clinical Psychology Masters Program was the solution for removing the barrier, but insufficiently.

Opportunities and success factors

Main success factors were the Motivation of the team at IOCN and the focus on the scientist practitioner paradigm. Raising awareness of the employees to the psycho-social needs of the oncological patients, ensuring an improved view of the psychological interventions is vital to achieve success. More resources could be useful for easier and quicker implementation of the screening and interventions

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BENCH-CAN Good practices 6

IMPLEMENTATION OF AN ADVERSE EVENT NOTIFICATION SYSTEM THAT ALLOWS TRACKING OF THE NOTIFICATION

Institution: ***Instituto Portugues de Oncologia do Porto (Portugal)***

Contact person:

Background

IPO has a Clinical Governance service whose mission is to ensure the continuous improvement of health care, being a decisive contributor for patient safety. This service receives and collects all the clinical risk notifications, implements corrective measures and monitors this. Containing the information collected, elaborate Quarterly and Annual Reports are written available to the whole institution. When employees make a notification to the Clinical Governance service they are able to track their notification to see what happens with it.

Creation and introduction

The creation of the adverse event notification system was triggered by the need to monitor the quality of the health services we provided to our patients, identifying areas that needed to change or be improved. The vision behind this was to grow and evolve in quality. The main disciplines involved were mostly physician, nurses and the board members. The goal was to improve the quality of the health services provided. The implementation of the system was communicated to employees through periodic newsletters and in service meetings. We tried to show them the importance of this project and that the main goal wasn't to punish people involved in adverse events (accidents, incidents with patients) but to identify situations that needed to be improved.

What is key for a well-functioning implementation of an adverse event notification system that allows tracking of the notification

The establishment of this support service didn´t need a big investment. It has an office with computers, one physician partially allocated, one nurse and one administrative in full time. The main differentiate investment is the software that supports the notification process.

Risks and opportunities and success factors

Barriers and Risks

The main barrier to implement the change was the resistance from staff that saw it as a way to control and punish their activity. We made some reunions to present the project and along time they understood the importance of it. This also formed the biggest risk factor, lack of engagement of all health professionals: their participation was crucial because without the communication of occurrences there was nothing to work with.

Opportunities and Success factors

The main success factor was the Professional's involvement and the perception of the importance of the project. One of the most important things in every change we make in people's routine is their involvement in the implementation of the project. People need to feel that their effort really counts to the success of the institution.

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BENCH-CAN Good practices 7

IMPLEMENTATION OF AN ELECTRONIC KIOSQUE SYSTEM FOR PATIENT REGISTRATION/ADMISSION

Institution: ***Instituto Portugues de Oncologia do Porto (Portugal)***

Contact person:

Background

In day-care area we have “Electronic Kiosks”, a tool to simplify all administrative process and a queue management system. It’s a system through which patients can manage their administrative process: check-in, check-out and continuity of care (future visits, home visits, exam preparations,...). The software also links with our ERP system and notifies the doctors when the patient arrives.

Creation and introduction

This project was a parte off the global strategy to reduce bureaucracy in the institute. The vision behind this was to affirm the centrality of the Patients. The main goals were: efficient allocation of resources and reduction of waiting times. The main professionals involved in the creation were Board Members, IT team, Patient Management Service, and IT suppliers. The main users of this system are the patients. When we implemented Kioskes we had a team of people to teach patients how to use it. Along time people became more independent in the use of this tool. Employees clearly understood the potential of this system to the patient. It also freed up time so they can do other tasks with the highest added value

What is key for a well-functioning implementation of an Electronic Kiosque system for patient registration/admission

The main investments were in IT infrastructure and software: we had to buy all the machines, develop software and create all interfaces with the several IT systems we had.

Risks and opportunities and success factors

Barriers and Risks

The main barrier was Some resistance of patients – which was however quickly overtaken. Along time they saw the potential of the tool, especially in the reduction of waiting times.

Opportunities and Success factors

The main success factor of the creation of the Kiosque was the fact that people like to use new technologies and in this case the benefits of its use had a big impact on the time the patient has to stay at the institution. We saw an empowerment of the patient. People have a big adaptive capacity but we need to be at their side in the change process.

BENCH-CAN Good practices 8

ESTABLISHMENT OF A CALL CENTER TO PROVIDE SUPPORT FOR CHEMOTHERAPY PATIENTS

Institution: ***Instituto Portugues de Oncologia do Porto (Portugal)***

Contact person:

Background

We have implemented a project in our Pathology Clinics that allows us to do a telephone follow-up of patients and their family. For such, there is a team of nurses who call patients to assess their state of health, and allows patients/family members to contact the team to clarify any questions and ask for advice.

Creation and introduction

The main reason for creating the Call Centre was to give close support to our patients. This project has it focus in two strategic vectors: “To affirm the centrality of the Patients” and “To grow and evolve in quality”. The main involved professionals in the establishment were Pathology Clinic leaders, physicians and nurses. As the patient can clarify any questions and ask for health advices we can reduce unnecessary attends to our urgency service. The establishment of the Call Center was communicated internally: through periodic newsletters and in service meetings; To patients: in their appointments at the hospital.

What is key for a well-functioning establishment of a Call Center to provide support for chemotherapy patients

The main requirement was a calm place where nurses could phone patients, telephones and computers with access to the electronic patient record.

Risks and opportunities and success factors

Barriers and Risks

No barriers were identified. A possible risk was that the patient couldn’t rely on this kind of service.

Opportunities and Success factors

The main success factor was a trustworthy relationship between the patient and health professionals. In changes that involve patients we need to assure that they trust us and recognize that the change can improve the health care services we provide them.

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BENCH-CAN Good practices 9

ESTABLISHMENT OF THE BREAST UNIT IN A PATIENT-CENTERED MANNER

Institution: ***Instituto Portugues de Oncologia do Porto (Portugal)***

Contact person:

Missing

BENCH-CAN Good Practices 10

INTEGRATED APPROACH TO CANCER CARE INCLUDING NETWORK COORDINATION AND MANAGEMENT OF THE NATIONAL CANCER REGISTRY

Institution: ***National Institute of Oncology, Budapest (Hungary)***

Contact person:

Background

The National Institute of Oncology is a national comprehensive center that treats cancer patients from all over Hungary and has been designated by the Ministry of Health as the reference center in Hungary to treat rare cancers. The National Institute of Oncology has an integrated, centralized approach to cancer care, which is achieved on various levels. It includes the establishment of the National Cancer Control Program (NCCP) and its continuous maintenance (updated every 3 years), the establishment of the National Cancer Registry and its management, and the organization and coordination of the Hungarian Cancer Network.

Creation and introduction

National Cancer Control Program (NCCP)

In 1996, The NCCP was developed with the leadership of NIO as part of a WHO initiative. The key stakeholders were organized into the National Cancer Control Committee, chaired by the Director General of NIO, Prof. Dr. Miklós Kásler. Key member of the Committee included clinicians, researches, lawyers, hospital managers, and government officials, who all participated in the development of the centralized approach.

The reason behind using an integrated, centralized approach to cancer care was to provide an equal opportunity to all patients nationwide to access the best cancer care possible. To achieve this goal, the national minimum requirements were established and the so-called progressive levels were introduced to set the minimum requirement for cancer care. (Level I: Cancer units, primary care, inpatient and outpatient specialized care; Level IIa: Cancer Departments at County Hospitals with no radiotherapy facilities; Level IIb: Cancer Departments at County Hospitals with radiotherapy facilities; Level IIIa: Regional Cancer Centers (in the city of Debrecen, Pécs, Szeged, and Szombathely); Level IIIb: National

Comprehensive Cancer Centre – National Institute of Oncology). Each progressivity level had certain criteria that had to be met by cancer centres such as training of staff, availability of equipment etc. After the centres were assessed recommendations were made for policy makers in order to ensure actions. Hospitals not meeting the minimum standards had to make improvements in order to be able to provide cancer care.

National Cancer Registry

The coordination of the National Cancer Registry was assigned to the National Institute of Oncology by a governmental decree in 1999 and the registry itself was established in 2000 with financial support from the World Bank. The earlier hospital based registry system has been organized into a population based registry supervised by a Committee. The statistics published are in line with the practices of European Cancer Registries. On the Institute's website those interested can search Hungarian cancer statistics including the number of cancer patients, diagnosis code, year, gender of patient, and geographic location (county).

Creating the National Cancer Registry and assigning its management to NIO had other important considerations as well. The main goals to be achieved were to decrease incidence and mortality and introduce new screening methods as well as increase efficiency. Cancer registry data also provides crucial information for policy makers on morbidity, mortality, financing capabilities, development of patient care and prevention activities, as well as environmental protection. Furthermore, various mortality rates also provide information on the quality of care.

Hungarian Oncology Network

In 2014, The Hungarian Oncology Network was established between NIO and the already existing four regional cancer centres in order to ensure patient access to high quality cancer care (with special attention to rare cancers) for better patient outcomes, and increased cost efficiency. The collaboration is focusing on various aspects of cancer care including the establishment of a common IT framework, education, mutual patient consultations, and scientific collaboration.

The http://www.honcology.net website was created for members of the network, which contains the protocols and guidelines, quality of care standards, and the epidemiological data of the cancer registry. The information was communicated at the management meeting to all department heads and the department heads communicated it to all staff.

The network site is accessible to all centres and serves as a basis for future research, clinical and other collaboration. The use of telemedicine and ICT tools for professional collaboration and medical consultations between the centres is currently under development, where smaller hospitals can also request second opinions from regional centres.

In terms of creating the oncological network the IT professionals of NIO played a major role. The management of the cancer centre has also taken an active role in centralizing cancer care efforts and in terms of financing various EU projects have helped to sponsor these initiatives.

What is needed for a well-functioning Integrated approach to cancer care

Some of the key factors included identifying the need to coordinate and harmonize nationwide network with designated roles of cancer care providers based on their progressive levels; developing and maintaining a nationwide cancer control program; having a designated management unit coordinating the activities; harmonizing data including the organization of a well-functioning Cancer Registry.

Risk and Opportunities and Success factors

Risks and barriers

Some of the main barriers in the implementation of the efforts included financial and time restraints and human resources, as well as bringing all stakeholders to the table.

The main risk factors included challenges with big data analysis and balancing stakeholders' interests by creating win-win situations for all. Some of the factors that contributed to the good practice were that NIO acts as a national institute with tasks identifiable on the national level; professionals at NIO were able to make recommendations to improve regional centres; and new pilot programs were introduced during the process, such as the colon cancer screening program.

Opportunities and Success factors

The main lesson learned during through a nationwide assessment of oncological care was that the weaknesses of the system were revealed and it created an opportunity for key stakeholders to address them.

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BENCH-CAN Good Practices 11

MONITORING THE IMPROVEMENT ACTIONS OF THE ANNUAL PATIENT SATISFACTION SURVEY

Institution: ***National Institute of Oncology, Budapest (Hungary)***

Contact person:

Background

In 2000, as part of the ISO 9001:2008 certification programmes, both an employee satisfaction and a patient satisfaction survey was implemented at the National Institute of Oncology in order to measure, monitor, and improve employee satisfaction as well as patient satisfaction. The implementation protocol along with the questionnaires was developed by the Quality Control Manager and the Nursing Director and was approved by the Director General and the questions are updated on as needed basis.

The strategic goal was to improve the overall quality at the institute and especially patient satisfaction and experience as well as to reduce non-compliances. The institute's overall quality management was to be improved by using the ISO 9001:2008 system, where the implementation and analysis of a patient satisfaction survey was part of the certification criteria.

Creation and Introduction

When the process was introduced a memo was sent by the Director General to all Department Heads informing them about the surveys. It was also announced at the monthly meeting for all Department Heads as well as the information was communicated at the Head Nurses' meeting.

The patient satisfaction survey (anonymous, paper-based survey) for both inpatients and outpatients is administered during the month of March each year the following way:

1. **Inpatients:**

The inpatient survey administration: The nurses at each ward distribute the survey to every inpatient leaving the institute during the month of March.

2. **Outpatients and day care patients:**

Outpatient survey administration: Each patient receives a survey when registering at the patient admission desk on every Wednesday.

Day care patient survey administration: The nurses distribute the survey every Monday, Wednesday, and Friday to every patient receiving day care treatment that day.

The surveys are collected in boxes placed throughout the Institute and it is the task of the Nursing Directorate to organize the logistics of administering the survey (e.g. Nursing Director informs the Head Nurses at their regular meetings, and Nursing Director's Assistant organizes the distribution of surveys to Head Nurses)

The surveys are processed and analysed by the Assistant at the Nursing Directorate and the Nursing Director prepares the following outcomes reports based on the analysis:

1. Summary report that is presented to the Director General.

2. Once the summary report is approved by the Director General each Clinical Department receives a detailed personalized report. The outcomes are discussed at the departmental meetings and the improvement actions that do not require a strategic decision can be addressed immediately are done on a departmental level (e.g. waiting area needs more chairs etc.).

3. Highlights of the patient satisfaction survey are also included in the Annual Audit Report, which is discussed with the Board of Directors (in the month of May each year). Strategic improvement actions are identified based on these discussions. Their implementation is monitored and they are evaluated at the next annual Audit Report meeting (each May).

The survey outcomes are also discussed at the strategic meetings with the institute's Board that takes place twice a month and focuses on matters concerning financing. The improvement actions of the patient satisfaction survey are also monitored at these strategic meetings.

What is key for a well-functioning monitoring of the improvement actions of the annual patient satisfaction survey

Some of the key factors included clearly identifying staff roles and responsibilities participating in the data collection, analysis, and follow-up actions; documenting the processes in the organization's policy and actively involving key stakeholders to participate in the survey; regularly updating the survey; proper communication to the management board; and integrating innovations based on identified needs for improvement.

Risks and opportunities and success factors

Risks and barriers

One of the challenges during the implementation was to make the employees distributing the survey understand its importance, which was emphasized by the Nursing Director and Quality Manager through various platforms such as the Head Nurses' meeting, training courses etc. Over the years, however it has become an integral part of the Institute's organizational culture. The collection of patient feedback is appreciated by staff as it serves as a mirror on their performance as well. It is also a source of motivation to staff when the survey outcomes are discussed at the departmental meetings and they receive positive feedback on their performance from patients. It was also crucial to put together questions that are appropriate, unambiguous and easily interpreted by a diverse patient population.

Currently the survey is paper-based and the data input is done manually, which is an additional effort from the Nursing Directorate beyond their day-to-day tasks (approximately 2 weeks of additional work). The success of the process is dependent on the diligent work of the Nursing Directorate and the nurses participating in the distribution of the survey.

Opportunities and success factors

In 2015 a total of 415 surveys were distributed to inpatients out of which 323 were returned and a total of 160 surveys were distributed to outpatients and day-care patients out of which 105 were returned, respectively.

The relatively high return rate (78% inpatient survey and 65% out and day-care patient survey) also shows that both employees and patients take the survey seriously and it has become an integral part of NIO's culture.

BENCH-CAN Good Practices 12

ORGANIZATION OF A PATIENT ADVISORY BOARD THAT MEETS REGULARLY WITH THE BOARD OF DIRECTORS

Institution: ***Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam (Netherlands)***

Contact person:

Background

The participation of patients in healthcare is regulated by law in the Netherlands since 1996. Each care institution is, as a result of this law (WMCZ), required to establish a Patient Council. The Patient Council has a statutory advisory capacity to the board of the hospital on topics such as

- The policy on treatment, care and support for patients
- The quality and safety of care
- Accessibility of the care institution
- Accurate and understandable information
- The policy on the welfare of patients like food, care, waiting lists, treatment and procedures for dealing with complaints.

Additionally, the Patient Council possesses lighter advisory powers on setting strategy and key organizational issues such as budget, annual accounts and reorganizations.

The Patient Council of the Antoni van Leeuwenhoek (AvL) consists of nine members; (ex) patients, their relatives or their survivors, who are elected by co-optation. Term of office is a maximum of 2 to 3 years. The Council is involved in (the development of) policies in all possible ways and consults on all topics that are important for patients, giving both solicited and unsolicited advice to the board of directors.

Members of the council are volunteers and are not professionals in the medical field. They are experts by experience. From a patient perspective, they can make a specific contribution to the policy of care institutes.

Creation and introduction

The Patient Council at the Antoni van Leeuwenhoek (AvL) was founded in 2004. At the time of the accession of van Harten to the Board of Directors cooperation models such as a joint Patient Council with other general hospitals or with another cancer clinic were first fostered in the years between 1996 and 2004. Both options were eventually organisationally unattractive. The Board then sought advice from the chairman of the Dutch Federation of Cancer Organizations (NFK), the same person who was responsible as Minister of Health in 1996 for the introduction of the WMCZ. Based on this advice, it was decided to establish a council for patients only for the AvL, with the caveat that the aim was to a limited representation of the NFK on the board.

The start has been prepared by an internal project, which was advised by the National Centre for Client Councils (LSR) for the drafting of regulations and for the first selection of members. Next steps were: appointing an executive secretary as an important link between the hospital and the council, introduction of the council in the hospital and of course a first official meeting with the board of directors.

What is needed for a well-functioning Patient Council

1. A board that appreciates, recognizes and promotes the importance of right of say and patient participation within the organization. A board that provides sufficient material and organizational support such as an administrative secretary, meeting space and expenses. But especially a board with an attitude that stimulates patient participation.

2. Readiness of the organization to inform the Patient Council on all relevant developments. Relevant information means information that is not too detailed or too specialized for non-professionals. But also not too broad or delivered at such a late stage that consulting or advisory adds little more.

   At the monthly meeting of the Council, the Council secretary informs the Council about current developments. Periodically there are dialogue consultations with members of the board and, depending on topical themes, with executives and managers. Policy papers and selected management information be introduced for discussion or information.

   The Council also receives input through regular visits to the wards, formulating questions to the patient panel of the hospital and, of course, through individual contacts with patients who approach the council with ideas and suggestions.

3. A well-functioning Council also means that the Council itself interprets its role well, a good middle place between a formal advisory role and a more informal role of

proponent and assessor of the culture of the hospital and the way it is perceived by the patient . The output consists not only of formal opinions, but also of comments on plans and policy.

Risk and Opportunities and Success factors

Risks and barriers

A balanced view of role is essential for both the hospital as for the Patient Council.

Good agreements and regulatory clarity are important, but a good casting is above all a question of culture.

The Patient Council takes work for the professional organization, while the efficiency is not always immediately visible. Working time is precious. Therefore it is important to involve the full Council, but not to questions referring to professional workflows.

The Patient Council itself must also be alert to a good balance between the more formal advisory role and the role of thinker. The legitimacy of the council is ultimately based on experience and from there, the council is the interlocutor for the hospital.

Besides the role view, continuity is a critical factor. Too long a tenure of members of the Council can lead to amateurism, excessive proceeding to inconsistent input. The maximum period of 2x3 years for members of the board is providing guidance.

Opportunities and Success factors

With a Patient Council, the hospital has the option to receive feedback from (former) patients and their relatives and survivors on the current state of affairs. Importantly, it involves (ex) patients involved in this hospital but not from a dependency relationship. In addition to existing (semi) professional national interest for patients a local Patient Council adds the benefit of a major commitment to this very hospital and has more space for informal consultations and early feedback for improvement. If all is well wear this contributes at all levels in an environment where user involvement is the default.

Patients have the opportunity to make their voices heard through the work of the Patient Council or directly. Individual complaints can be voiced through another channel, but the Patient Council gives patients the opportunity to think about the policy, culture and affairs of the hospital.

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BENCH-CAN Good practices 13

PROVIDING IMAGE GUIDED TREATMENT FOR PATIENTS IN SURGERY

Institution: ***Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam (Netherlands)***

Contact person:

Background

In the Netherlands Cancer Institute we perform different types of image guided surgery. A recently introduced practice is image guidance for surgery in the pelvic area (gynecologic surgery, urologic surgery, colorectal surgery) which will be extended to liver surgery. Preoperative images are translated into the operating theatre. The current location of the tumour or lymphoid metastasis is visualized relative to the surgeon his instrument by means of electromagnetic tracking patient tracking using sensors. Because of navigation for these types of surgery, surgeons are aided with more selective excisions; lymph nodes out of standard excision areas can be localized, surgical time can possibly be reduced, and complications may be reduced.

Creation and introduction

The main reason for the implementation of image guided surgery was the fact that preoperative, there are unlimited imaging modalities which can tell us with great accuracy where the tumour is located and what size is has. Surgery itself uses, most of the time, similar instruments (especially for tissue recognition) as 20 years ago even though incredible technological imaging advances have been made. To translate imaging from the radiology department to operating theatre a clinical research team and implementation team was set up. The vision was to improve surgery by image guidance and in the future also in vivo tissue recognition this research started and in house developed hard- and software was designed and clinically implemented.

Image guidance can eventually lead to better survival with less complication and can be used for all kinds of surgery or treatments options. Development of this method gives the Netherlands Cancer Institute a leading position in this development which is interesting for commercial and subsidizing partners. Prof. Theo Ruers (surgeon) leads this research line in

close collaboration with Dr. Koert Kuhlmann (surgeon), Dr. Jasper Nijkamp (Senior Post-doc), Bas Pouw (post-doc) and Oleksandra Ivashchenko (post-doc)

The changes for the surgical procedure were communicated by informing every employee involved in these procedures in person or by email. Hospital wide people know about this procedure because of posts on the local intranet, media attention, or word of mouth.

What is key for a well-functioning provision of image guided treatment for patients in surgery

The following aspects were key for the implementation of image guided surgery:

- Man power to facilitate these types of procedures.
- In house developed software that needed to be approved for safe clinical use.
- preclinical and clinical studies to assess the value of this technique.

Risks and opportunities and success factors

Barriers and Risks

A barrier for implementing image guided surgery could be lack of enthusiasm among surgeons. A very important aspect to introduce a new surgical technique is the enthusiasm of the surgeons about the technique. This will determine if the method will be successful. Risk factors that were identified include:

- Non acceptable accuracy of the technology.
- To time consuming with the great delays in the procedure.
- Lack of support by people involved in the procedure.

Opportunities and Success factors

The main success factor of the implementation was the achievement of good results together with perseverance and precision from the involved researchers. You have to make sure that all steps are taken in multidisciplinary setting. Both the radiological and surgical personnel should contribute to implement a successful procedure.

BENCH-CAN Good practices 14

PROVIDING IMMUNOTHERAPY TREATMENT (TIL) TO PATIENTS

Institution: ***Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam (Netherlands)***

Contact person:

Background

Tumour-infiltrating lymphocytes (TIL) are lymphocytes found within tumours. A metastasis, containing TIL, is surgically removed from the patient. The TIL is then isolated and expanded ex-vivo to very large numbers. Patients receive a preconditioning chemotherapy regimen, consisting of cyclophosphamide and fludarabine, before re-infusion of large numbers of TIL. Additionally patients receive high-dose bolus interleukin-2 to support the continued growth and activity of infused TIL.

Creation and introduction

The reason for implementing the TIL treatment at the NKI-AvL was that over the past few years melanoma incidence has steadily been rising, resulting in an increase in melanoma related mortality. Historically median overall survival for patients with metastatic melanoma was between 6 and 9 months, despite treatment. Research involving treatment of patients with metastatic melanoma with tumour-infiltrating lymphocytes at the National Cancer Institute (Bethesda, USA), showed consistent >50% response rates. This high response rate, with a substantial number of long-lasting and durable responses has also been confirmed in other centres (i.e. Tel Aviv, Amsterdam and Houston).

Multiple studies have shown consistent >50% response rates in patients with metastatic melanoma treated with TIL, of which some long lasting and durable. This is much higher than what oncologists could achieve previously with chemotherapy and later immunotherapy. For example dacarbazine (a chemotherapeutic) only showed response rates of around 10-15% and so does ipilimumab (immunotherapy, blocking CTLA-4 on the activated T-cell).

Multiple people were involved in the process of leading the introduction of the TIL. Our team from the GMP production facility is responsible for the production of the TIL. Multiple surgeons at the NKI are responsible for the excision of a tumour, from which we can harvest

the TIL. Adequate and involved nurses and physicians look after the patients when admitted to the internal medicine ward. Experienced data managers and data monitors at our trial office are involved in for example registering/randomizing patients and gathering and interpreting patient data.

The main goal is to see if treating patients with tumour-infiltrating lymphocytes could be a new treatment option for patients against metastatic melanoma. We will do so by measuring toxicity, progression-free survival and overall survival. In addition, to evaluate the feasibility to generate a personalized immunotherapy for every patient.
The introduction of the TIL was communicated to the employees in multiple meetings. For example, we held a meeting where all key group members involved were available to discuss the change. We also held meetings at the internal medicine ward for nurses and physicians. We further discussed the TIL trial at multidisciplinary meetings, with surgeons, pathologists and radiologists.

What is key for a well-functioning provision of immunotherapy treatment to patients

Critical requirements to be in place in order to drive the introduction of TIL were mainly financial. We needed the finances to be able to pay for expenses made. For example the production of TIL, the blood tests, CT-scans and admission of the patient to the internal medicine ward. Besides financial, time was also a critical requirement. When a patient is admitted to the internal medicine ward he/she is looked after by 1 specialized nurse. This specialized nurse cannot help other patients during the TIL treatment period which leads to an increase in human resources required.

Risks and opportunities and success factors

Barriers and Risks

We experienced no real barriers while implementing the change in the organization. However, the financial barrier was initially large. When we received temporary reimbursement for a period of 4 years by the Ministry of Health, this barrier was immediately removed.

Identifiable risk factors that could confine the implementation of TIL are for example toxicity and costs. If TIL treatment would lead to long-term or irreversible sequelae for the patients, implementation as a new treatment option would be difficult. If the costs for the TIL treatment would severely exceed the costs of treatment with current drugs (including immunotherapeutic drugs), implementation would be difficult as well.

Opportunities and Success factors

Main success factors that contributed to the success of TIL are the confirmed 50% response rate observed in the first 10 treated patients, including 2 long-term remissions, and the motivation of all personnel involved in TIL therapy, including GMP production technicians and pharmacists, nurse practitioners, PhD student, medical specialists, internal medicine ward personnel etc.

Lessons learnt during the process of implementing the change were, amongst others; the importance of good communication with all key members involved in the TIL process, but also good understanding of potential side-effects seen during TIL treatment, which led to amendment of the protocol.

BENCH-CAN Good practices 15

ESTABLISHMENT OF AN INSTITUTION-WIDE TRANSLATIONAL RESEARCH PORTAL

Institution: ***Netherlands Cancer Institute - Antoni van Leeuwenhoek, Amsterdam (Netherlands)***

Contact person:

Background

The Translational Research Portal (TRP) is a website dedicated to translational research. At the Netherlands Cancer Institute (NKI), an OECI accredited comprehensive cancer centre, employees find the portal on the landing page of the intranet. The website is organised in four sections corresponding to four phases of a translational research project. Each section contains a listing of links that guide the researchers and link out to websites, registration forms, documentation and other items relevant to translational research. Examples are "Start non-WMO study: IRB review (Institutional Review Board)" and "Catalogue: An overview of research datasets, biobanks and clinical data".

Also, the TRP serves as communication channel of the Translational Research Board. This board consists of principle investigators, clinicians and support staff. At the monthly meeting translation research related strategies and tactics are discussed and advised to the board of directors. The minutes of the meetings, documents discussed and slides presented are published on the TRP monthly.

Creation and introduction

The biobank and research IT facilities at NKI identified a lack of awareness amongst researchers about the availability of facilities and policies about translational research. Therefore the facility leaders engaged all translational research stakeholders and made an effort for a TRP supported by the institute's Translational Research Board.

A team was assembled to develop the TRP; it consisted of facility leaders (biobank, research IT), a science communication advisor (public relations dept.), an information management advisor (central IT department), a quality assurance officer (biometrics department), a data manager/developer (research IT) and the secretary and chairman of the Translational Research Board. Their goal was to create one place for all relevant information and provide

guidance to translational researchers. Initially, legislation, code of conducts, policies and guidelines were identified and an overview of available support facilities was made. Then, the page was designed based on a project life cycle. 1) Start project, to *register and review*, 2) Execute project, to *experiment and collaborate*, 3) Scientific output, to *consolidate and publish*; and 4) New Hypothesis, to *search and explore*. Finally the site was implemented, reviewed and made available.

The introduction of the TRP to the researchers was done with a promotion campaign. A send-alert was headline on the main page of the intranet, the website was featured in the quarterly newsletter for research, links to the page were placed on the most visited pages of the intranet and the TRP was presented at the yearly staff meeting. After the launch, many positive feedbacks were received and the visitor count of the page ranked second.

What is key for a well-functioning support service for patients and their families

The TRP contributes to the translational research infrastructure of NKI in general and therefore benefits patients and families only indirectly. As such, the TRP is key for ethical and legal compliance and efficient and effective use of patient data and samples for translational research. Specifically it might result in cost reduction, more scientific collaboration and better research outcomes.

Risks and opportunities and success factors

Risks

The following risks were identified that could block the success of the TRP.

- No commitment of all relevant stakeholders
- No support of the intranet for a custom page
- Lack of awareness of presence of the site
- Lack of usage after initial launch
- Not “listening” to the researchers / irrelevant content

All these risks were contained. We involved Translational Research Board members and staff of the most relevant support facilities at early stages. We identified the intranet ‘owner’, which is the public relations department. The central IT department provides technical support. By organizing a coordinated launch and installing an editorial board we generated awareness and reached sustainability. By having the page reviewed by key end-users we made sure the page contents are relevant and useful.

Opportunities and success factors

The two main success factors are the across departmental collaboration and the perseverance of the team. Because of the TRP, translational researchers at NKI now have better access to information, data, tools and expertise. For future development there is the opportunity to 'personalize' the portal, i.e. for managing 'my' translational research projects. A digital workspace in envisioned that includes patient sample ordering, data set archiving and several more features to further enhance the support for translational research at NKI.