



Deliverable No. 14.1

Specification of patient involvement demands in the p-medicine scenarios

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ABSTRACT:

This deliverable outlines the state of the art of ALGA questionnaire validation and the development of three studies that investigate cancer patients' need for information relative to their own health status. The surveys cover patients' attitudes towards general and scientific health information, and towards different type of sources involved in information delivery, in order to understand what is needed from a new decision support tool that helps patients become more involved in decisions about their treatment.

KEYWORD LIST: Patient needs, patient empowerment, psychological profile, patient questionnaires

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¹ R=Report, P=Prototype, D=Demonstrator, O=Other

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1 Executive Summary

The main objective of this deliverable is to assess patients' information and involvement needs. Not all patients however wish information about their illness, and many do not wish to share decision making. We have created online questionnaires and interviews to understand patients' needs, preferences and motivation to be involved in shared decisions, and their need for information associated with their health condition. Furthermore, personal markers, such as readiness to be involved, educational level and quality of life, are important factors which need to be built in to the assessment of appropriate planning of the patient journey.

The ALGA questionnaire has been devised to provide much of this data, and has been discussed in Deliverable 2.5. The data analysis for the validation of the tool on healthy people volunteering in 3 European Countries (England, Germany and Italy) has commenced and this has led to a new version of ALGA specific for cancer patients.

As two of the disease foci in p-medicine describe children with acute leukaemia or Wilm's tumours, we have started to develop a version of ALGA for children and their parents.

2 Introduction

Purpose of this document

The grand plan for Work Package 14, is to build tools which on the one hand provide clinicians with information about the cognitive attributes of each individual patient which will contribute to deeper understanding of expectations, fears, attitudes e.g. to risk, educational level, mental state. This will greatly assist the physician in future interactions with his or her patient and in particular improve communications and handling of information by that patient. On the other hand we also plan tools to help the patient absorb information given in the doctor-patient interview, process it and use it in subsequent discussions concerning therapeutic and follow-up management.

Close interactions with WP 13 are in place as that team will be developing decision support tools, and require information on patients' information needs, and expectations around decision making.

It is clear that this area is advancing very fast, led by, or required by the accelerated speed of discovery about the molecular nature of cancers, and the opportunity to tailor eventual therapies, e.g. radiation dose, and field or specific antibodies or targeted molecules to exploit those individual molecular mistakes in a patient's particular tumour.

The deliverable therefore sets out our approach to gathering this information and analysing it to inform the efficient building of tools, which we believe will vastly improve the outcome for cancer patients, both adults and children.

It must be recognised that some therapeutic decisions are not difficult. Certain cancers of the rectum have been researched by examining ideal outcomes decided by patients, and agreed by their surgeons. Local recurrence and faecal incontinence are the two determinants, which lead to only one course of action namely a specific type of resection of the bowel cancer, so called AP (Abdominoperineal) resection. The patient can take it or decline any treatment, (Maysa et al, 2009). But looking at breast cancer forty years ago mastectomy was the only option for a woman, whereas now, she has a choice of lumpectomy, local irradiation, adjuvant chemotherapy, hormones, or antibodies, and then a variety of choices for reconstruction of the breast with or without prostheses. Such options are not only available, but are now discussed in public – a good example of the last, prostheses, has been front page news for several weeks due to late complications following certain implants and controversy about blame and compensation.

It is important to bear in mind when planning p-medicine tools that doctors are occasionally resistant to giving patients information, several resent the use of shared decision tools and few use them (Caldon et al, 2011, Brace et al, 2010 and Harrison et al, 2009)

This deliverable looks at the patients' needs primarily, not the physicians but it is important to realise the issues surrounding eventual implementation of information tools. We have addressed what patients wish to know, and few surprises emerge, how they seek (if they seek) information, what use is made of the Internet, what makes sources trusted, and whether multimedia and entertainment tools would be welcomed. The literature until now is sadly lacking in definitive studies in this area - discussed by Maddock et al (2012) for eCancer. The field of assessment of adoption of shared decision making was reviewed by Legare et al (2010) and they reported only five randomised clinical trials amongst a total of 6764 relevant documents in the Cochrane Database of Systematic Reviews. Clearly strict validation of the existing tools is unacceptably poor. The results presented here add significantly to the literature, and have extra value as they have been obtained from volunteers speaking differing mother tongues. The tools foreseen in pMedicine should be so simple to use that they are applicable in any country.

The first questionnaire designed by the IRIDE (Interdisciplinary Research Centre on the Decision Making Process) team for ecaner will be used in the coming year to start to address some of the above issues, and in particular to address patients' wishes and expectations described in the following deliverable. While previous questionnaires have adopted a standard "Quality of Life" style, they have failed to probe cognitive issues which patients have and which can contribute to communication blocks, misunderstandings and imperfect patient management. These gaps have been filled in this study

3 Patients' involvement demands

3.1 Patient use of research resources

3.1.1 Background

The nature of malignant disease requires patients to learn about and comprehend the illness, make difficult decisions regarding ensuing treatment, and cope with the consequences of the illness. It has been found that having relevant information not only helps cancer patients to understand the disease, but it also facilitates their decision-making and coping (Cassileth et al. 1980, Iconomou et al. 2002).

Only a limited number of studies have examined the information sources that cancer patients use to seek needed information (Rees and Bath, 2000). More studies are certainly required on this topic. Understanding the phenomenon of information source use among cancer patients is important because interventions are needed to ensure that these patients are exposed to a range of information sources and are substantially informed about the management of this complex disease (Schapira et al. 1999).

More recent research indicates that cancer patients, during their illness, have a variety of information sources available to obtain the information needed to learn, decide, adjust and cope (Mills & Davidson, 2002; Raupach & Hiller, 2002).

In this study, the author conducted a survey in order to understand which are the information sources and types of information cancer patients prefer the most. A major barrier to understanding information is educational level, and a small number of studies have indicated that linguistics and numeracy are critical in "low literacy" patients (Smith et al, 2008 and Lipkus et al, 2010 respectively). More optimistically a number of recent studies suggest that information presented within multimedia or "entertainment" formats can be effective in those at risk patients (Smith et al, 2010, Jibaja-Weiss et al, 2011, and Allen et al, 2011)

3.1.2 Methods

A brief and focussed survey questionnaire has been created that concentrates on the following two main areas:

- The interest for both general information and scientific research on the patient's own cancer
- The patient's preferences for information format and the sources that deliver it

The aforementioned areas have been developed in 8 questions. Participants were asked to respond to each question using a 5 point Likert scale.

3.1.3 Participants

Sixty-six cancer patients volunteered to participate to the study, filling the online questionnaire.

3.1.4 Results

As emerging from Table 1, the most popular and used source of general information is the Internet, while the other sources do not show a strong difference in preferences. Interestingly, almost 30% of respondent will never go to the library for health information.

Table 1 - Percentage of respondents preferring the different information sources for looking for general information. (1=very often, 5=not at all).

Answer Options	1	2	3	4	5
Internet	72.7%	18.2%	4.5%	4.5%	0.0%
Books	21.0%	32.3%	22.6%	16.1%	8.1%
Library	17.5%	17.5%	22.8%	14.0%	28.1%
Charities	28.3%	26.7%	11.7%	20.0%	13.3%

Encouragingly enough, an interesting result from the questionnaire shows that 62% of participants want to know about the latest research on their own cancer.

Not surprising at all, however, the majority of our respondents will look for a simplified version of the latest findings for the general public (almost 90% of them are likely or very likely to use this simplified version, see Table 2). This result confirms the difficulty that patients have in understanding medical language and suggests that physicians have to tailor their communication to patients' needs and health literacy, considering that a big proportion will also be interested to look for original papers. From the results it seems that a significant proportion of participants prefer to have both versions. It might be that the clarified version is used to complement the scientific version for a better understanding.

Table 2 - Participants preferences for scientific sources vs clarified version for the lay public (1=very likely to use; 5= not likely at all to use).

Answer Options	1	2	3	4	5
Original scientific paper	34%	32%	19%	10%	5%
Clarified version for the general public	67%	19%	13%	2%	0%

As Table 3 shows, ignoring the information obtained directly from the physician, even though Charities seem to satisfy participants' need for this type of health information, the preference is more than double when we consider the possibility to obtain information using the Internet.

Table 3 - Percentage of participants' preference relatively to the different sources of information (1= very likely to use; 5 = not likely at all to use).

Answer Options	1	2	3	4	5
Internet	66%	20%	13%	2%	0%
Books	16%	28%	32%	16%	9%
Library	11%	23%	30%	18%	18%
Charities	31%	21%	12%	21%	16%

When we stress the use of Internet, and investigate which type of website cancer patients are entering, the result should make professionals reflect on patients' needs for information. In fact, more than the 90% of people look for scientific research on a "search engine" and give relatively low importance to Charity websites and Government health service websites (see Table 4).

Table 4 - Percentage of participants' preference relatively to the different sources of online information when searching for the latest scientific research (1= very likely to use; 5 = not likely at all to use).

Answer Options	1	2	3	4	5
Search engine	72%	20%	7%	2%	0%
Charity website	32%	32%	25%	12%	0%
Government health service website	31%	34%	16%	15%	5%

Patients show the same attitude when we propose videos as information sources describing the latest scientific findings or research, In fact, also in this case, the majority of respondents strongly prefer a clarified version of the scientific findings (60% of respondents) to the original scientific version (43%), and also in this case, that is, when searching for videos, people prefer a search engine, probably because a search engine will include information delivered also by Charity and Government Health Service website.

3.2 Patient online information needs survey

3.2.1 Background

As shown from the results of the questionnaire at point 3.1, patients are increasingly turning to the Internet to supply them with key information relatively to their health condition.

In order to better understand how cancer patients and their family deal and cope with online information, and to understand better their communication needs, an online questionnaire has been developed.

The vast majority of patients with cancer want a great deal of specific information concerning their illness and treatment. Failure to disclose such information on the grounds that

significant numbers of patients prefer not to know is untenable (Jenkins, Fallowfield & Saul, 2001). Given the large number of topics judged by patients to be important and the complexity of the information required, it would be very difficult to communicate this information in oral discussion during typical consultation visits (Bernstein, Promislow, Carr, Rawsthorne, Walker & Bernstein, 2011). In this informational complexity, and as we just demonstrated, the internet has been increasingly used as a resource for accessing health-related information.

The aim of this study was to evaluate the use of the internet among cancer patients. Supplementing physician-patient consultations with well-designed written information or a Website recommendation may produce more effective communication and education.

3.2.2 Methods

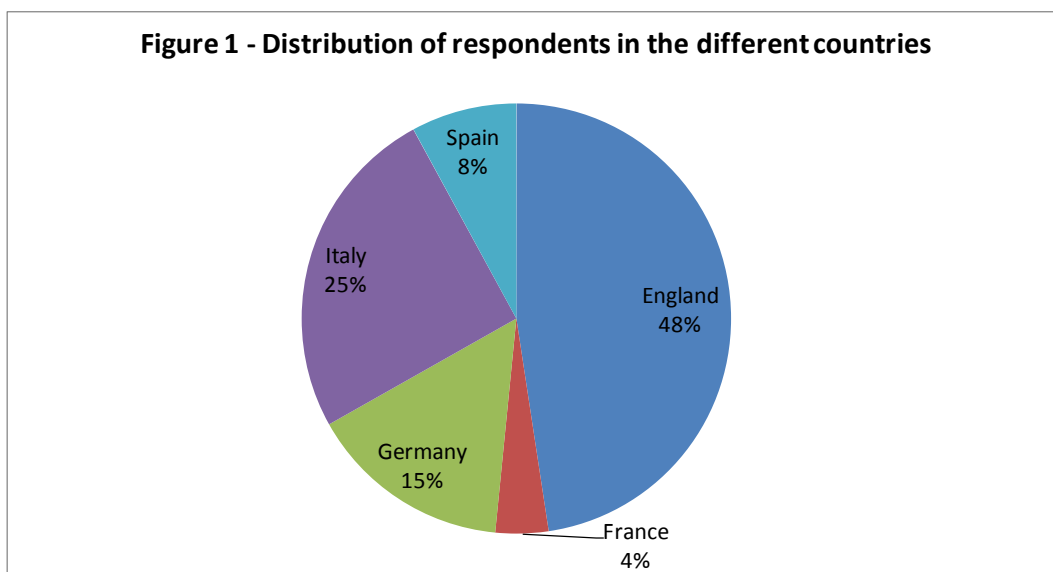
The survey was conducted in five languages: English, French, German, Italian, and Spanish. Collectively, they covered most cancer specialities.

The questionnaire concentrated on three main areas:

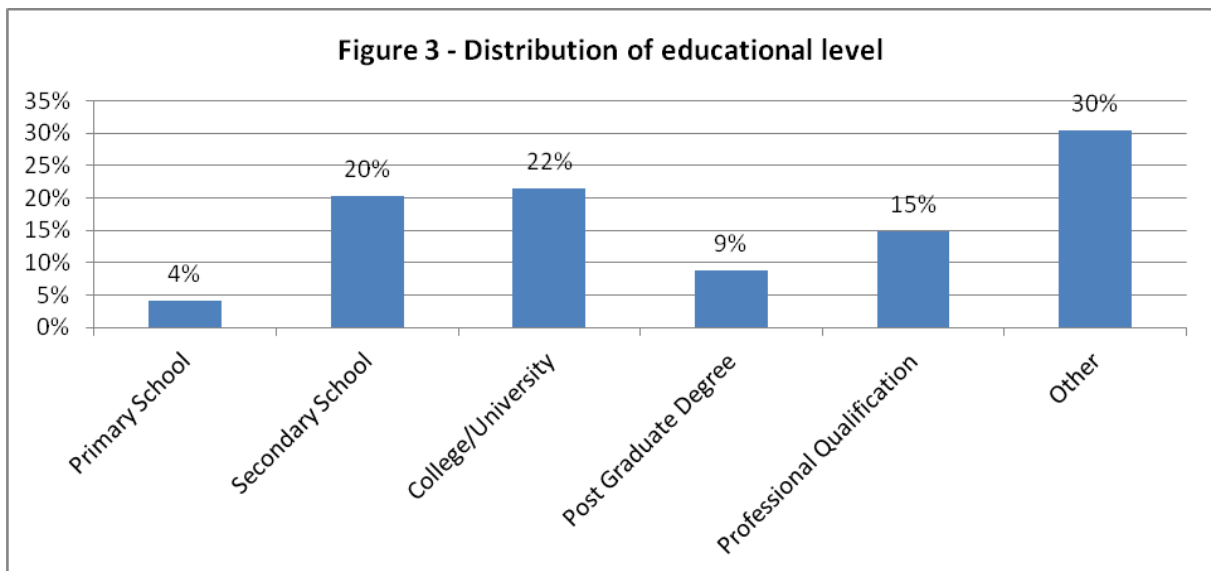
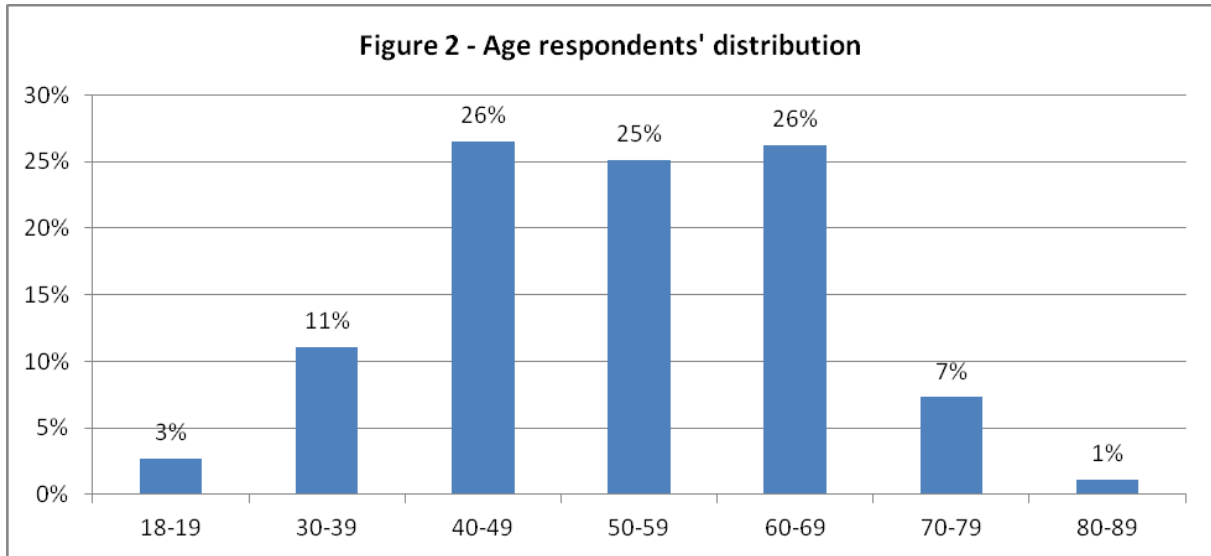
- 1) Demographic information;
- 2) Information about the medical condition of the patient or that of a family member;
- 3) Information about how and why the patient accesses information about cancer online. This last area measured the accuracy the respondent perceives relative to online information, preferences for different sources of information, their use, and the factors that affect subsequent use of online information.

3.2.3 Participants

Four hundred and seventy nine participants from England, France, Germany, Italy, and Spain filled the questionnaire. Figure 1 shows respondents' distribution in the different Countries.



The sample is normally distributed according to age (Figure 2). The proportion of women compared to men responding to the questionnaire is double (respectively 69% and 31%). Relatively to education (Figure 3) only 4% of respondents has an education lower than Secondary School level.



3.2.4 Results

Despite the difference in sample size in the different European Countries, a preliminary analysis showed no differences in response to the critical questions. For this reason, the responses of the 5 different Country versions were merged all together. (It is noteworthy that there is an almost complete absence of decision making tools in France).

As we can see in Table 5, the majority of patients who accessed the questionnaire considered the information they encounter online accurate most of the time. However, data from Table 6 suggests that despite patients using the Internet to gather information about their cancer condition, they still continued to put more trust in information from their doctors and health professionals for their treatment decisions.

Table 5- Percentage of respondents about the accuracy of information founded online.

Answer Options	always	Mostly	occasionally	Sometimes	never
Online accuracy	3.4%	55.7%	25.6%	14.9%	0.4%

Table 6 - Percentage of respondents considering the influence of different sources of information on treatment decisions.

Answer Options	Always	Frequently	Occasionally	Never
Health professionals	72.0%	25.0%	3.0%	1.0%
Internet	4%	32%	50%	14%
Printed material	5%	39%	45%	10%
Medical Journal	3%	26%	31%	41%
Advice from other patients	3%	24%	51%	21%
Family or friends	3%	27%	50%	20%
Advocacy or other support organizations	6%	31%	41%	22%

As table 7 shows, respondents are sensitive to all types of information they might find online and that are related to their physical illness or psychological and emotional condition. There is however a strong agreement among people to be particularly sensitive, and therefore have preferences for, information strictly related to the treatments they might undergo, to the possible side effects and to information about strategies that can make their general condition more comfortable. It seems they need to be reassured and helped in what it seems to be the major cause of threat for their life.

Table 7 - Percentage of respondents' preferences on the type of information they would look for on internet.

Answer Options	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
My diagnosis	46.5%	35.7%	7.4%	4.7%	6%
Causes of spread of cancer	49%	37%	10%	2%	2%
Treatment Options	60%	30%	6%	2%	2%
Side effects of treatment	63%	29%	4%	2%	3%
Local information (e.g., support groups, health facilities)	50%	39%	8%	1%	2%
clinical trials	36%	42%	18%	2%	2%
Getting help with daily tasks, eg cooking, cleaning	23%	37%	21%	14%	5%
Financial advice or support	30%	34%	20%	10%	6%
Speaking online with people in similar circumstances	34%	37%	19%	4%	6%
Diet and nutrition	40%	41%	15%	2%	2%
Physical activity and promoting recovery	38%	45%	12%	3%	2%
Online counseling	25%	32%	29%	10%	5%
Employment related or legal advice	28%	35%	24%	7%	6%
Family members risk of getting cancer	35%	32%	19%	8%	7%

Independent of the source of online information (online forums, blogs, email, social networking sites) what people care about is the ease in the use of the specific type of source and the possibility to have access to that information all day long (see table 8), suggesting the patient's need to find at any moment the answer to their questions, doubts and fear.

An important factor that leads people to decide for a particular site, when looking for online information, is the necessity for information to be updated and qualified by expert authors.

Finally sources which guarantee patients' support in social and economic areas of their lives are well used.

Independent of how the respondents use the Internet to look for information about their condition, most of them compare several different online sources. They prefer to personally search for information and only few people will be willing to devolve the searching to other people, even family and friends.

Moreover, the subjective perception that Internet information is not confusing and damaging their coping behavior is coherent with patients' perception that the Internet actually helps them in their decisions about treatment. More specifically 52% of respondents agree or strongly agree that having access to information from the internet has helped them make treatment decisions (see Table 8). A similar question measured by the questionnaire and reported in table 6, shows that the percentage of respondents that consider the Internet as a useful source for treatment decision is significantly lower (36% of respondents in table 6). This difference in response might be due to the different frame that has been used in the two questions: "How you use internet sites" and "What or who influences your treatment decisions?" respectively. It is possible that in the first mentioned frame, respondent felt more responsible for their actions concerning the use of Internet (they are the agent in that sentence) overestimating the influence of internet on their treatment choices. On the other hand, in the second mentioned frame, among the possible options Internet is compared with Health Professionals, which traditionally are trusted more and might have lead respondents to underestimate the influence of the Internet.

Table 8 - Percentage of respondents' use of internet sites.

Answer Options	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
I search across several sites when looking for information	45%	40%	8%	5%	2%
I focus on one trusted site when looking for information	27%	37%	15%	17%	4%
I am satisfied that I can find reliable information about my condition	21%	47%	23%	7%	2%
I ask friends and relatives to find information for me	2%	13%	9%	41%	35%
I would have more confidence in online health information if endorsed by a professional body	34%	40%	16%	6%	5%
Having access to information from the internet has helped me make treatment decisions	21%	31%	22%	15%	12%
Having internet information has made me more confused about my condition and treatment options	4%	17%	19%	38%	23%

Despite whether the influence of the internet on treatment decisions is perceived by 36% or by 52% of respondents, both percentages are still low if compared with the 90% of people that look for treatment options in the Internet. Why the remaining 40% of respondents who are willing to look for treatment information for their cancer using the Internet eventually do not use that information?

3.3 Patients' involvement demands survey

3.3.1 Background

Patients' involvement in their own healthcare or that of their families can only be built upon an understanding of health and being able to use that knowledge. The relatively new concept of 'health literacy' implies involving patients directly in the knowledge acquisition and decision process. In other words, it means being able to find, understand, and use health information to make sound decisions (Nutbeam D, 2000).

The aforementioned studies focused on cancer patients' interests in latest scientific findings and the sources that are used most often to collect information. In order to have a complete picture of cancer patients' needs, a study has been started in to give a better understanding of what is needed from a new decision support tool that helps patients become more involved in decisions about their treatment.

3.3.2 Methods

A survey questionnaire has been created that focuses on the following main areas:

- The specific relevance of information for treatment decisions, with attention to the type of information they would like to gather to reach the subjective optimal choice (e.g., the latest new treatments and their effectiveness, the remaining quality of life, side effects of possible treatments), the format they would prefer the information to be delivered by the physicians (e.g. internet, oral vs. written information), and the level of understanding of the delivered health information
- The type of information they would like to collect on the specific disease they have, both on the cancer treatment, effect on the quality of life and on the efficiency of the Institution where they are going to be managed.
- The relevance of the patients' psychological needs
- The familiarity with Internet sources and technological device

3.3.3 State of the art

Currently forty-five questionnaires have been collected on line among English patients. Data collection is still going on.

4 Questionnaires (e.g. specific CRFs) for patients enrolled in clinical research and daily clinical care

Introduction

As described in D2.5, the ALGA questionnaire has been created in order to integrate psychological and personal variables into multiscale data systems containing heterogeneous data from a patient. This process will eventually greatly improve the predictive power of decision support systems that have been developed on the basis of these data systems. This will lead to better and more efficient decision support tools for physicians.

For this purpose, it is necessary to validate the questionnaire in different European countries. Furthermore it is necessary to tailor a version of the ALGA questionnaire for cancer patients.

4.1 State of the art of ALGA Questionnaire and a tailored version for the cancer patient

As described in D2.5, validation of the questionnaire in at least another sample of healthy subjects is needed. In the last period we collected data on the English population. This data distribution comprises 163 completed questionnaires, 51% women and 49% men, with a normal distribution across age.

At the moment, WP14 is working on data analysis for the validation of the questionnaire.

A preliminary analysis has confirmed the 4 areas to focus on as the main components of an individual's profile: psychological aspects, psychosocial aspects, cognitive aspects and perceived health states.

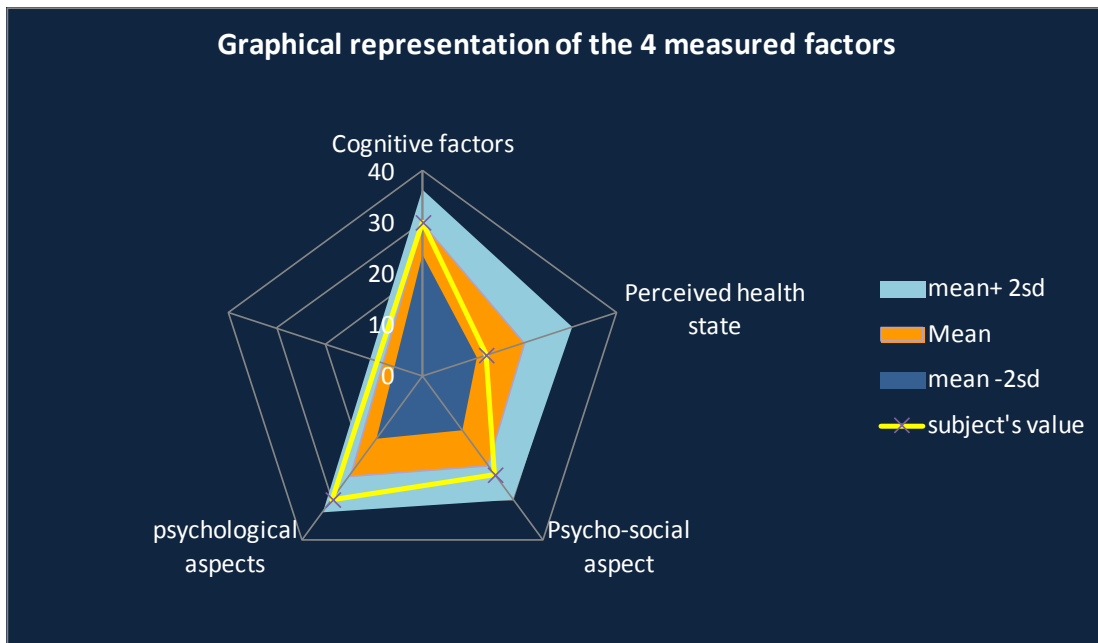
Each component is characterized by different subcomponents, as follows.

1. Psychological aspects:
 - a. Anxiety
 - b. Depressive symptoms
 - c. Self-efficacy
2. Psychosocial aspects:
 - a. Social abilities
 - b. Financial problems
 - c. Sexual problems
 - d. Body image
3. Cognitive aspects:
 - a. Memory and attention
 - b. Rumination
 - c. Cognitive closure

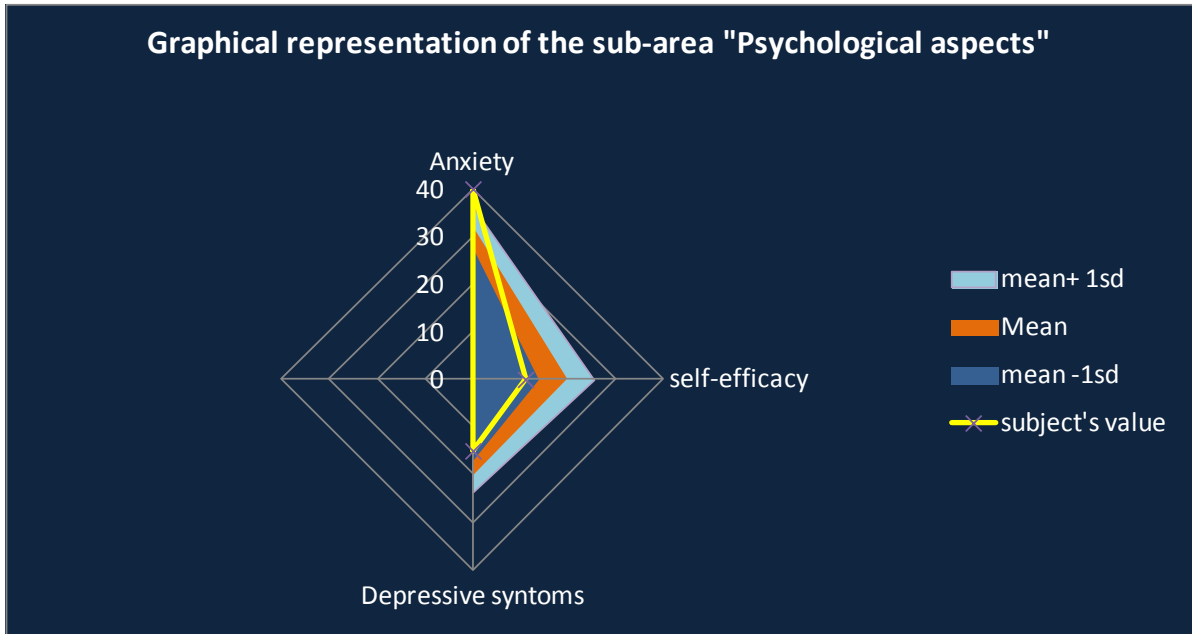
4. Perceived health states:

- a. GSRH
- b. Pain
- c. Fatigue
- d. Physical abilities
- e. Appetite

The final analysis will produce normative values that will be used to compare the patient’s value. The output delivered to the physician will be a radar graph that synthesizes the patient’s position compared to the mean and standard deviation of the normative group: A graph relative to the general individual profile related to the 4 main areas (or components) and a graph for each sub-area (an example is displayed below).



G-Factors	Mean+ 2sd	Mean	Mean -2sd	Subject's value
Cognitive factors	36.29	29.90	23.52	30
Perceived health state	30.70	20.95	11.21	13
Psycho-social aspect	29.95	21.62	13.29	24
Psychological aspects	32.97	24.16	15.35	30



Psychological Aspects	Mean+ 2sd	Mean	Mean -2sd	Subject's value
Anxiety	40.77	32.286	23.80	43
self-efficacy	31.22	19.714	8.21	12
Depressive symptoms	26.91	20.476	14.04	10

ALGA-C for patients

At the same time, a new version of the questionnaire has been created, specifically for cancer patients (ALGA-C). In the new version, questions on the health literacy level of the patient, and previous involvement of the patients in situations related to cancer that affected family members or friends have been added. This last information will be useful to distinguish and understand different coping behaviors among “expert” patients and “naïve” patients. The assumption is the patient’s coping behavior will be different in those patients who previously experienced a cancer indirectly through friends and family members. This information together with the information collected by the ALGA questionnaire, might give a better understanding of the modalities the professionals should use to interact with and empower the patient.

To measure the health literacy level of the patient, a question has been added: “Do you perform activities in health services?”. We expect that people who are active in health for work or in their hobbies will cope differently compared to patients who are completely naïve.

Finally, to measure a patient’s previous experience with cancer the following questions have been added (the same questions are presented twice, for family and for close friends):

- Has a cancer ever been diagnosed in your family (parents, children, siblings, partners)?
- If yes, when was the cancer diagnosed?
- What was the diagnosis?
- Did this person undergo surgery?
- Which treatment did this person received?
- Has this person recovered?

The aforementioned questions will be treated separately from the data derived from the original ALGA questionnaire, and will be used as additional information to provide a more exhaustive profile of the patients.

The questionnaire is ready to be administered to patients and data collection is starting at the IEO, Milan, Italy.

Next steps:

- data from patients will be analyzed following the same procedures we used for healthy subjects;
- Data obtained by the questionnaire will be used to create the patient's personal profile and to monitor the patient's quality of life, thereby facilitating the patient's involvement in the clinical decision process and finally leading to patient empowerment.

4.2 Empowering children with cancer and their families – K-Alga for parents and K-ALGA for children

Our main assumption is that in order to empower children with cancer it is necessary to start with the whole family.

When a family member is faced with a terminal illness, the impending death presents a crisis and a challenge to the entire family as a system. As a parent, the fact that your child has cancer is one of the worst situations to face.

According to the family systems theory (e.g., Bateson, 1971) individuals cannot be understood in isolation from one another, but rather as a part of their family, as the family is an emotional unit (Kerr & Bowen, 1988).

Previous studies demonstrated that psychological symptoms (e.g. anxiety) are frequently displayed in the end-of-life care period and cause severe suffering in children (Hechler, Blankenburg, Friedrichsdorf et al., 2008). As mentioned previously, families are systems of interconnected and interdependent individuals: what happens to one family member affects the other members. In turn, how a family responds to adversity influences the child's responses and functioning, in a circular sequence of effects (Patterson and Garwick, 1994). A bidirectional effect can be found between parental difficulties and low empowerment in children with cancer.

Parent distress has been found to be positively related to distress in children. For example, children of depressed mothers display a variety of internalising and externalising symptoms, above and beyond those displayed by children of non-depressed mothers (Brennan, Hammen, Katz, & LeBrocque, 2002; Langrock, Compas, Keller, Merchant, & Copeland, 2002). Similarly, anxiety in parents has been linked to anxiety in children (Langrock et al., 2002; Whaley, Pinto, & Sigman, 1999). Parents of children with cancer may display more internalising difficulties than parents of healthy children (Dahlquist, Czyzewski, & Jones, 1996; Dockerty, Williams, McGee, & Skegg, 2000; Hoekstra-Weebers, Jaspers, Kamps, &

Klip, 1999), which in turn may leave children with cancer more vulnerable to internalising difficulties.

Accordingly, how a child copes with his/her illness depends strongly on the family environments. Cohesion, expressiveness and conflict seem to be critical factors for the adjustment of the whole family to the children dramatic situation (Hammen, Brennan, & Shih, 2004; Drotar, 1997; Varni, Katz, Colgrove, & Dolgin, 1996). However, children in a positive family environment (e.g. high expressiveness and cohesion, and low conflict) are more likely to adjust well. For a child with cancer, cohesive and expressive families may be more capable of ensuring the adjustment of each family member, and thereby buffer parent and child distress. Varni and colleagues (1996) examined aspects of family environment related to child adjustment and found that in families with a child newly diagnosed with cancer, cohesion and expressiveness were associated with fewer child internalising problems. Unfortunately, greater conflict and lower cohesion and expressiveness have been found in families of children with a chronic illness, as well as in families with a distressed parent (Eiser, 1990; Kashdan et al., 2004). In families with low cohesion and high conflict, for example, a father's distress can also exacerbate problems within the family and increase the likelihood that children will be distressed (Phipps, Dunavant, Lensing, & Rai, 2005). Moreover, the diagnosis and treatment of cancer may disrupt the family environment (McGrath, 2001), possibly leaving children vulnerable to internalising problems.

In other words, high family cohesion may serve to protect children who have a distressed parent (Hammen et al., 2004). In these families, children may receive support from well-adjusted family members, rather than the distressed parent (Robinson, Gerhardt, Vannatta, Noll, 2007).

To describe families adapting to stressful life experiences, including chronic illnesses Patterson (1988) developed a theoretical model, the FAAR model, where individual and family outcomes are conceptualized as the result of a process whereby a family balances their demands (cumulative stressors and strains coming from individual, family and community sources) with family capabilities, which include resources (from individual, family and community sources) and coping behaviors. This balance of capabilities to demands is influenced by the interpretations and meanings the family gives to their circumstances. These meanings can focus on the demands or resources a family is experiencing, as well as their worldview or perspective.

It is important to understand the relative balance between perceived positive and negative aspects of the parental cancer experience. That might help explain how variability in family responses potentially affects how the child copes to her/his own situation and the quality of life of childhood cancer survivors.

4.2.1 K-Alga for parents and K-ALGA for children

Understanding family members' interpretation and meaning of the situation and their worldview and perspective, together with coping behaviors, resources and emotional reaction (Luce, 2005) is a crucial step to tailor family-professionals interaction with the final goal of empowering both the family and the ill child.

As we saw, children whose parents were distressed were more likely to be distressed themselves. Subgroups of children may be particularly vulnerable, indicating a need to identify further mechanisms of risk and resilience and to develop family-based interventions.

For this purpose, a questionnaire dedicated to parents will be created to measure the aforementioned aspects (K-ALGA for parents). The questionnaire will provide a profile of both parents that will help physicians to efficiently interact with them and eventually, if

appropriate, suggest to them some educational training in order to limit their child's distress and enhance his/her empowerment and coping behavior.

On the other hand, a questionnaire dedicated to children and adolescents will be created (K-ALGA for children), to understand how the child is dealing and coping with the situation. A projective task will be used that requires a child to tell stories about standardised drawings. Interpretation is based on the notion that when a child is presented with an ambiguous drawing, he or she will project his or her own concerns, thoughts, conflicts, and ways of coping into the stories. This projective task permits the evaluation of a child's feelings that is less susceptible to social desirability and defensive strategies.

A comparison between the Roberts Apperception Test for Children (RATC, McArthur & Roberts, 1982) and the Blacky Picture Test (Blum, 1950; Blum, Hunt, 1952) is under evaluation in order to select the most reliable for children with cancer.

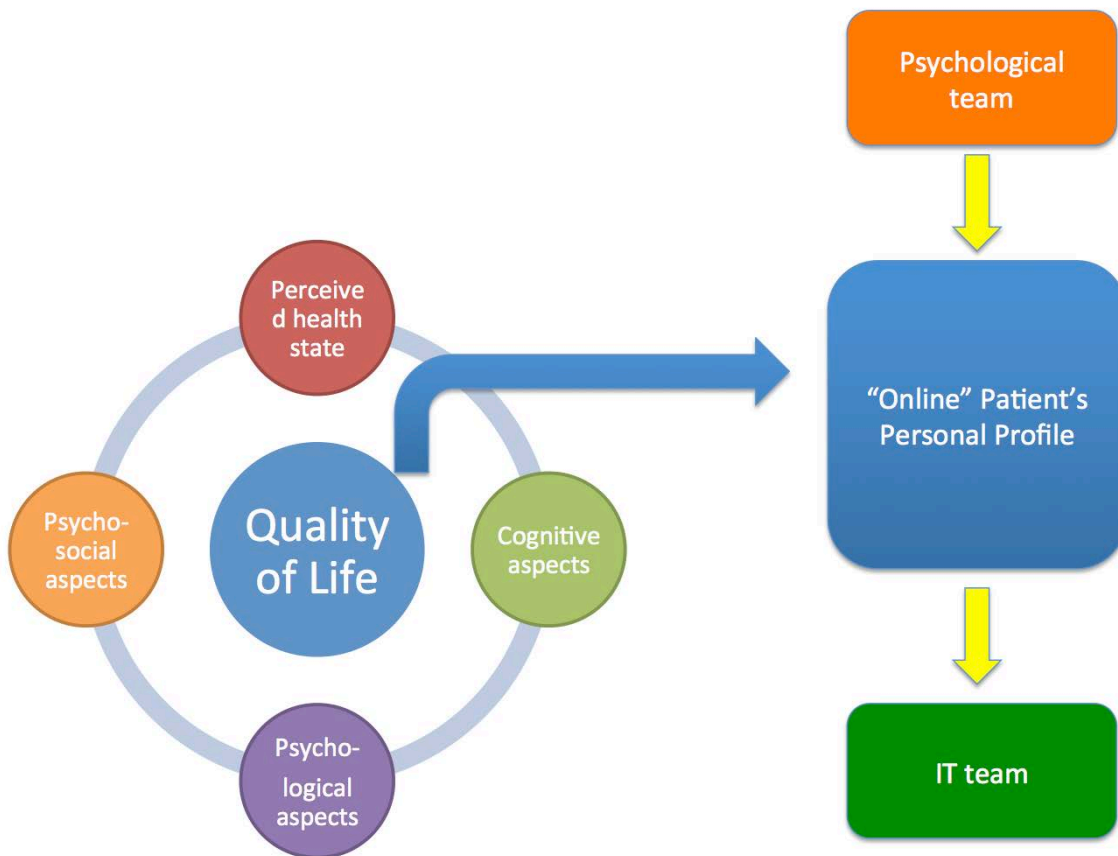
The questionnaires will be administered to children from 6 to 18 years old and their family. The validation will be on healthy families.

5 Conclusion and next steps

The deliverable addresses the context of patients' information needs within p-medicine's overall goals. It reviews key literature sources, and describes investigations, mostly questionnaire derived, carried out by ecaner within the last 15 months. The data accumulated will inform the next stages of work within the Patient Empowerment part of the project, WP14, and within WP13 dealing with Clinical Decision Support Tools.

5.1. Next Steps

This diagram represents how a patient's individual profile will feed into their record, with interpretation and translation from the psychological team to produce an output. This output will be used by the IT team to categorise patient's needs, allowing for information to be displayed in a way that suits the individual.



The following steps will be progressed over the coming months:

- Test the PHR system within IEO
 - For this to happen ethical approval must be gained
- Validate the visual display of results on doctors
- Create and validate K-ALGA questionnaires
- Develop rules framework for patient information display
- Develop informed consent management rules

5.1.1 For the IT-Team

- Patients will answer the questionnaire using an iPad half an hour before the encounter with the physician
- The output should be a summary (both graphical and text-based) representing the Patient Personal Profile and based on the 4 areas investigated by the questionnaire
- Physicians need to have it when they see the patient with guidance over communication style and the information needs of the individual patient

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Appendix 1 - Abbreviations and acronyms

SOA Service Oriented Architecture

AP Abdominoperineal

IRIDE Interdisciplinary research centre on the decision making process