

INTENT

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| Deliverable D.T4.2.1: Assessing partner and pilot site expectations of a virtual 'know-how' centre |

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1. Summary

Examples of features requested by the survey participants from VKHC

* **Repository of model and guidelines**
  + indicator sets: appropriate (implementable) description of indicators
  + links to other websites containing validated, understandable and in native language info concerning all cancer types (e.g. NCI, PDQ, etc), so that I can provide to my fellow patients’ material to understand better the disease
* **Benchmarking tool**
  + wish to compare performances and indicators from my institution with those of other institution with the aim of identifying the difference from standard or best practices
  + written explanation resuming the results
* **Analysis of gaps**
  + good practices from other centres linked to the weakest points of my own centre
  + contact person from a centre, which showed a much better performance
* **Repository of good examples**
  + detailed materials (e.g. procedures) describing experiences in other centres
  + include all-stakeholder viewpoints
  + documentation of benefits for patients
* **Other points**
  + friendly accessibility, easy language, not jargon
  + materials on multicultural habits
  + whether the patients themselves would have access to evaluation on individual cancer centres
  + patient organizations to also be involved in usage of PCCC
  + access to data (accessibility, waiting times, treatment success, experience, side effects of treatment, etc.) should be via phones, tablets and computers
  + access content related to other Centers across Europe

1. Survey instructions

As one of the outputs of INTENT project, the **Virtual know-how centre (VKHC)** should be developed as an **on-line web-based portal** accessible for partners and interested stakeholders.

VKHC should primarily be a **repository of good practices** in delivering patient-centred care. VHKC should include **key materials prepared by the INTENT project: patient-centred care model (PCCM), its implementation guidelines, indicator sets, etc.** and link them to collected **examples of good practices and innovative solutions** for implementing the PCCM principles as described in the previous session.

Integral part of the VKHC will be an **online benchmarking tool**, allowing the authorised personnel from participating centres to **collect data** on indicators of particular centre or to collect individual responses (from patients or staff) through online surveys, and to **perform benchmarking exercise** between participating centres (e.g. comparison of results with standards, best performers, etc.)

**Survey of ‘user stories’ from potential Virtual know-how centre users**

We would like to ask representatives of all involved project partners and their stakeholder panels for opinions and requirements for design of the Virtual know-how centre, notably online benchmarking tool. Please **collect short statements (in written form) from participants of your local stakeholder panel**, according to the description and examples below. Each partner site should collect and provide at least five user stories, which **show key expectations from the virtual know-how centre with online benchmarking tool** and its functionalities. You may collect the user stories during the local stakeholder panel/local consensus meetings as an interactive exercise by explaining the VKHC concept to participants and handing out a blank peace of paper on which they can to provide their user stories following the below format.

***General format***

As a **[please insert your role]**,I want to **[please insert the requirement or feature of the virtual know-how centre]**,so that **[please insert the desired objective]**.

***Example***

* As a **hospital manager**, I want to **benchmark the performance of my hospital according to the different PCCM dimensions**, so that **I could easily identify in which aspects the centre possibly deviates from PCCM standard or practice achievable best performers.**
* As **patient representative**, I want to **find out easily where the role of patient representatives is within the PCCM**, so that **I could effectively participate at the implementation of the PCCM at the particular cancer centre**.
* As **potential user**, I want to **easily access the virtual know-how centre on mobile devices (smart phones or tablets)**, so that **I could use the knowledge also without PC immediately available**.

***Please also collect any more general thoughts about the structure of the Virtual know-how centre, its content and features to improve its ease of use.***

We kindly ask the coordinators at the pilot sites to collect at least 5 user stories at each site and any additional feedback they may have regarding the VHKC and send them to RNDr. Ondřej Májek, Ph.D., Institute of Health Information and Statistics of the Czech Republic.

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1. User stories from the NIO, Budapest

* As a **quality manager**, I want the virtual know-how center to **provide good practice examples in patient centeredness** **as well as guidelines on how to measure patient centeredness**, so it can **help hospital management to learn from other centers about the implementation and patient centeredness measures can be become of the quality management system of the institute.**
* As a **policy maker**, I want the know center’s g**ood practice examples to reflect the point of view of all stakeholders (patients, hospital management etc.)**, so it **can assist policy makers when** **making relevant policy decisions or updating existing policies.**
* As a **hospital manager**, I want to be able to **compare the benchmarking data with other hospitals,** so that **the hospital performance can be compared internationally.**
* As a clinician, I **want to see practical examples in the know-how center of patient centered activities that demonstrate benefit to patients**, so that **others can learn from them and patient centered care can be improved at the hospital.**
* As a patient representative, I **want the know-how centers to give examples on good collaborations and practices of other patient organizations internationally**, so that it can help **patient organizations to improve their practices and further benefit patients.**

1. User stories from CRO, Aviano

* As a **Quality Manager**,I want to **have good practices from other centres linked to the weakest points of my own centre** so that **I can quickly implement these good practices in my own centre as well**. At the same time, I want **to be alerted automatically (by email) from the know-center when there are new good practices or other changes in the system** so that **I am always up-to-date.**
* As an **Oncologist**,I want to **find materials on multicultural habits**,so that **my skills to interact with patients from abroad (Arabs, Chinese) improve.** At the same time, I want that **when I looked at the benchmarking results of my Institute there is also a written explanation resuming the results and there is a general description concerning the financial and political situation concerning health economics of my region/nation;** so that **I can fully understand the performance of my centre in the present health economic situation.**
* As a **Patient Education expert**,I want to **find detailed materials (e.g. procedures) describing experiences in other centres**,so that **these documents can help me to improve my service**. At the same time, I want that **each axis in the benchamarking tool has a concise and comprehensive definition,** so that **I can easily understand the topic.**
* As a **Patient Education expert**,I want to **find a contact in the website, especially for the benchmarking tool**,so that **if I need help to fill the benchmarking tool, I can find an answer**. At the same time, I want that **when my centre shows weaknesses in a particular axis/indicator, we are provided a contact person from a centre, which showed a much better performance in the same area/indicator,** so that **I can contact the other centre and learn from their experience.** Last but not least, I want to **have a forum platform where all the participating centres can comment.**
* As a **Patient, who is part of a patient association,** I want to find **links to other websites containing validated, understandable and in my native language info concerning all cancer types (e.g. NCI, PDQ, etc),** so that **I can provide to my fellow patients material to understand better the disease.** At the same time, I want to **find a contact to speak to someone in case I want to have more infos. I want to find practical infos on how to get back to work after the disease. I want to find the list of referral centres for each single tumour.**

1. User stories from IOV, Padova

* As a **physician**, I am interested in **comparing the results** from my hospital with those reported in the other institution with the aim of **identifying weaknesses and strengths** of my institution and consequently **act to improve the quality** of the health care provided to patients
* As a **psychologist** involved in patient education programs I wish to **compare the expectations of patients and family members of my center with those of patients in the other care cent**ers who participate in  the project and evaluate common changes to the present care programs in order to provide patients with new inputs to increase their active participation in care
* As a **psycho oncologist** I wish to identify the degree of the **importance of the patients' needs through the PCCM indicators** so that will allow the health team to improve its relationship with patients
* As **volunteers associations coordinator** (for IOV), I wish to **compare performances and indicators** from my institution with those of other institution with the aim of identifying the difference from standard or best practices
* I has been working as **research nurse** at Centro Trials of Istituto Oncologico Veneto and I'm involved in all clinical trials, (phase I, II, III and IV) conducted at our Institute. I always takes an active role in all protocol studies, and I collaborate in ECM courses and trainings program for advanced nurses. Now I am full time coordinates the work of other research nurses in Oncology and I participate in works for national and international events cancer. I wish to enter as a "research nurse group" at the Virtual Know-how center to have a comparison with the standards of the participating centers in **clinical and quality of life oncology research**.
* As **patient and also as volunteers association president** I believe important that the point of view of patient is considered in all phase of the process of care, then also in VKHC. I ask to VKHC a **friendly accessibility, easy language, not jargon**. Moreover I wish to see **associations will be involved as all other actors**, for example when VKHC will propose indicators about Quality of life or when VKHC will evaluate the best practices to publish.
* As a **patient representative**, I consider important that the person/patient is truly and effectively placed at the center of the treatment pathway. To realize the PCCM it is necessary to focus on improving communication between patient/caregiver and care team and on patient empowerment in the decision-making process. In the survivorship phase it is essential that the patient is made aware of all the health professionals involved in rehabilitation (physiatrist, physiotherapist, psycho-oncologist, sexual consultant, nutritionist, endocrinologist, etc.) in order to be able to recover the different aspects of his/her quality of life.

1. User stories from MMCI, Brno

* As the **Patient Representative** at Czech Republic, I see the advantages of PCCM mainly for the management of medical facilities so that the **management of the facilities could easily compare their processes with “ideal” standards**. As a representative of the patients, I actually agree with the examples provided to us (below). For patient organizations, respectively, for other patient representatives, it would be good to have a clearly defined position, so that they could easily transfer the requirements of the patients to the management of the hospitals. This is probably the most important thing, which the model should fulfil. Another question I have is whether the patients themselves would have access to evaluation on individual cancer centres?
* As the **Volunteer Representative** at Czech Republic, I want the patient organizations to also be involved in usage of PCCC so that volunteers might have good insight on the situation involving care for the patient. It would be very good if **volunteers and representatives of patient organizations could also use the online tool**.
* As the **Medical Manager**, I want to make sure that the tool collects and provides general information on patient centeredness and enterpneunership in the field of patient centerdness so that it **provides useful information on the results of self-evaluation** (for the purposes of patient centerdness), it provides **information for implementation** of patient centered care model context
* As the **Policy maker representative**, I believe that benchmarking in healthcare system is one of the most important tools for enhancement of quality of medical services. The healthcare providers do not always have the most accurate data. Also managers and bodies owning the providers miss complex overview for managing, which could be efficient in the field of economics, but also in the patient centered care. I **would like the online benchmarking tool to give complex overview for all the stakeholders mentioned above** so that IHIS and, through them, the **Czech Ministry of Health could easily access and publish comparable data**. Evidence based medicine is, however, similar through the entire globe. Therefore, it is important to have such available benchmarking at least at the EU level.
* As a **Clinician**, I want the benchmarking tool to **collect data representing the weakest point** that arose from the questionnaires spread by INTENT so that the topics that arose from PCCC INTENT questionnaires were the ones that need attention. It is easier to **check improvement by using benchmarking tool**.

1. User stories from OOI, Ljubljana

* As a **healthcare director**, I want tables or columns that would allow me to get a better look at the content.
* As **patient representative**, I want access to data (accessibility, waiting times, treatment success, experience, side effects of treatment, etc.) should be via phones, tablets and computers. However, it will be difficult to say whether anyone will be able to access whatever information is available to him.
* As a **potencial users**, I want to access content related to other Centers across Europe. I would be most interested in accessibility, queues, research information, new guidelines, quality and holistic patient care.

Other comments

* After the conversations I have had with people, they are mostly of the same opinion that VKHC was made up and accessible to patients and other users in an understandable way. Clear guidelines, with no unnecessary information to trick users. We know that websites have a lot of information that is unclear to patients.

Advantages:

* Establishing comparisons between hospitals will certainly have a good effect on their work. It does not matter how many patients will actually use the network, there will be a situation where hospitals can be separated in more / less, more / worse, longer / shorter, etc. Institutions' executives will be assigned the role of 'being watched', which will certainly trigger a greater effort to address particularly unnecessary and quickly resolving deficiencies.

Risks:

* Given that the main addressees, if I understand correctly, are patients, there will certainly be a multitude of "false alarms": people, lay people will inevitably misunderstand, or at least misinterpret, and file complaints, requests, etc. . Many, even most, will be unjustified. This will recruit the services of the hospitals, there will be announcements dangling among "readers' letters", etc. But at least some comment will be warranted and that is enough to make such a project useful.