Assessing the organizational needs of cancer patient groups in Croatia and Romania
“Better together”: Dragonboat races have become popular events to raise awareness and funds for breast cancer associations. Paddling helps breast cancer survivors manage their post-treatment, improves their quality of life and increases their chances of survival. The races organized by ESCA and others are a chance for people to bond and realize the benefits and enjoyment of working together, and for corporations and communities to get involved in the fight against cancer.

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BETTER TOGETHER

Assessing the Organizational Needs of Cancer Patient Groups in Croatia and Romania

Michael Hathorn, MSc, consultant to the UICC
Silvia Perel-Levin, MSc, head, health-care coordination department, UICC
For further information, or to obtain copies of this report, please contact:
International Union Against Cancer (UICC)
62 route de Frontenex
1207 Geneva
Switzerland
Tel. +41 22 809 1811 or fax +41 22 809 1810
Email: info@uicc.org
www.uicc.org

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EXECUTIVE SUMMARY

Receiving a cancer diagnosis changes the life of an individual dramatically. Even in the most supportive environment, it brings fear and uncertainty. The illness affects not only the cancer patients, but also their family, partners and friends. It brings physical and emotional challenges, as well as financial implications.

Effective patient groups address many of the patient's needs by providing services such as emotional support and information. Their community services and targeted messages often reach vulnerable individuals. In many countries, their advocacy efforts have improved access to quality information, care and services, thereby improving the quality of life of cancer patients and their families.

To support the effective development and sustainability of patient groups, particularly in resource-constrained countries, the International Union against Cancer (UICC) conducted a pilot project involving select patient groups in Romania and Croatia. This study was designed to produce a qualitative analysis of the organizational development opportunities for four existing patient groups by assessing their current capacity and needs. The four main objectives of this pilot project were:

1. Review the mission and objectives of selected patient groups in two countries in South-Eastern Europe;
2. Assess their capacity to fulfil their mission, enhance patient support and engage in advocacy efforts;
3. Identify the needs of patients and families in the communities they serve, in order to evaluate which services would contribute the most, taking into account the resource constraints of each patient group; and
4. Develop a series of recommendations to increase the capacity of the patient groups, specifying actions and required resources.

Following the meeting of a variety of patient groups and stakeholders during a first visit to each country, four patient groups were chosen to participate in the pilot study. A combination of field visits, direct observation, guided discussions and semi-structured interviews provided a strong basis for analysing the capabilities of the patient groups selected, taking into consideration the social and health-care contexts within which the groups operate.

A series of general recommendations are provided that apply to the four groups in the study in seven main areas:

1. Mission and governance
2. Services delivery
3. Managing and developing a volunteer organization
4. Partnerships and stakeholder development
5. Financial management and fundraising
6. Media and promotion
7. Educational and information resources

In addition to the general recommendations, specific recommendations are provided to each group individually. Capacity building requires skill building and the necessary resources to achieve the group’s objectives, and this study undertakes to provide some initial direction to each of the participating patient groups.

The field observation and qualitative methodology employed by this pilot project provide an approach that could be used to conduct further assessments and support capacity building efforts for patient groups in South-Eastern Europe and other regions.
1. INTRODUCTION

To support the effective development and sustainability of patient groups, particularly in resource-constrained countries, the International Union against Cancer (UICC) conducted a pilot project involving select patient groups in Romania and Croatia. This study was designed to produce a qualitative analysis of the organizational development opportunities for four existing patient groups by assessing their current capacity and needs.

Receiving a cancer diagnosis changes the life of an individual dramatically. Even in the most supportive environment, it brings fear and uncertainty. The illness affects not only the cancer patients, but also their family, partners and friends. It brings physical and emotional challenges, as well as financial implications. Effective patient groups address many of the patient’s needs by providing services such as emotional support and information. Their community services and targeted messages often reach vulnerable individuals. In many countries, their advocacy efforts have improved access to quality information, care and services, thereby improving the quality of life of cancer patients and their families.

In the developed world, patient groups are generally well established and are an integral part of the healthcare community. In resource-constrained countries, however, patient groups are still in development and do not yet enjoy the same level of recognition. If current trends continue, an increasing number of new cancers will occur in the developing world. Building the capacity and effectiveness of patient groups is therefore increasingly becoming a priority in the fight against cancer in developing countries.

In countries struggling with limited resources available for health care, civil society organizations can be a welcome source of information and physical and psychological support for cancer patients who may receive minimal care within the government framework. This study chose to focus on patient groups, a component of the cancer care community that will likely become increasingly important in meeting the needs of cancer patients and their families in developing economies such as Romania and Croatia.

The field observation and qualitative methodology employed by this pilot project provide an approach that could be used to conduct further assessments and support capacity building efforts for patient groups in South-Eastern Europe and other regions.

General recommendations are made in section 4.3.4 that apply to all four patient groups, while tailored capacity-building recommendations are included at the end of each group’s section. Capacity building requires skill building and the necessary resources to achieve the group’s objectives, and this study undertakes to provide some initial direction to each of the participating patient groups.
Health-care economics – some background information

According to the World Health Organization (WHO), government spending on health care has an impact on the level and quality of services that a country offers. In Western Europe, the most recent statistics available from WHO show that the percentage of a country’s gross domestic product (GDP) spent on health care ranged from a low of 7.9% in Greece to a high of 11.5% in Switzerland.\(^1\) By comparison, in 2005 Romania spent 5.1% of GDP on health for its population of over 21 million people, resulting in a US$433 per capita investment.\(^2\) Similarly, Croatia spent 7.7% of GDP on health care in 2005 for its population of 4.5 million, which translates as 14.1% of total government expenditures.\(^3\) This equates to US$917 per capita spending in Croatia, which is double the per capita rate in Romania, yet still significantly below average Western European levels. By contrast, in 2004 Switzerland spent US$4,011 per capita on health care and Greece US$2,179.\(^4\)

Clearly, government investment in health care is to some extent a function of the GDP or wealth of a country. For example, according to the statistics above, if Romania were to achieve Greek levels of per capita spending, it would have to increase its spending by a factor of five. This would consume over 20% of the GDP. The longer-term solution is for Romania to increase its GDP so that health expenditures rise in line with its new prosperity. Unfortunately, this longer-term solution does not address the needs of cancer sufferers in the near and medium term.
2. PILOT PROJECT OBJECTIVES AND METHODOLOGY

2.1. Pilot project objectives

The four main objectives of this project are to:

- Review the mission and objectives of the selected patient groups in two countries in South-Eastern Europe;
- Assess their capacity to fulfil their mission, enhance patient support and engage in advocacy efforts;
- Identify the needs of patients and families in the communities they serve, in order to evaluate which services would contribute the most, taking into account the resource constraints of each patient group; and
- Develop a series of recommendations to increase the capacity of the patient groups, specifying actions and required resources.

These objectives can be achieved by assessing and understanding each patient group within the context of the larger social and health-care environment in which they operate.

Additional objectives include:
(1) field testing a methodology for conducting this type of analysis in other countries; and
(2) developing a questionnaire that may be useful for conducting this type of study in other countries. Although beyond the scope of this pilot project, it is also anticipated that information gathered in the course of this study could be used in the development of support materials, such as patient group handbooks or field manuals.

2.2. Pilot project methodology

This pilot project was undertaken in three phases: preparation, field data collection, and analysis and recommendations.

Phase I – Preparation

During this phase, an advisory group was established to provide input on the pilot project planning. The group developed a questionnaire (see appendix) for use in the field. The researchers then conducted a thorough search to identify cancer patient groups in each country and make initial contact with representatives of each group to gauge their interest in participating in the study.

Jeff Dunn, UICC’s strategic leader for capacity building, provided valuable input for the construction of the questionnaire used in this study.

Phase II – Field data collection

The field data collection phase consisted of two trips to each country, with the first visit dedicated to meeting with a wide variety of patient groups and visiting health-care institutions and other organizations with an interest in cancer. During the course of the four country visits, representatives from ten organizations in Romania and 15 organizations in Croatia were interviewed (see appendix). Additional interviews with members of the patient organizations, hospital medical staff and other individuals were also conducted during each country visit, resulting in over 50 people providing data for the pilot study.

In the second country visit, the approach was to gather data from representatives of the four patient groups and some of their key stakeholders by direct observation and guided discussions. This visit also involved the collection of specific information on each group, using the questionnaire developed for this pilot project. Jeff Dunn, UICC’s strategic leader for capacity building, provided valuable input for the construction of the questionnaire used in this study.
Phase III – Analysis and recommendations

This third phase focused on analysing the qualitative data gathered during the field visits and developing recommendations for the four patient groups. The advisory group met for a second time to review the proposed analysis framework and develop a structure for the final report. In addition, an overview of the field research findings was presented.

Overall methodology

In terms of overall methodology, the combination of field visits, direct observation, guided discussions and semi-structured interviews provided a strong basis for analysing the patient groups’ capabilities and making recommendations to improve their capacity. While originally only one field trip had been planned, two field visits to each country proved to be necessary in order to: a) help choose which groups would be analysed further, based on initial discussions; and b) build trust and improve communication with the participating groups.

The field trips were necessary to develop an in-depth understanding of the individual contributors’ perceptions, and to corroborate these perceptions through direct observation. The researchers were able to combine the comments and perceptions gathered and follow up on the emerging themes in subsequent meetings.

The analytical approach adopted throughout this pilot study was qualitative rather than quantitative: the themes and conclusions were drawn from the combination of information gathered through interviews and through direct observation.

2.3. Patient groups selected for the pilot study

As a result of the initial visit to each country, four patient groups were chosen to participate in the pilot study. The key criteria used to select the patient groups were the following:

- An interest and willingness to participate in the study;
- A relatively stable group with a track record of operation;
- A patient group that may benefit from the recommendations.

The four patient groups that best met the criteria above were chosen and agreed to participate in the pilot study:

In Romania
1. Asociatia Bolnavilor de Cancer (ABC) Brasov
2. Amazonia

In Croatia
1. Europa Donna Hrvatska
2. Reach to Recovery

Three of the four patient groups chosen focus on breast cancer, but this was incidental as the group selection was based on the stated criteria.

For each of these patient groups, an in-depth semi-structured interview was conducted with group representatives to determine their level of functioning and identify opportunities for improving the group’s capacity.

The analysis framework laid out in the next section is designed to assess what major social and health-care aspects of the country’s environment have an impact on the patient group, and to conduct an investigation of each group’s capacity.
3. ANALYSIS FRAMEWORK

The analysis framework recognizes that patients and their families are the primary recipients of the patient group services. Patient groups exist within a larger social and health-care context and are influenced by the nature of these elements. In turn, patient groups may also exert influence on the health-care and social spheres through a network of stakeholders and by their actions and programmes.

To understand the opportunities for the patient group to increase its capabilities, this study undertakes to:

1. Understand the social and health-care contexts in which it operates
2. Identify the current structure and capacity of the patient group
3. Identify the strengths and weaknesses of the patient group
4. Make recommendations based on an analysis of the above

In short, the analytical framework considers the following three elements:

1. Social context
2. Health-care context
3. Patient group themes (common)

These three elements are used to highlight the country-level findings that provide the context for the patient groups, and to highlight common patient group findings identified through the research.

Common themes for the two countries (Romania and Croatia) are identified in section 4 and followed by an identification of common themes across the four patient groups. This provides the basis for a deeper, more focused analysis on each of the patient groups in sections 5 and 6.

The analysis for each patient group takes the social and health-care contexts into account and focuses on the following areas:

1. Organizational capacity assessment
   Each patient group is analysed in terms of its mission and governance structure, services, management, key stakeholders and financial capability, taking into account at least the following criteria:
   • Mission and governance
   • Services delivery
   • Managing and developing a volunteer organization
   • Partnerships and stakeholder development
   • Financial management and fundraising
   • Media and promotion
   • Educational and information resources

2. SWOT (Strength, Weakness, Opportunity and Threat) analysis
   The SWOT approach is designed to situate the patient group within the context of its environment, in order to identify strategic and tactical opportunities that exist from improving performance, while minimizing the impact of organizational weaknesses and environmental threats:
   • Analysis of the patient group’s strengths and weaknesses
   • Identification of the opportunities and threats that exist in the external environment
   • Matching of organizational and environmental profiles to determine options for action and recommendations

3. Recommendations
   The recommendations derive from the SWOT analysis and explore at least the following three areas:
   • Building strengths
   • Addressing weaknesses
   • Establishing new capacity
4. COUNTRY-LEVEL AND OVERALL PATIENT GROUP FINDINGS

4.1 Social context themes

The prevailing belief among patients, family members, volunteer workers and medical professionals interviewed for this study was that cancer is a low social priority and that cancer patients live under the stigma that they suffer from an incurable disease. The respondents perceived that employers are reluctant to retain staff who have been diagnosed with cancer, and that their families are reticent to discuss the topic of cancer and the challenges they face in dealing with an afflicted family member. Patients interviewed often described a sense of “shame” and “hopelessness”. Attention also focused on the perceived lack of accurate information on cancer available to the public and cancer patients. This was identified as a barrier to progress in overcoming the prevalent social stigma.

The study participants maintained that cancer care was a low social priority and that greater investment in modern cancer care equipment and facilities was needed. They also perceived that the government did not invest enough in social awareness programmes on cancer. The public cancer facilities visited during the course of the study appeared to require significant investment in infrastructure and equipment, while the few private clinics visited were of a higher standard. Regarding public awareness, the respondents pointed out that most activities in this area are undertaken by local NGOs or cancer organizations with limited budgets.

In sum, in both countries the study respondents maintained that there was a lack of public understanding of cancer and of the support required by cancer patients and their family members. It was widely perceived that the psychological impact of a cancer diagnosis on both patients and family members was poorly understood and badly supported by the medical profession and existing social services. In their interviews, the medical doctors working in the cancer field agreed that members of their specialty are under tremendous pressure to see many patients, and do not have the time – or often an understanding of the psychosocial aspects of the disease – to provide effective counselling or an appropriate context for the proposed treatment.

Palliative care was another area of great concern identified in the interviews. Medical professionals and patients pointed out that it is only recently, and reluctantly, that some doctors are beginning to prescribe opiates to address the chronic pain of terminally ill patients. During a hospice visit in Romania, the researcher engaged in a lengthy discussion with a medical professional who had lobbied extensively for the use of opiates as an acceptable medical practice for the chronic pain relief of terminally ill patients. The doctor considered that the main challenge was the mindset of medical practitioners, the majority of whom were very reluctant to prescribe opiates for pain relief.

Basic social services – including information resources, legal support and adequate financial support for those unable to work – were considered underdeveloped by our study participants. They also suggested that civil society groups do not often engage in strong advocacy efforts to defend or protect the rights of their segments of society. There was one notable exception recently in Bucharest: the ministry of health had removed cancer as a medical specialty area, and coincidentally there was a severe shortage of...
cancer drugs available in the country. In response, a street protest was organized in May 2007 by a coalition of cancer patient groups comprising the Federation of Cancer Patients Association to demand respect for their rights and restore cancer as a medical specialty. This protest drew extensive media attention, including international coverage: in the UK’s The Independent newspaper, journalist Jeremy Laurance suggested that the Romanian ministry of health had “eliminated medical oncology as a separate specialty, slashing at a stroke one of the high-cost areas of medicine, on the grounds that cancer patients are not economically productive.”

In the face of internal protest and extensive national and international media coverage, the ministry of health reversed its position and retained medical oncology as a specialty area. The ministry also agreed to engage in dialogue with representatives of the patient group federation on government cancer policy, and to review their demands. The protest had only involved about 100 participants but succeeded in gaining media attention, raising public awareness and forcing a dialogue with the government.

An important service that patient groups claim to provide to their members is to help them navigate the bureaucratic health-care system and gain access to proper treatments and follow-up. A complicating factor cited on a number of occasions during the interviews is the long-standing social practice of patients rewarding doctors with an extra gift for their treatment. Historically, rural patients provided an in-kind payment of crops or livestock. According to our interviews, the current practice is that patients are expected to reward their doctors with small standard payments for performing various services. This was perceived as a barrier for patients lacking the means to pay.

The entry of Romania into the European Union (EU) places certain obligations on Romania with respect to the rights of cancer patients, and Croatia is coming under pressure as they make their case for entry into the EU. The European Cancer Patient Coalition (ECPC) was established in 1993 to represent all cancer patient groups in Europe and has a membership numbering over 250 patient organizations for all types of cancer. Several of the group members we interviewed had attended ECPC events and found them beneficial. European lobby groups such as Members of Parliament against Cancer (MAC) focus on helping EU citizens and patients in their fight against cancer. Additionally, the EU has clear legislation on patient rights. This gives the patient groups a number of allies and an advocacy platform that they have yet to fully exploit. Throughout the course of this study, the researchers observed that most patient groups preferred to act independently and did not actively seek opportunities to join forces with other patient groups in their country to achieve common objectives.

Another theme that emerged during the interviews was the difficulty in navigating the bureaucracy of the health-care system. Respondents reported that bureaucratic procedures to obtain certain health-care benefits were sometimes unclear and that government responses were often slow or inadequate. Examples cited by respondents included the provision of prosthetic devices, qualifying for disability insurance, and obtaining clear information on government programmes. They also expressed low confidence in the speed of health-care reform, citing bureaucracy as a barrier.

The four groups in this study all reported that they provided some form of assistance to members and cancer patients in navigating the bureaucracy and challenges of the health-care system in their home country.

Given the social context, patient groups have a significant opportunity to drive change in
the two countries studied, but will likely succeed in raising public awareness, influencing public policy and providing key social services only if they combine their resources and work together.

To summarize, the field research uncovered six common social themes prevalent in both Romania and Croatia, as follows:

- Social context themes
- Low priority of cancer as a societal issue
- High social stigma for cancer patients
- Low public awareness of key cancer issues, and support required
- Underdeveloped social services for those handicapped by cancer
- Lack of strong advocacy efforts by civil society
- Highly bureaucratic and slow governmental response

### 4.2 Health-care themes

One of the most obvious and prominent health-care themes in Romania and Croatia is the current state of the health-care infrastructure in both countries, reflecting a legacy of underinvestment in modern health-care facilities, equipment and data gathering. The overall health-care statistics referred to in the introduction of this report provide a context for the magnitude of this issue.

A glaring deficiency in the health-care system reported by respondents in both countries is the lack of an effective cancer registry. Without accurate statistical data, it is impossible to develop a focused national cancer plan and allocate resources according to current and projected needs. In both countries, legislation mandates cancer reporting, but in practice the systems are deficient. In Romania for instance, cancer reporting has been compulsory since 1980, yet the actual process and categories of cancer registries are not properly defined.

In effect, it is difficult for either country to assess the true burden of cancer on their societies. This makes it difficult to develop a national cancer strategy to allocate limited resources based on accurate data.

The field visits carried out during this project confirmed that the cancer treatment facilities in both countries were in need of significant investment to increase the number of beds, the quality and quantity of the medical equipment for chemotherapy and radiology, and the number of qualified medical staff providing treatment and attending to the patients. All the cancer wards we visited were characterized by doctors and patients as crowded, and the emphasis was on limited stay and rotation of beds for new patients. The equipment and techniques used to diagnose and grade tumours were reported to be often substandard. This impacts the next stages of treatment, including the correct formulation of radiation and chemotherapy treatments. In one unit visited, a doctor reported that three of the four radiology machines were not functioning properly, and claimed this was a common occurrence. In another unit, hospital staff showed us an older cobalt machine, which was operating at maximum capacity.

Given this context, there is a relentless focus on efficiency. The norm reported by those interviewed was for doctors to see 40 or 50 patients a day, spending less than ten minutes with each patient. The doctor-patient relationship was often cited as difficult, with doctors unwilling and unable to take time to discuss the diagnosis, treatment and expected outcomes. Patients were simply informed of their diagnosis, provided a prescription for required medicines and told that they would be scheduled for surgery, radiation therapy, chemotherapy, or some combination of treatments. Usually, surgical procedures could be scheduled with little or no delay, and interviewees confirmed that there were minor and predictable delays for radiology and chemotherapy treatment.

Another challenge reported by patients and doctors was for patients to acquire the prescribed medication. At the time of our field visit in Romania, the cancer drug supply at the institute we visited had been depleted, and an auction was taking place with the major suppliers to obtain fresh supplies. Interviews confirmed that this was not unusual. There was also concern expressed that some of the latest treatments had not been “approved”, so were not available under the government health plan, yet could be purchased privately. A similar situation was reported in Croatia, but is better characterized as shortages of specific drugs rather than a wholesale lack of cancer drugs.

Health professionals operating in the public sector described above are poorly paid compared to their counterparts in Western Europe. The field interviews revealed that medical professionals often worked several jobs, including a private practice, to compensate for low pay in the government system. Also, the social practice of doctors receiving additional payments for services performed in the state institutions was partially justified by some doctors interviewed as providing much needed additional income. This practice was also attributed to nursing staff, and further increased the costs for patients in hospital. The negative effect of this is that service priority
that they were actually doing and each group’s insistence to cooperate with each other, Romania was their unwillingness. Interviews with patient groups in recognizing their value. With the majority of doctors not from only a handful of doctors, received most of their referrals revealed that the patient groups only intermittently use the facility. Interviews with patient groups only intermittently use the facility. Interviews revealed that the patient groups received most of their referrals from only a handful of doctors, with the majority of doctors not recognizing their value.

A consistent theme of the interviews with patient groups in Romania was their unwillingness to cooperate with each other, and each group’s insistence that they were actually doing something valuable, while the other groups were merely talking and not delivering. Several interviewees attributed this rivalry at least in part to their competition for limited funds and to personality clashes between the various group leaders. As mentioned earlier, the Federation of Cancer Patient Associations in Romania was able to successfully challenge government policy in May 2007 and gained a seat at the government table to make their demands known. There are other examples where the Romanian groups came together for a specific event, but they do not consistently work together on a common agenda. The researchers noted that patient group ABC Brasov has taken the lead in trying to bolster the Romanian Federation, but has so far met with limited success. The Romanian Cancer Society located in Cluj has also worked closely with ABC Brasov to engage the Federation of Cancer Patient Associations in a common effort, with limited success. On several occasions, respondents declared that “the federation” existed only on paper and was not a viable entity.

In Croatia, the rivalry amongst patient groups was reported as less visible and acrimonious, but a similar degree of non-cooperation is present: each group places emphasis on its own objectives, neglecting the larger objective of cancer control and advocacy in the country. Again, however, there are examples of cooperation, such as the advocacy work undertaken jointly by the Senologic Society and Europa Donna to support the development of a national cancer screening programme for breast cancer.

The Croatian League Against Cancer was also active in the advocacy work to support the national cancer screening programme for breast cancer. The League Against Cancer is an example of a Croatian cancer organization that maintains an inclusive approach to cancer groups, offering membership to all types of cancer organizations and producing information materials for general distribution. The League Against Cancer also hosts public events that Croatian cancer groups are invited to participate in.

The main reported health-care themes common to Romania and Croatia are summarised as follows:

- Underinvestment in health care:
  - Cancer registries nonexistent or ineffective
  - Ageing infrastructure
  - Limited number of hospital beds
  - Older equipment for diagnosis and treatment
- Focus on efficiency rather than effectiveness
- Health-care professionals underpaid
- Little guidance provided by medical professionals to patients on how to cope with the emotional aspects of their diagnosis, and few referrals to patient groups
- Underdeveloped support structures for cancer patients
- High rivalry and low willingness to cooperate among the various patient groups

4.3. Patient group common themes
In this section, the focus is on identifying common themes across the four patient groups, using the groups’ responses to the questionnaires and other information gathered during the field visits. Based on this analysis, a common set of recommendations is made that applies to all four patient groups.
4.3.1. Profile

Three of the four patient groups chosen have international affiliations with parent groups that provide structure, process and information to their affiliates. For instance, the written statement of purpose or mission of each of these groups derives from their international affiliate. The fourth group, ABC Brasov, does not have an international parent affiliation but actively promotes the European Charter of Patient Rights Declaration and has links with the European Coalition of Cancer Patients (ECPC) and the Members of European Parliament Against Cancer (MAC), among others.

Although each group has a written statement of purpose, it was not always clear how the group translated this purpose into short- and medium-term actions. The general impression is that the groups operate in an opportunistic manner rather than tightly focusing on their mission.

A common challenge identified by each group is operating with a staff working on a primarily volunteer basis, typically drawn from the group’s membership. Staff availability varies, and is restricted to after normal business hours for those who work. The tough economic environment forces many to work several jobs and further reduces the potential pool of capable volunteers. The membership composition for the four groups was reported as over 90% cancer survivors, with family members comprising the majority of the remaining 10%. In each case, the researchers question how effective the patient groups are in identifying, communicating with and engaging their membership in patient group activity. The apparent tendency is for each group to have a “loose” definition of membership and thereby claim larger memberships than they actively serve. While all four groups claim to make use of computers to manage their membership, we observed a heavy reliance on paper files and focused lists of the more active members. With respect to communication, three of the four groups have a website yet are communicating with the membership primarily by telephone and mail as the majority of members do not have internet connections or make use of email.

Four groups report continuity of care, peer education and information dissemination as common areas of focus, whereas two groups – ABC Brasov (Romania) and Europa Donna (Croatia) – rate advocacy as an additional high-priority area. The capacity of the four groups to deliver services across these key areas varies considerably and is explored in each group’s detailed analysis later in this report.

When asked what was needed to increase group effectiveness, the four groups identified additional funding, volunteers (staff), and training, but there was little evidence of concrete and systematic plans to acquire the desired resources. With respect to effectiveness, the four groups rated themselves as performing at an average level of 8 on a 10-point scale, with 10 being maximum effectiveness. The belief seemed to be that increased funding was the major driver of effectiveness and that they were performing at a very high level with the level of funding and human resources available. There was little awareness that improvements in group governance, structure and process could be key drivers of effectiveness, nor was effectiveness measured in any systematic way.

The common themes of the four group profiles are summarized in the table below.

Group profile – common themes

- All four patient groups have international affiliations; three have international parent organizations
- All have a written statement of purpose
- The majority of staff are volunteers
- Over 90% of the members are cancer survivors
- All groups focus on improvement of continuity of care, peer education and information

Hospital life, Romania (photographs courtesy Oncologic Romanian Association)
• Two of the four groups identified advocacy as a high-priority (Europa Donna, ABC Brasov)
• Communication with volunteers and members takes place primarily by telephone and mail
• Money, volunteers and training were identified by the patient groups as the top three items to drive increase in effectiveness
• Self-rating of effectiveness was an average of 8 on a 10-point scale

4.3.2. Group organization, services and management

Interviews with representatives of the four groups demonstrated a close link between the services provided by the patient group and the stated mission or purpose of the group. With respect to the services offered, the group representatives assessed member satisfaction as varying from medium to high, yet were unable to articulate clearly what needed to happen to increase the satisfaction and effectiveness of service delivery.

When needed improvements of services were identified, no vision was offered with regards to what steps could be taken to achieve these gains. In this respect, there is a clear lack of management and future planning of service delivery.

The governance structure for each group includes at least one medical professional on the board, and each organization has an elected president. The NGO or national organization status requires a properly constituted board under Romanian and Croatian law, which probably provided an impetus for creation of a board. Given that, it was difficult to ascertain how effectively the board members were being used to further the aim of their respective organizations.

It is important to note that presidents of the organizations tend to serve long terms of at least six years. The organizations are therefore limited in their ability to replace non-performing leaders or to create the interim accountability that goes with an election.

Group organization, services and management – common themes
• Services provided link closely to the mission of the patient group, but consistency and quality of services varies considerably
• Groups self-rated member satisfaction with services as medium to high, with low recognition of possibilities for improvement
• All groups have a president and board of directors, with medical professionals serving on the board

Relationships with beneficiaries

Patient groups can create relationships of mutual benefit, but in the context of this study, only Europa Donna and Amazonia reported providing services to other patient groups. The main support they provide is cancer information and training for patient group members, with Europa Donna Hrvatska providing training to Reach to Recovery members, and Amazonia in Romania providing information and support to ABC Brasov.

Relationships with the general public involve promoting group activities through a website for three of the four groups (all except ABC), and all use brochures and literature to raise awareness of their activities among the general public.
An important channel for communicating with the public is the publicity provided by newspaper, radio and television appearances, where groups are able to discuss the support they provide to cancer patients, other areas of work and upcoming events. These infrequent publicity opportunities are free of charge and can potentially have a high impact on public awareness. Of the four groups, only Amazonia reported that they had not capitalized on this opportunity, but had targeted newspapers for their first publicity efforts. From the interviews, it was clear that the groups are not proactively cultivating relationships with the press with the purpose of identifying opportunities for publicity.

And finally, the four groups keep records of all people who attend their events, and claim to have some mechanisms to keep membership informed of group activities. In most cases, word of mouth is used to update the “active membership” on what is going on, or flyers are prepared for group distribution.

Relationships with beneficiaries – common themes

- Two of the four patient groups – Europa Donna and Amazonia – provide services to other patient groups; the main support provided is information and training.
- Three of the four groups – Europa Donna Hrvatska, Amazonia, and Reach to Recovery Croatia – promote their activities to the public through a website; all four groups are in close contact with health professionals.
- Publicity is limited and involves both local radio and television appearances to discuss work in the cancer field; three of the four groups participate in these forums.
- All groups keep records of people who attend their events, and claim to keep membership informed of group activities.

Patient group financing

The most striking statistic in this area is the breakdown of financing: two patient groups – Reach to Recovery Croatia and Europa Donna – claimed to receive 90% of their financing from the government, while the other two – Amazonia and ABC Brasov – claimed 90% of their funds came from pharmaceutical companies. Of the four patient groups, only Amazonia does not seek government financing through stipends or grants, relying instead on the parent foundation Renastera for the remaining 10% of its needs. Heavy reliance on a single major source of financing is very risky and the groups are well advised to seek multiple sources of funds.

All groups have found membership fees to be an ineffective means of raising funds, as members tend to have little disposable income. For this reason, although three out of the four groups have a nominal membership fee, it is waived if members can’t or won’t pay.

Perhaps the most overlooked source of funding is that of international NGOs in the cancer field who would be interested in supporting local patient groups in their home countries. It was clear during the interviews that fundraising knowledge was limited in the four groups, and that the skills required to go through the application process for international funding were untested.

All groups reported using donated resources such as meeting rooms, photocopying and postage. In addition, companies often sponsor conference attendance for select patient group members.

Patient group financing – common themes

- Government financing through stipends and grants used by three of the four patient groups, with Amazonia the only patient group not using this source of financing.
- Two patient groups – Reach to Recovery Croatia and Europa Donna Hrvatska – rely on the government for 90% of their funding.
- Pharmaceutical companies are important contributors to two patient groups: Amazonia and ABC Brasov claim over 90% of their revenues from this source.
- Membership fees are not significant in the budgets of the four patient groups.
- International funding is not sufficiently explored.
- All groups depend on donors for meeting rooms and administrative resources such as photocopying, postage, etc.
- Conference attendance for various members occasionally sponsored by companies.

4.3.3. Partnerships and networks

All four patient groups in the study need to work on developing partnerships and networks, as to date they have only taken small steps in this area. All the patient group representatives interviewed demonstrated a limited understanding of who their stakeholders were and how they might be leveraged to achieve their group’s objectives. While they all agreed that greater opportunities were available through international institutions and NGOs, none were able to identify specific approaches to capitalize on those opportunities.

There was unanimous recognition that health-care professionals were important stakeholders, yet interviewees
were unable to identify specific ways to strengthen relationships with those who were supportive of the group, and to seek out new relationships with those yet to be involved. Doctor referral to the patient groups adds credibility and is important to bring services to the widest audience possible.

One of the most powerful stakeholders for these groups is the ministry of health. The two Romanian patient groups, Amazonia and ABC Brasov, systematically focused on building relationships with members of the ministry of health and lobbying for their cause. Three of the four patient groups recognized that the local government was an important stakeholder.

In Croatia, the Europa Donna patient group partnered with the Croatian Senologic Society and successfully lobbied the government for national screening guidelines for breast cancer involving breast cancer mobile screening units. In this case, the president of the Croatian Senologic Society was a member of the Europa Donna board, and the partnership of these two organizations had a significant impact on national policy.

**Partnerships and networks – common themes**

- Concept of stakeholders not well understood and all groups gave a limited list of partners until prompted.
- All underutilize their links with international institutions and NGOs.
- Each group identified health-care professionals as key stakeholders, but there was little understanding of how to develop these relationships further, with main barriers being time availability and professionals’ attitude towards the groups.
- Doctor referrals to the patient groups are not an established practice, except for a small group of doctors.
- Three of the four patient groups – Europa Donna, Amazonia and ABC Brasov — focus on relationships with the ministry of health, attempting to make their views known and influence policy.
4.3.4. General recommendations for building capacity

The main challenge for the four groups is to build skills and capacity in the key areas required to develop their patient organization and its ability to meet the main objectives. In the recommendations listed below, seven areas are identified for skill building and development. Each of the four groups needs to gain a greater understanding of what it takes to succeed in each area and apply that in practical terms to their own unique organization and situation.

The overall recommendation for the four groups is that they each link closely with international/national affiliates or “centres of excellence” for guidance, skill development and training on the seven areas identified below:

1. Mission and governance
   Focus on effective governance practices, with greater frequency of elections to key positions and accountability for achieving the organization’s objectives.

2. Services delivery
   Develop a clear and focused service delivery approach that addresses the highest priority needs of the group membership.

3. Managing and developing a volunteer organization
   Build skills for managing a volunteer organization. Make better use of information technology to manage membership, volunteer and stakeholder contacts – currently all are over-reliant on a paper-based system.

4. Partnerships and stakeholder development
   Engage in partnerships with similar cancer and health organizations to leverage collective resources in areas such as advocacy and events. Build networks in the healthcare profession as well as in government, media and support organizations.

5. Financial management and fundraising
   Develop alternative sources of funding and support – both local and international – with a focus on funding carefully defined initiatives.

6. Media and promotion
   Find opportunities to reach cancer patients and potential group members. Cultivate media contacts and proactively seek publicity opportunities. Join forces with related organizations to stage events that will draw media coverage.

7. Educational and information resources
   Link with existing high quality educational and information resources to support the patient groups and provide members with targeted information.
SELECTED PATIENT GROUP ANALYSIS
5. ROMANIA PATIENT GROUPS ANALYSIS

5.1. Asociatia Bolnavilor de Cancer (ABC) Brasov

Background

ABC Brasov was founded as a national organization with NGO status in 2001. Its stated purpose is to establish and support a Romanian network of independent and locally operated ABC patient groups. The four main goals that the group prioritized and committed to in 2007 were:

- Advocacy for cancer patients at the national level;
- Peer education and patient information;
- Improvement in the continuity of care, including emotional support;
- Offering services and knowledge-based training to other patient groups.

The leadership of ABC Brasov claimed a high degree of effectiveness in reaching the above goals and reported high levels of satisfaction from the cancer patients participating in the programmes. The main requirements identified during the interviews to increase effectiveness of the organization were 1) increased training for all ABC groups, 2) additional funding to hire staff and 3) funding support from state institutions.

ABC Brasov is a founding member of the Federation of Cancer Patient Associations in Romania. The group confirmed other reports that the federation exists more as a concept than as an effective advocacy group.

The ABC organization claims to have 1,200 members in Brasov, including patients and volunteers, and 2,500 members in the ABC branches across Romania. The volunteer membership also includes ten students from the local university’s social work, law and medical programmes, as well as a qualified lawyer who advises on issues of Romanian law regarding cancer patients.

With respect to activities and accomplishments, ABC Brasov published a 2006 list of activities it participated in – these included organizing a joint theatre event with the P.A.V.E.L. cancer patient association to raise public awareness; scheduling regular group meetings and individual meetings with patients; arranging patient group field trips, and arts and crafts workshops during the Easter period; recruiting student volunteers from the university; and organizing a booth at ROMEXPO health fair in Bucharest where information was distributed to over 3,000 people. There was no information available on the quantity of services provided in terms of number and attendance of patient group meetings in 2006.

Regarding patient group meetings in 2007, ABC Brasov reported that it held meetings four times a week. Attendance ranged from 12 to 20 patients per meeting, and meetings addressed a wide variety of topics, including relevant Romanian legislation, new treatments available, music and art therapy, nutrition, and guided relaxation techniques.

5.1.1 Organizational capacity assessment

Mission and governance

Representatives of ABC Brasov defined their organizational mission as the establishment and support of independent ABC patient groups throughout Romania. The main forms of support were defined as assistance in starting meetings, provision of high quality literature, and leading advocacy efforts for the patient groups. In a period of six years, they have built a reported base of approximately 3,700 members.
The board structure was reported as consisting of the president, three cancer survivors from different cities drawn from the membership, a volunteer and a financial expert. All board positions are elected every two years at the ABC’s general meeting. This election cycle supports a high level of accountability for board members.

The board has an annual scheduled meeting where it reviews the annual activity report and financial report to account for its annual revenues and expenditures of a reported €15,000. According to the information gathered, there were no medical professionals serving on the board in 2006. Medical professionals are rated by ABC Brasov as one of the most important group of stakeholders. We recommend expanding the board structure to include at least two posts for these professionals: one from the medical field and one from social work.

Services delivery

ABC Brasov described the main services that it provides as: 1) cancer patient group meetings, individual meetings and group activities; and 2) lobbying and advocacy efforts at the national and local levels.

With respect to group meetings, ABC Brasov reported that there is a high demand, but that members’ satisfaction level suffers because the organization is constrained in the number and type of meetings it can provide given current resources. The leadership indicated that more space was needed to hold additional group meetings, and that the volunteers needed specialized training in psycho-oncology, communication and group facilitation. At present, the group meetings – which take place four times a week in Brasov – are facilitated by one person. This places limitations on opportunities for additional meetings and also affects regular meetings when the facilitator is not available.

We attended an ABC patient group meeting at the facility in Brasov. The discussions during the meeting confirmed the perception that more meetings were needed on a variety of subjects relevant to cancer patients. Group meetings where external speakers were invited to talk about treatment options, nutrition and other topics were reportedly well received by participants, but considered too infrequent. Cancer patients also mentioned that they would like to have more group excursions and special activities with group members.

In addition, several volunteers were interviewed regarding the home and hospital visits they conducted with cancer patients. The common theme that emerged was that they would benefit from training in how best to communicate with and support cancer patients during one-to-one interactions.

ABC Brasov identified training of staff, volunteers and cancer patient members as a critical need to improve their ability to deliver additional services in patient group meetings, group activities and one-to-one meetings with cancer patients. The recommendation is for ABC Brasov to prioritize needs and seek resources to fund the training needed to increase the quality and quantity of its services.

A further recommendation is that the training effort should be restricted to training a small group of highly motivated individuals who could then hold regular training sessions to support groups across the ABC network in Romania. This would build ABC Brasov’s capacity, allowing it to fulfil its future objective of providing regular trainings that would assist the functioning of ABC groups nationwide.

ABC Brasov reported involvement in a number of activities aimed at raising public awareness about cancer and cancer patients:

- Participated in Pink October and provided logistical support;
Hosted a “Cancer Survivor Day” in Brasov and invited all cancer groups to join;

Federation sponsored signature campaign for breast cancer prostheses support by health fund;

Federation collected signatures calling for psychologists and social workers to be assigned to oncology departments;

Organised Cancer United Campaign in July 2006, collecting signatures calling for the European Parliament to support cancer patient rights;

Federation sponsored lung cancer public information and awareness campaign in November 2006.

A major concern expressed in the discussions with ABC Brasov was the lack of knowledge and skills for launching an effective public advocacy campaign. The President of ABC Brasov cited the ECPC as a European organization that provided training in health policy and advocacy, indicating a strong interest in attending this training. Another ABC representative proposed the view that there was no tradition of pushing the government authorities to honour civil rights generally, and that cancer patients were ranked low among health-care priorities.

Developing public advocacy knowledge and skills is an important priority for ABC Brasov. As described in the previous section, a small group of highly motivated individuals should be selected to undertake training in this area. Grants and other means of funding could be sought to cover the cost of building capability in advocacy.

Managing and developing a volunteer organization

The ABC model of gathering independent groups under a national umbrella has reportedly attracted 3,700 members nationwide in a period of just over six years. A critical challenge is how to manage and grow an organization that delivers high-priority services of an acceptable quality level in a consistent manner.

Based on the interviews with patient group members and other stakeholders, our impression is that the prioritization of ABC’s services reflects the patient group membership requirements. However, it was clear from the discussions that the consistency and quality of the services offered could be improved significantly.

Throughout the interviews, the leadership of ABC Brasov consistently identified training and skill development in the service area as key priorities. They did not focus on the need to develop management skills to support the development needs.
of the organization. Also, the leadership did not communicate a clear strategy for expanding the organization and managing the increased demands of new patient groups and their membership.

We recommend that the leadership undertake training in the management and development of volunteer organizations to ensure the organization can meet its commitments.

Partnerships and stakeholder development

With respect to partnerships, ABC Brasov has strong relations with the members of the Federation of Cancer Patient Associations and seeks out opportunities to lobby for patient rights alongside other groups representing cancer and other diseases.

ABC Brasov identified public hospitals, health-care professionals, pharmaceutical companies, international groups and NGOs operating in the field of health care as their main stakeholders. The local university in Brasov was also mentioned as an important stakeholder, providing volunteers from the medical, social work and law schools to assist the organization.

Financial management and fundraising

ABC Brasov reported that pharmaceutical companies contribute 90% of their total annual funds, local governmental organizations, 8%, and donations from NGOs, 2%. The funding profile reported contains some risk should one or more of the larger pharmaceutical donors reduce their contributions. In order to manage this risk, ABC Brasov should develop new sources of funding.

The only additional source of funding reported to be under consideration was the income tax provision that allowed individuals and organizations to direct 2% of their income tax to the NGO of their choice. No clear plan was proposed as to how ABC would try to make use of this opportunity.

We recommend that ABC Brasov focus on increasing NGO donations of funds and in-kind contributions, such as training to address the skill gaps identified in the previous sections. This type of funding often requires the preparation of a targeted programme or project plan that clearly specifies the objectives of the project, how the objectives will be achieved, the benefits that will result and the funding needed. A further recommendation is that the leadership at ABC Brasov identify individuals that have the capability to support them in the preparation of these types of proposals.

Another funding source worth exploring further is in-kind contributions for meeting space. Once the capacity to conduct more group meetings is developed, the main related cost will be a space for hosting them.

Media and promotion

ABC Brasov does not have a website. We recommend that they investigate this cost-effective means of communication: through a website, the organization can provide information on its services, as well as specific resources for the general public, patient groups and patient group members.

Developing a website is a useful exercise as it encourages the organization to present itself in a structured manner. It is also a factor in creating credibility with the international organizations it interacts with.

ABC Brasov reports that they actively pursue publicity opportunities through local radio and newspapers. They send preformatted messages and press releases to the media, hoping to generate enough interest for the messages to be transmitted. This is a cost-effective approach that provides some protection against ABC’s previous experience of being misquoted in the press. We recommend that this practice be developed further and adopted by the ABC network of patient groups nationwide.

During the interviews, direct contact with health...
We observed that most printed materials were low quality photocopies.

We recommend that ABC Brasov make use of the facilities available through the Renasterea information centre at the Bucharest Institute of Oncology. This centre was described as having extensive information on the latest treatments for cancer, including Internet access to academic journals and literature from the world’s leading medical schools and institutes.

ABC Brasov’s main challenge is to develop its staff and volunteers’ skills and capabilities in the areas identified previously, so that they are better able to meet the needs of the cancer patients they work with. The organization’s leadership needs to develop its basic management skills, in particular management and development of volunteer organizations. The recommendation is that the organization link with NGOs that can provide this type of training.

By developing the required skills, ABC Brasov can begin to:
1. increase the quality and quantity of services provided to patient groups and cancer patient members;
2. develop the organization and manage it more effectively; and
3. enhance their ability to raise and manage funds.

5.1.2. SWOT analysis

The following analysis identifies the internal strengths and weaknesses of the patient group in seven key capacity areas. It also includes the main opportunities or threats external to the patient group that can help or hinder the organization in building on its strengths. The results of this SWOT analysis are used to identify and prioritize the recommendations.

Analysis of ABC Brasov’s strengths and weaknesses in seven key areas

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
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<tbody>
<tr>
<td>Mission and governance</td>
<td>• Clear mission statement</td>
<td>• Board does not include medical professionals</td>
<td>Need to include at least two medical professionals on the board (one medical doctor and one psychologist)</td>
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<td></td>
<td>• Governance structure formalized with 2-year election cycles for board members</td>
<td>• All materials provided in Romanian so less accessible to stakeholders outside Romania</td>
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<td>Service delivery</td>
<td>• Consistency of services provided with stated mission and goals</td>
<td>• Meeting facilitation in Brasov reliant on one staff member</td>
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<td>Need to develop skills of staff and volunteers</td>
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<td>• Little or no training given to volunteer staff on delivering services to cancer patients</td>
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Resources for information and education of cancer patients are poorly developed. During the interviews, the brochures and printed materials were described as low quality, and funds for printing, insufficient.

Another recommendation is to establish a toll-free number or answering service that cancer patients, their family members and members of the public can call for information. ABC Brasov may wish to collaborate with other groups to provide this service if the cost is too high.

**Educational and information resources**

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<tr>
<td>Managing and developing a volunteer organization</td>
<td>• Committed staff &lt;br&gt; • Excellent links to international organizations with experience in this area</td>
<td>• Over-reliance on limited staff inhibits ability to grow &lt;br&gt; • Skill gaps identified in management &amp; organizational development</td>
<td>Need training and skill development in management and organizational development of volunteer organizations</td>
</tr>
<tr>
<td>Partnerships and stakeholder development</td>
<td>• Strong links with other patient groups &lt;br&gt; • Small pool of committed doctors &lt;br&gt; • Volunteer programme with local university &lt;br&gt; • Commitment of pharmaceutical sponsors</td>
<td>• Challenge of recruiting more health professionals who could refer patients to the groups &lt;br&gt; • Challenge of influencing the ministry of health and local government authorities &lt;br&gt; • Lack of strong ties with NGOs and international organizations</td>
<td>The first two challenges identified require a persistent and long-term effort to change attitudes, practices and policies &lt;br&gt; Need to develop greater ties with NGOs and international organizations</td>
</tr>
<tr>
<td>Financial management and fundraising</td>
<td>• Strong sponsors with mutually beneficial relationship &lt;br&gt; • Financial person on the board</td>
<td>• 90% of funding provided by pharmaceutical companies &lt;br&gt; • No plan for raising additional funds and increasing number of donors</td>
<td>Need to broaden the number of donors to reduce the risk that one or more donors will reduce funding and significantly affect the organization</td>
</tr>
<tr>
<td>Media and promotion</td>
<td>• Developing publicity opportunities &lt;br&gt; • Emphasis on personal contact with patients and doctors</td>
<td>• No website &lt;br&gt; • Little evidence of media and promotional planning</td>
<td>Need to develop a website (including an English version) to become more accessible to local and international stakeholders</td>
</tr>
<tr>
<td>Educational and information resources</td>
<td>• Access to high quality materials based on international standards and benchmarks &lt;br&gt; • Link to Renasterea information centre</td>
<td>• Low quality of printed materials &lt;br&gt; • Information and training needed for staff and volunteers in areas specific to their respective roles</td>
<td>Need to upgrade quality of printed materials and benchmark against international standards for content &lt;br&gt; Additional education and information resources should target staff and volunteers</td>
</tr>
</tbody>
</table>
The strength and weakness profile above highlights that ABC Brasov has significant work to do in each of the seven capacity areas.

The leadership of ABC Brasov has an established strength in developing links and working relationships with other patient groups. The president actively promotes the Federation of Cancer Patient Associations in Romania, and is involved in advocacy efforts at the national level. ABC Brasov also draws student volunteers from the social work, medical and law departments of the local university to offer much needed expertise. In addition, ABC Brasov works on building relations with other international organizations by attending conferences, participating in patients’ fora, and reaching out to international coalitions.

The pattern of weaknesses associated with each capacity area focuses attention on the need for ABC Brasov leadership to obtain skills in management and organizational development. The group’s priority focus should be to increase capacity in two key areas: 1) service delivery and 2) managing and developing the organization. These are both longer-term development areas and require a significant investment of management time. The leadership must analyse the skills required by management and volunteers to deliver the highest priority services to meet the expanding demand. In turn, staff and volunteer education will be required to build the necessary skills and capacity to meet this demand.

In the governance, media and financial management capacity areas, ABC Brasov has an opportunity to achieve “quick wins”. Expanding board membership to include stakeholders from the health-care community is an important step that can be readily achieved. With respect to financial issues, the ABC Brasov leadership can begin to build skills by seeking funding for specific project proposals.

5.1.3. Recommendations

Developing organizational capacity requires a significant investment of energy, time and resources, and the purpose of this section is to provide a focus on high-priority areas. General recommendations are described in section 4.3.4., that apply to all four groups in the study. The specific recommendations identified in this section are for ABC Brasov and are based on an analysis of the patterns of organizational strengths and weaknesses described in the previous section. They are designed to address high-priority areas where improvements will yield the greatest capacity benefits for the organization.

In addition, recommendations are made for “quick wins”, opportunities to make changes that can be achieved quickly and that support the longer-term capacity development of the organization.
### High-priority recommendations

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service delivery</strong></td>
<td>The immediate need is to recruit additional people (external or trained volunteers) to provide group facilitation for meetings and other member events. A select group of volunteers should be trained to run meetings, and this training could be extended to the wider ABC network. In addition, graduate student volunteers from the university could be trained to facilitate meetings and lead discussions on various topics. As a next step, the overall model for delivering services should be assessed, with a view to gaining better understanding of the service priorities and resources required to deliver the services. “Service delivery” is closely related to the area of “managing and developing the organization”, and it is recommended that ABC Brasov leadership and a few key volunteers undertake skill development in the management of service delivery.</td>
</tr>
</tbody>
</table>
| **Managing and developing the organization** | Use the network of international organizations that ABC Brasov has contact with to identify training opportunities for managing and developing a volunteer organization. Of particular relevance to the leadership of ABC Brasov are skills in the areas of:  
  - Basic management;  
  - Assessment of organizational needs and planning;  
  - Developing a strategy for the organization;  
  - Identifying key skills required to deliver the various services provided by the organization;  
  - Recruiting and training volunteers to support the organization’s administrative and service delivery needs. |

### “Quick Win” recommendations

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td><strong>Mission and governance</strong></td>
<td>Add two medical professionals to the board of directors – one medical doctor and one psychologist, possibly drawn from the university faculty. This is a good start to building further links with the medical stakeholder community.</td>
</tr>
</tbody>
</table>
| **Media and promotion**                   | • Develop a simple, inexpensive and low-maintenance website to present the organization, its mission, accomplishments and services, in both Romanian and English. Students and possibly volunteers can be recruited to work on this focused project. Seek direct sponsorship to cover the costs of hosting the site.  
  • Identify a sponsor to underwrite the purchase of an inexpensive printer or use of copy service to print group information materials. |
| **Financial management and fundraising**  | Identify a joint project with another patient group that has experience in creating project proposals with requests for funding. Gain experience through joint preparation of the project proposal.                                                                 |
5.2. Amazonia

Background

The Amazonia association was founded in February 2006. Its publicly stated objectives are to:

• promote humanitarian actions dedicated to breast cancer patients;
• promote medical education relating to breast cancer patients;
• strengthen the spirit of solidarity among breast cancer survivors;
• ensure media coverage of breast cancer and other related issues.

The programmes it offers are designed to provide support for breast cancer prevention, detection and treatment.

The leadership confirmed its commitment to providing information on the disease, proper treatment, specialized medical assistance and psychological support.

Amazonia has a very strong relationship with the Renasterea Foundation, which describes itself as a Romanian-based foundation for education, health care and culture. Renasterea has been a member of Europa Donna since 2003, and is also part of the European Breast Cancer Coalition. Renasterea hosts Amazonia at its headquarters and donates office space and some administrative services.

Amazonia reports a number of accomplishments since its creation in 2006:

• Establishment of the website www.cancerdesan.ro which introduces the organization and provides breast cancer survivors and their family members with information about the disease, treatment, medications, legal rights and psychological support.
• Partnership with the Renasterea Foundation to include Amazonia members in the Renasterea Medical Centre’s social programme, which provides free-of-charge access to medical services, including evaluation, breast medical exams, mammography and ultrasound.
• Partnership with the Renasterea Foundation’s information centre located in the Bucharest Oncology Institute, where visiting breast cancer patients and their families are informed about the benefits of joining Amazonia.
• Translation of various materials including “Your Guide to Breast Cancer Treatment” and “Your Guide to Reading Medical Breast Cancer Bulletins” from the site www.breastcancer.org. In addition, Amazonia arranged for the transcription and adaptation of the “Breast Cancer Rehabilitation Post-Surgery” video by Miranda Esmonde-White.
• Follow-up with members regarding their treatment and state of health, and information about important tests to re-evaluate their treatment progress.
• Partnership with the Hospice Foundation to distribute breast prostheses without charge to Amazonia members. Demand has exceeded capability in this instance, with a total of 67 prostheses distributed and a waiting list of 100 patients.
• Regular meetings held at their offices for information exchange with patients.
• The development of a complementary therapy programme combining allopathic and naturopathic medical procedures under the supervision of an oncology specialist.
• Together with Renasterea, Amazonia has strong links with the Europa Donna Coalition.

5.2.1. Organizational capacity assessment

Mission and governance

In the interviews, Amazonia representatives articulated a clear mission statement: to “protect
and promote the rights and interests of breast cancer patients as well as those who are at risk of developing this type of cancer."

The publicly stated and written objectives identified in the section above were consistent with the priority goals that Amazonia listed during the interviews, and for which it provided examples of accomplishments. Amazonia emphasized the strong links to Renasterea and Europa Donna, and there appeared to be high consistency between the missions of these organizations.

With respect to governance, Amazonia reports that its board consists of a president, two medical doctors and a psychologist, who meet formally two to three times per year and exchange information informally on a regular basis. The president of the board is also a programme manager for the Renasterea Foundation but is primarily dedicated to Amazonia. The organization lacks a separate steering committee and committees dedicated to specific topics.

The board may benefit from wider inclusion of stakeholders to increase its depth of perspective. This could be achieved by including a representative from the Amazonia patient group membership and another with a business or media background.

**Services delivery**

Amazonia describes itself as a national cancer patient group, yet it is organized to provide services primarily in Bucharest. According to our interviews, Amazonia membership includes 140 breast cancer patients, a limited number of family members and 12 doctors.

During one in-depth interview, the Amazonia representative cited their five main goals in order of priority as:

1. Peer education and dissemination of information;
2. Improving the continuity of care;
3. Improving access to integrated care;
4. Monitoring patients’ state of health; and
5. Mediating between patients and medical staff.

The main services identified by Amazonia were closely linked to their goals. For instance, Amazonia organizes periodic peer group meetings and leads discussions on a variety of topics, including cancer medications, treatment progress, emotional challenges, family issues and pain management.

The organization provides one-on-one visits and telephone support to cancer patients – these services are carried out by members who have received training, but also by untrained members, so there is a risk that the consistency and quality of support could vary. An investment in training for volunteer staff is advisable. It is worth noting that Amazonia is the only one of the four patient groups that has a toll-free telephone number available to the public.

Amazonia facilitates members’ and breast cancer patients’ access to the Renasterea Diagnostic Centre, a modern facility with “state-of-the-art” diagnostic equipment. This centre supports women who have limited means or no medical insurance by providing consultations, mammograms and ultrasound exams at very little cost.

We attended a session led by the doctor responsible for the complementary therapy programme mentioned earlier. The goal of this programme is to improve the quality of medical care by combining allopathic and naturopathic approaches to cancer care. The programme is sponsored by Amazonia and open to all members. The patients present reported a high degree of satisfaction with this programme and many of these members had volunteer commitments with Amazonia. During the patient group session, several members shared their experience of how Amazonia’s assistance had helped them gain
access to proper care and relevant information at various stages of their diagnosis and treatment. All members of the group acknowledged having access to helpful printed materials from Amazonia, and several members reported that Amazonia had attended medical appointments with them and provided financial assistance to purchase drugs.

In addition, Amazonia reported that they were able to support all 140 cancer patient members during the different stages of diagnosis and treatment, beginning with the diagnosis of an abnormality and continuing through to hospitalization and post-hospitalization periods. Amazonia tracks the progress of each of its members and follows up at six- and 12-month intervals to assess their treatment progress and needs. This work is currently undertaken by one person only, who reported that additional support will be needed to provide this level of service if the membership continues to expand.

Managing and developing a volunteer organization

One of our observations is that Amazonia seems to be operating near the limit of its capacity to deliver the quantity and high quality of services currently provided to the expanding membership.

The organization seems to be at an important stage of its development, where financial and non-financial organizational resources need to be increased to meet anticipated increases in the demand for services. Specific management capabilities and skills are required to meet the challenges of effectively managing and developing a growing volunteer organization.

The organization is highly dependent on the president and one other staff member who show high commitment and passion for their work, yet neither of them were able to articulate a strategy for expanding the organization and coping with increased demands. Both of these individuals have engineering backgrounds and could benefit from training on developing and implementing a strategy for building a volunteer organization.

Partnerships and stakeholder development

With respect to partnerships, Amazonia claims strong ties with Renasterea, Europa Donna and the Hospice Foundation. Respondents emphasized the importance of international institutions providing knowledge, standards and guidelines to Romanian patient group organizations, including Amazonia.

Within Romania, however, Amazonia does not have close ties with other cancer patient groups, is not a member of the Federation of Cancer Patient Associations, and reported limited contact with two patient groups, ABC Brasov and Oncologic Rom. This merits further exploration, as there may be mutually beneficial opportunities to join forces with other patient groups on advocacy efforts, training and events.

Amazonia identified patients, health-care professionals and pharmaceutical companies as their top three stakeholders. The ministry of health was also mentioned as an important stakeholder, providing political support for the patient group concept and potential reform of the health system.

With respect to health-care professionals, doctors were described as “gatekeepers” for patient access, and only a small proportion of doctors made regular referrals to the patient groups. Two important barriers to improved doctor care cited during the interview were (1) the limited time spent with patients and (2) the “mindset” or attitude of doctors toward cancer patient groups.

Amazonia reported having focused on cultivating relationships with local health-care units and technicians, with some success, but had worked less closely with nurses, who they found to be un receptive to the patient groups.

Pharmaceutical companies provide much needed funds to Amazonia, and the relationship
was reported as strong and mutually beneficial.

The main challenge for Amazonia in this area is to develop further ties with health professionals, in order to educate them and to reach the cancer patients in their care. Two important areas for improvement mentioned by Amazonia were post-operative care and raising doctors’ awareness concerning newer treatments that are not yet available in Romania.

Financial management and fundraising

Amazonia reported that two pharmaceutical companies contribute 90% of the total annual budget, while the Renasterea Foundation provides the remaining 10%, largely through donation of office space and materials. While this close association with the pharmaceutical companies is mutually beneficial (the group’s members also gain access to new treatments through clinical trials), it is also very risky, should one or both of them reduce their contributions. In order to control this risk, it is important to further diversify the number of funding sources.

The only potential source of additional funding that Amazonia identified was the federal government. The recommendation is to identify additional opportunities for funding, including the European Union and NGOs. This may require Amazonia to prepare funding proposals for specific projects that they wish to undertake.

Media and promotion

Amazonia developed a website to ensure that breast cancer survivors, their families, and interested members of the public have access to useful information about breast cancer. Through this medium, the organization provides information on the services it offers, as well as specific resources for organization members and patients.

Amazonia places a strong emphasis on direct contact with patients and health-care professionals to promote its activities and the benefits of membership in the organization. They also invest in flyers that are distributed at hospitals and by medical staff.

In the interviews, respondents did not mention actively generating publicity through local broadcast and print media, but did identify newspaper promotions as a future opportunity. In order to reach more potential members and increase awareness of the general public, it is advisable to take a more structured approach to promotional activity. We strongly recommend developing a plan that includes publicity as well as media placements.

Educational and information resources

Educational and information resources for cancer patient members appear relevant and sufficient. Group members reported that they benefited from these materials and that they were of high quality.

Amazonia is linked to the Renasterea information centre at the Bucharest Institute of Oncology. This centre was described as being well equipped with the latest information available about cancer prevention and early detection of breast cancer. Extensive information can also be found on the latest treatments for cancer. In addition, the centre provides Internet access to academic journals and literature from the world’s leading medical schools and institutes.

The challenge for Amazonia is to develop its staff and volunteers’ skills and capabilities so that they can better meet the needs of the cancer patients they work with. In addition, as mentioned earlier, the staff faces the challenges of managing and developing the organization, raising and managing funds, and communicating with stakeholders.

5.2.2 SWOT analysis

The following analysis identifies the internal strengths and weaknesses of the patient group in seven key capacity areas. The external environmental factors are taken into consideration in the formulation of recommendations, and the results of the analysis are used to identify and prioritize the recommendations.
### Analysis of Amazonia’s strengths and weaknesses in seven key areas

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mission and governance</strong></td>
<td>• Published mission</td>
<td>• Limited breadth of board</td>
<td>Structured in the approach to governance, and benefits from the link with Renasterea</td>
</tr>
<tr>
<td></td>
<td>• Formalized governance structure that includes medical professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Link with Renasterea on mission and governance</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Service delivery</strong></td>
<td>• Services provided closely linked to mission and goals</td>
<td>• Service delivery model difficult to scale</td>
<td>Important to re-evaluate the human and financial requirements for service delivery Additional training required to ensure consistency of service with volunteer staff</td>
</tr>
<tr>
<td></td>
<td>• Services judged as high quality by recipients</td>
<td>• Staff reaching capacity</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Insufficient training of staff</td>
<td></td>
</tr>
<tr>
<td><strong>Managing and developing a volunteer organization</strong></td>
<td>• Committed staff</td>
<td>• Over-reliance on limited staff inhibits ability to grow</td>
<td>Need training and skill development in management and organizational development of volunteer organizations</td>
</tr>
<tr>
<td></td>
<td>• Excellent links to international organizations with experience in this area</td>
<td>• Skill gaps identified in management &amp; organizational development</td>
<td></td>
</tr>
<tr>
<td><strong>Partnerships and stakeholder development</strong></td>
<td>• Strong international partnerships</td>
<td>• Challenge of recruiting more health professionals to refer patients to the groups</td>
<td>The two main challenges identified require a persistent and long-term effort to change attitudes, practices and policies</td>
</tr>
<tr>
<td></td>
<td>• Small pool of committed doctors</td>
<td>• Challenge of influencing the ministry of health</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Commitment of pharmaceutical sponsors</td>
<td>• Weak links with other patient groups</td>
<td></td>
</tr>
<tr>
<td><strong>Financial management and fundraising</strong></td>
<td>• Strong sponsors with mutually beneficial relationship</td>
<td>• 90% of funding from two sources</td>
<td>Need to broaden the number of donors to reduce the risk that one or more will reduce funding and significantly affect the organization</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• No plan for raising additional funds and increasing the number of donors</td>
<td></td>
</tr>
</tbody>
</table>
### Capacity area

<table>
<thead>
<tr>
<th>Media and promotion</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
</table>
|                     | • Professionally designed website  
• Emphasis on personal contact with patients and doctors | • Not taking advantage of publicity opportunities  
• Little evidence of media and promotional planning | A successful media and promotion plan could substantially increase the number of new members |

<table>
<thead>
<tr>
<th>Educational and information resources</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
</table>
|                                       | • High quality materials based on international standards and benchmarks  
• Link to Renasterea information centre | • Insufficient information and training for staff and volunteers | Education and information resources should also target staff and volunteers |

Amazonia’s strength and weakness profile highlights the fact that the organization has a strong base to build on in each of the key capacity areas. Nonetheless, significant work is required in each area to continue developing the capacity of the organization.

The strengths that Amazonia has in each of the key capacity areas are in large part attributable to the strong relationships that the organization has with its local patron, the Renasterea Foundation, and its links to established international organizations such as Europa Donna. Governance principles, guidelines, standards and information are drawn from these external sources to underpin the structure and operation of Amazonia.

The pattern of weaknesses associated with each capacity area focuses attention on important organizational development challenges: addressing them will require specific and varied skills. These challenges involve different levels of complexity – for example, adding members to the board of directors to increase stakeholder representation is a relatively straightforward action, whereas building management and organizational development skills will require a sustained investment in time, effort and funds from the group’s leadership.

For Amazonia, the priority focus should be on increasing capacity in two key areas: 1) service delivery and 2) managing and developing the organization. These are both longer-term development areas and require a significant investment of management time. The leadership must analyse the skills required by management and volunteers to deliver the highest priority services to meet the expanding demand. In turn, staff and volunteer education will be required to build the necessary skills and capacity to meet this demand.

In the governance and financial management capacity areas, Amazonia has an opportunity to achieve “quick wins.” Expanding board membership to include additional stakeholders and skills can be readily accomplished. In terms of financial management, the Amazonia leadership can start exploring options to increase the donor base and reduce funding risk with the board.

#### 5.3.2. Recommendations

General recommendations are described in section 4.3.4., that apply to all four groups in the study. The specific recommendations identified in this section are for the Amazonia patient group and are based on an analysis of the patterns of organizational strengths and weaknesses in the previous section. They are designed to address high-priority areas where improvements will yield the greatest capacity benefits for the organization. In addition, recommendations are made for “quick wins”, opportunities to make changes that can be achieved quickly and that support the organization’s longer-term capacity development.
## High-priority recommendations

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| Service delivery                    | Perform an assessment of the current service delivery model as follows:  
  • Identify and validate the highest-priority needs of the current group membership and match them to the services provided;  
  • Review the financial and human requirements to deliver the current services and identify what resources are required to expand those services in each service area;  
  • Identify alternative means of expanding current high-priority services – e.g. additional staff, trained volunteers or some mix of the two;  
  • Anticipate new services that the organization may provide for discussion with stakeholders and the board. |
| Managing and developing the organization | Make use of the links with international organizations to identify training opportunities for the leadership to gain management and organizational development skills for volunteer organizations. |

## “Quick Win” recommendations

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mission and governance</td>
<td>Add two members to the board to increase stakeholder representation and deepen the board’s skill base – one volunteer from the membership and another member with business and/or media experience.</td>
</tr>
<tr>
<td>Financial management and fundraising</td>
<td>Prepare a “white paper” or summary of potential funding sources that could be approached for general donations or specific projects, and present to the board.</td>
</tr>
<tr>
<td>Partnerships and stakeholder development</td>
<td>Sponsor a joint training opportunity and/or advocacy event that would strengthen Amazonia relationship’s with local patient group organizations.</td>
</tr>
<tr>
<td>Media and promotion</td>
<td>Establish a toll-free number for Amazonia.</td>
</tr>
</tbody>
</table>
6. CROATIA PATIENT GROUPS ANALYSIS

6.1. Europa Donna Hrvatska

Background

Europa Donna Hrvatska was founded in Croatia in 1993 as a national organization and member of the Europa Donna European Breast Cancer Coalition located in Milan, Italy. Europa Donna Hrvatska was fully integrated into the Croatian League against Cancer until 1999, at which point they separated from the League and registered as an independent organization with their own constitution and governance structure. In 2007, the organization reported 47 established groups throughout Croatia, and over 5,000 individual members.

Europa Donna Hrvatska reports that its basic mission is to:

- Promote breast cancer awareness in Croatian society;
- Promote the dissemination and exchange of factual, up-to-date information on breast cancer in Europe;
- Inform and advise the Croatian public about breast cancer as the leading fatal cancer for women;
- Emphasize the need for appropriate screening and early detection;
- Promote the best possible treatment, rehabilitation (medical, psychosocial, vocational) and palliative care;
- Ensure that all women fully understand any proposed treatment and care options, including entry into clinical trials and their right to a second opinion;
- Promote the advancement of breast cancer research;
- Advocate for professional training of health-care professionals;
- Acknowledge good practice and promote its development;
- Demand regular quality assessment of medical equipment.

During the interviews, the organization’s leadership emphasized their strong relationship with the Croatian Senologic Society, specifically in relation to advocacy efforts for the establishment of a Croatian national screening programme for breast cancer. In addition, one of the medical doctors serving on the Croatian Senologic Society board also serves on Europa Donna Hrvatska’s board, and representatives of both organizations reported this as beneficial.

The organization gave details of a number of activities undertaken in 2006, including:

- advocacy in the areas of prevention, early detection and optimal treatment for breast cancer;
- providing information to the public and organization members on breast cancer; and
- offering services to other patient groups – specifically, training and information on breast cancer provided to Reach to Recovery members.

Nada Kraljevic, President of Europa Donna Hrvatska (photo courtesy Europa Donna Hrvatska)
in Croatia. The organization also sponsored advocacy events such as Pink Ribbon Day and Daffodil Day. All activities are consistent with the organization’s focus on advocacy.

Europa Donna Hrvatska representatives identified the two primary goals of its advocacy and lobbying activities nationwide as:

- the establishment of a Croatian national screening programme for breast cancer; and
- the development of a national programme for breast cancer treatment and care.

The leadership reported success on the first goal in 2006, with the launch of a Croatian national screening programme for all women between the ages of 50 and 69. Two mammography mobile units have been deployed, which are capable of completing 56,000 exams in a five-year period. The expected outcome of this programme is a reduction in breast cancer death rates by 25% for the target population over the five-year period.

With respect to the second high-priority advocacy goal, Europa Donna Hrvatska intends to support the establishment of specialized breast cancer units that meet European guidelines and employ a multidisciplinary approach. This is to be undertaken as part of the advocacy efforts to establish a national programme for breast cancer treatment and care.

6.1.1 Organizational capacity assessment

Mission and governance

During the interviews, Europa Donna Hrvatska representatives emphasized their strong relationship to the Europa Donna Breast Cancer Coalition and provided a clear statement of their purpose. The information in the interviews was consistent with the documentation provided by the organization and the mission is supported by relevant goals and activities.

With respect to governance, the organization reported that its board of directors consists of a president, three medical professionals and four cancer survivors who meet formally twice a year. In addition, a general assembly is held twice a year and attended by at least one representative from each of the patient groups. In 2006, the general assembly attracted about 100 participants.

The medical doctor and board member who is also a member of the Croatian Senologic Society board attended one of the meetings with us. He attested to the close and productive working relationship of the two organizations in pursuit of their common goals.

Our impression was that Europa Donna Hrvatska had a relatively strong governance function, which benefited from the cross-board membership with the Senologic Society. In addition, it benefits from a mix of doctors and cancer survivors on the board. However, we also recommend adding depth to the board by adding a nurse, as well as member with a business background and one with a media or public relations background.

Services delivery

In the interviews, Europa Donna Hrvatska members described the organization as one that emphasizes advocacy, awareness and education as its service priorities. The organization seeks to mobilize volunteer members to support its advocacy efforts with various stakeholders, and to raise awareness on issues related to breast cancer and breast cancer patients.

One main stakeholder group requiring services is the organization’s membership. Approximately 90% of members are cancer patients, who require information to gain better understanding of the medical and psychological issues related to breast cancer diagnosis, treatment and recovery. The information resources provided by Europa Donna Hrvatska and the support of other group members are important to build a base of educated, informed members. In turn, the
patient member stakeholder group is a pool from which volunteers emerge to carry on the organization’s advocacy work. Our first recommendation, therefore, is to strengthen the existing 47 groups as much as possible by increasing the training and information sessions that will build member knowledge and group strength.

During one of the interviews, the leadership identified services that the organization provided or supported:

- Special events – Daffodil Day, Pink Ribbon Day
- Group education sessions with guest lecturers
- Fundraising
- Public education through mass media
- Training for other patient groups
- General advocacy and awareness (e.g. national screening programme)

The main advocacy efforts of the organization are closely linked to the its goals and are aimed at a number of stakeholder groups, including the general public, health-care professionals, government officials, and breast cancer patients and their families.

During the interviews, the leadership identified three main barriers that the organization needed to overcome to improve its effectiveness in delivering services. The first challenge is lack of volunteers: the organization believes it needs more knowledgeable individuals with the skills required to do advocacy work. The second challenge is lack of funding to support the full range of advocacy efforts and programmes, and the third is lack of public and political support – this was one of the key issues that the organization tries to address through advocacy efforts aimed at increasing awareness and knowledge.

Our recommendation is for Europa Donna Hrvatska to begin by developing their membership and volunteers’ capabilities, in order to achieve a greater impact on public awareness and advocacy at local level.

The potential creation of a programme called “Mother and I” was discussed during one of the meetings: the idea is to establish a session of one hour per year in public schools for high school students to learn about breast cancer prevention and detection. This would accomplish two main goals: first, making the younger generation more aware of breast cancer and better able to identify issues early; and second, using the younger generation to influence the older generation’s attitudes to breast cancer and to transmit valuable information on prevention and detection. This type of programme could be delivered at little or no cost by trained volunteers in their local areas.

Managing and developing a volunteer organization

As mentioned in the previous section, the leadership identified a lack of volunteers and insufficient funding as the two main challenges facing the organization. These challenges confront most volunteer organizations at some point in their development, and they can tax even the best-prepared managers. During the interviews, however, the respondents were not able to articulate an approach for increasing the number of qualified volunteers or identify a strategy for raising additional funds. The person responsible for the overall management of the group has a health-care background and could benefit from training on managing and developing a volunteer organization.

Partnerships and stakeholder development

During the interviews, Europa Donna Hrvatska representatives focused on two key partnerships: one with Europa Donna, the parent organization in Milan, and the other with the Croatian Senologic Society. With regards to their relationship with the parent organization, representatives emphasized the provision of an overall mission statement, governance structure, information, standards and guidelines, which have been fundamental to the development of the national organization in Croatia. By contrast, the partnership with the Croatian Senologic Society was described as being more focused on the achievement of common advocacy efforts and goals in Croatia, including efforts to support the establishment of a Croatian national screening programme for breast cancer.

Europa Donna Hrvatska cited close relationships with supportive health professionals at the University Hospital for Tumours and with organizations and societies concerned with breast cancer as being critical for the achievement of its goals. The Croatian Oncological Society, the Croatian League against Cancer, and the Croatian Psychosocial Oncology Association were mentioned as important collaborators. Several patient groups, including Reach to Recovery and the Stoma Group, were also identified as relevant stakeholders.

Local and national governments were also considered important stakeholders, but the relationships required further development. Relationships with the local/regional governments were described as stronger than those with national government. The local government provided funding, but political support...
from the government was characterized as poor at both local and national levels.

A main challenge identified during the interviews was that of working more closely with doctors and nurses as a way to develop institutional and political support for their advocacy platforms. An example cited was the successful working relationship Europa Donna Hrvatska had established with a select group of doctors at the University Hospital for Tumours. The organization would like to engage more doctors in substantive discussions on breast cancer issues and to have more doctors address their groups on topics of special interest in breast cancer. The main barrier cited to furthering relationships with health professionals was the attitudes and mind-set of some individuals, who were not open to Europa Donna Hrvatska’s work.

We recommend intensifying efforts along the lines of the broad-based approach currently used, placing additional emphasis on developing ties with health professionals. Using dialogue and up-to-date information, more health professionals can be influenced to think differently about the issues and needs of cancer patients.

Financial management and fundraising

Europa Donna Hrvatska reported that local government provided approximately 90% of the total funds for operations, with the remaining 10% coming from other sources, including fees paid by the 47 national groups. Relying so heavily on a single source of funding is very risky: in the event of changes in government funding policies, the organization could quickly find itself in financial difficulty.

The organization also identified in-kind contributions, such as loan of meeting rooms in the local hospitals, health professionals donating their time to Europa Donna Hrvatska events, and special training for members provided once a year by the Europa Donna parent organization in Milan.

We recommend establishing a broader base of funding by actively soliciting funds from other national and international sources, including the European Union and NGOs. This could take the form of grants, funded project proposals or in-kind contributions of training and training materials, for example. Such fundraising approaches require the preparation of targeted grant and project proposals.

Media and promotion

The organization’s activities are promoted through a variety of sources, including their website (www.europadonna.hr), infrequent publicity opportunities provided by local radio and newspapers, and through direct contact with their membership, health professionals and other community groups. According to group representatives, there were also occasional invitations to appear on television programmes to discuss breast cancer. The respondents reported that they did not actively seek out publicity opportunities but did take advantage of them when they were offered. We recommend that the organization become more proactive in their relations with the media, actively seeking out opportunities for publicity.

The website is currently available in Croatian only. We recommend providing an English-language version to enable the group to promote their activities to an international audience.

In the interviews, the organization emphasized the importance of direct contact with their existing membership, health professionals, breast cancer organizations and community groups. In fact, relationships with supportive medical professionals in the University Hospital for Tumours and with a number of cancer societies were cited on several occasions as very important in the achievement of the organization’s goals.

Educational and information resources

The Europa Donna Breast Cancer Coalition in Milan operates as a parent organization to the Europa Donna national organizations and levies.
Better Together

a membership fee of 500 euros annually. One benefit of membership is access to educational and information resources. For instance, the parent organization provides an annual training opportunity to members free of charge. However, members must travel to Milan to take advantage of this service and, as a result, only a few members from the Croatian organization have participated in the training. Training programmes and materials are also provided to the national organizations for use in their home countries.

Europa Donna Hrvatska reported that it makes use of the training materials provided, and twice a year offers free two-day training sessions to members of the 47 groups in its national network. So far the sessions have been held in Zagreb and one other city, and there is scope for holding them in other cities and increasing the number of sessions. To expand this training programme, we recommend training a small group of motivated volunteers to conduct the training sessions.

In addition, the parent organization provides the latest guidelines and other information resources to its members. This provides an important source of current, high-quality information. Europa Donna Hrvatska reported that they make some use of the information resources provided, translating the flyers into Croatian for the benefit of their membership. The interviewees recognized that there was scope for greater use of the information resources available.

Our conclusion is that the educational and information resources provided by the parent organization can be further leveraged to develop the knowledge and skills of the 47 groups in the Croatian network. We recommend placing more emphasis on translating and making use of training and information materials provided by both Europa Donna in Milan and other sources.

6.1.2. SWOT Analysis

The following analysis identifies the internal strengths and weaknesses of the patient group or organization in seven key capacity areas. The external environmental factors are identified when they impede or prevent the organization from building on their strengths or addressing internal weaknesses. The results of this analysis are used to identify and prioritize the recommendations.

### Analysis of Europa Donna Hrvatska’s strengths and weaknesses in seven key areas

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Mission and governance  | • Medical professionals and cancer patients on the board                  | • No business or media/public relations experience on the board | Add a nurse to the board  
Add a board member with business experience and one with media or public relations experience |
| Service delivery        | • Strong local partnership with Croatian Senologic Association  
• Focused approach on what services to deliver  
• Large and geographically distributed membership and potential volunteer base | • Volunteer base lacks appropriate knowledge and skills | Develop membership knowledge and volunteer capabilities  
Further investment in training required |
<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Managing and developing a volunteer organization | • Membership base of 5,000  
• Nationwide organization with 47 groups | • Limited management capabilities in strategy and planning for volunteer organizations | Leadership should attend training on management and organizational development                        |
| Partnerships and stakeholder development         | • Strong international partnership  
• Small pool of supportive health professionals  
• Strong links with other associations and groups | • Challenge of involving more health professionals in support of advocacy work | Engaging health professionals is a key challenge and requires a persistent and long-term effort to change attitudes and practices |
| Financial management and fundraising             | • In-kind contributions are a potential growth area | • Reliant on government funding as a single source for 90% of funds | Diversify funding base to reduce risk                                                             |
| Media and promotion                              | • Good materials available through Europa Donna in Milan  
• Some media experience related to large events | • Reactive approach to media opportunities  
• Infrequent exposure in local press and on radio and TV | Develop media contacts and pursue a more focused and planned approach to generate publicity      |
| Educational and information resources            | • High quality educational and information resources available through the parent organization | • Lack of focus on leveraging international resources through the Croatian national network | Replicate the training available in Milan using members who have attended the Milan training sessions |

The strength and weakness profile for Europa Donna Hrvatska highlights the fact that the organization has significant strengths to build on in most of the key capacity areas. Nonetheless, significant work is required in each area to continue developing the organization’s capacity.

The pattern of weaknesses associated with each capacity area focuses attention on the need for Europa Donna Hrvatska leadership to gain skills in management and organizational development. In addition, the organization needs to develop a proactive media strategy in support of its advocacy mission. The priority focus for Europa Donna Hrvatska should therefore be to increase capacity in three key areas: 1) service delivery; 2) managing and developing the organization; and 3) media and promotion. These are longer-term development areas that require a significant investment of management time.

In the governance, educational and financial management capacity areas, Europa Donna Hrvatska has an opportunity to achieve “quick wins”. Expanding board membership to include two new members, one with media experience and the other with business experience, will enhance organizational capacity in two important skill areas. With respect to the financial area, leadership could focus on the current risks and create a board-level discussion on opportunities to expand the donor base.
6.1.3. Recommendations

General recommendations are specified in section 4.3.4, that apply to all groups in the study. The specific recommendations for Europa Donna Hrvatska identified in this section are based on an analysis of the patterns of organizational strengths and weaknesses described in the previous section. They are designed to address high-priority areas where improvements will yield the greatest capacity benefits for the organization. In addition, recommendations are made for “quick wins”, opportunities to make changes that can be achieved quickly and that support the longer-term capacity development of the organization.

### High-priority recommendations

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<tr>
<th>Capacity area</th>
<th>Recommendations</th>
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</thead>
</table>
| **Service delivery**                              | - The immediate need is to strengthen volunteers’ knowledge and skills in advocacy. A select group of volunteers should be trained to conduct skill-based training in this area, and deployed across the organization to train other volunteers. This would help fulfil the organization’s stated longer-term goal of providing more training in critical areas to members of the 47 groups nationwide.  
- As a next step, the overall model for delivering services should be assessed with a view to better understanding the service priorities and resources required to deliver the various services. We recommend that the board member from the Senologic Society be involved in this exercise to provide a perspective that spans both organizations.  
- This area of “service delivery” is closely related to “managing and developing the organization”, and we recommend that the leadership and a few key volunteers develop their skills in the management of service delivery. |
| **Managing and developing the organization**       | The organization should use the resources of Europa Donna in Milan and other international sources to help identify suitable training in the management and development of volunteer organizations. Specific topics and skills should include:  
- Basic management skills  
- Assessment of organizational needs and planning  
- Developing a strategy for the organization  
- Identifying the key skills required to deliver the services provided by the organization  
- Recruiting and training volunteers to support the administrative and service delivery needs of the organization |
## “Quick Win” recommendations

<table>
<thead>
<tr>
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<th>Recommendations</th>
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<td>Recruit members who have attended international training sessions and get them to train a select group of volunteers to deliver training on a variety of topics. This effort supports the service delivery need in the high-priority recommendations above and is a low-cost method of building educational capacity within the organization.</td>
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<tr>
<td><strong>Financial management and fundraising</strong></td>
<td>Get the president to prepare a paper for board review outlining financial requirements for various aspects of the operation and identifying potential new sources of funding. The dialogue surrounding this topic will focus attention on the organization’s reliance on government funding and likely raise new possibilities.</td>
</tr>
</tbody>
</table>

### Media and promotion

We recommend developing a proactive media approach as a top priority in support of the organization’s advocacy mission. The goal is to achieve free press coverage or media publicity. To achieve this, it is important to build relationships with individuals in media companies, and to provide them with clear messages, some of which they will judge as newsworthy. Important steps include:

- Making regular telephone or personal contact with representatives from the local and national media, and following up by sending them prepared text on the specific topic that you are contacting them about
- Following up with media contacts after receiving coverage
- Training a select group of volunteers to develop media relationships and work on the prepared messages

### Quick Win recommendations

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6.2. Reach to Recovery Croatia

Background

Reach to Recovery Croatia was founded in 1993 by the Croatian League Against Cancer as a national organization and an affiliate of Reach to Recovery International (RRI), an international network hosted by the International Union Against Cancer (UICC) in Geneva, Switzerland. RRI describes its mission as mobilizing breast cancer survivors “to give freely of their time and experience to assist and support other women facing the same challenge”. Reach to Recovery Croatia operates according to the guidelines and principles of RRI, and is also referred to locally as the Croatian Group of Women Volunteers Who Have Undergone Breast Cancer Surgery (VOPUB). During interviews, the group’s priority goals were described as:

• Peer support for cancer patients and – if possible – their families, before and after operations or other medical treatments;
• Peer education and dissemination of information about breast cancer; and
• Improvement of continuity of care – this involves lobbying the government for prostheses and patient support, as well as for a disability classification for patients who have undergone a breast operation.

Reach to Recovery Croatia started up in 1994. At the time it was a group of eight volunteers working in the University Hospital for Tumours in Zagreb. At the time of our interviews in 2007, the organization reported 21 volunteers working in the organization, with 17 considered active and essential to the organization. The volunteers are required to have over four years’ experience recovering from breast cancer, and are assessed by the organization in terms of their psychological and physical suitability for taking on the demands of peer support work.

Reach to Recovery Croatia reports that in the last 12 years it has conducted 2,500 visits to patients and provided support to over 6,000 women as well as some family members.

The organization holds its peer support meetings once a week in the University Hospital for Tumours. The average meeting lasts 2-3 hours and attracts small groups of up to five participants. The VOPUB reports holding education seminars and workshops for regional mentors and volunteers. Monthly supervision of the volunteers takes place by expert regional mentors. They also report participating at advocacy events with other patient groups.

6.2.1. Organizational capacity assessment

Mission and governance

Reach to Recovery Croatia representatives presented a clear statement of the organization’s mission, and identified goals and activities consistent with that mission. The relationship with Reach to Recovery International provides the Croatian organization with guidelines and standards.

With respect to governance, the organization has a board of directors consisting of the president, a psychologist and three cancer survivors from different cities in the Reach to Recovery network. The board lacks a representative with medical or nursing experience, and our impression was that there is an opportunity to revisit the skills needed on the board and recruit individuals with those skills. We recommend adding at least two members to the board – one oncologist and one individual with business and/or organizational development skills. This would provide the organization with additional expertise in critical areas.

Currently all board members are breast cancer survivors – while that may be a requirement...
for those providing peer support to breast cancer patients, it might be less crucial for board membership. A suggestion is to recruit from the family members of cancer patients assisted by Reach to Recovery Croatia who could bring business and organizational acumen to the group. For the health professional, it would be good to select someone who understands the benefit of the psychosocial model endorsed by Reach to Recovery Croatia and who is committed to developing this approach.

Services delivery

Respondents identified the main services provided by Reach to Recovery Croatia as emotional, social and psychological support to new patients delivered through:

- One-to-one visits by specially trained members;
- One-to-one telephone support by specially trained members; and
- Group education sessions with guest lecturers.

In addition, Reach to Recovery Croatia volunteers participate in Europa-Donna-sponsored training and provide information to other patient groups on breast cancer.

In order to increase the effectiveness of the organization and its ability to increase the delivery of services, one interviewee suggested that the organization needed: 1) more volunteers, 2) additional funds; and 3) a paid administrator to free up time for the president and volunteers, who are currently handling all aspects of the group’s administration.

The service model described by the president relies on carefully screened and trained volunteers who have survived at least four years post diagnosis and are judged to be psychologically and physically suited to providing peer support for breast cancer patients. While this approach may help ensure quality and consistency of the support, the main challenge for expanding service delivery is increasing the size of the volunteer base: it currently numbers 17 active volunteers, with only six of these operating in Zagreb. The remaining 11 volunteers are based in the 10 largest cities in Croatia and organize their activities based on their assessment of local needs. In Zagreb, the volunteers are committed to the University Hospital for Tumours, which reportedly deals with 55% of breast cancer cases in Zagreb. Reach to Recovery Croatia reports having made little effort to develop a relationship with other Zagreb hospitals to serve their patient populations: the rationale provided was that, given the limited number of volunteers, the organization does not have sufficient resources to serve other hospitals.

Our impression is that the recovery-time condition for volunteers is limiting opportunities to increase the volunteer base. In addition, the focus on contact with patients in hospitals does not appear to be followed up by ongoing peer support for discharged patients. Patients will therefore only have a relatively short period of exposure to Reach to Recovery Croatia volunteers. Another observation is that the ability to identify potential volunteers is further reduced by the organization’s lack of strong links with the medical oncology community, which could be a source of referrals.

Recommendations to address the volunteer challenge include:

- shortening the time of survival condition, while retaining the psychological and physical health criteria;
- holding a support group for discharged patients who would like to continue with the peer meetings; and
- improving relations with medical doctors and nurses and seeking volunteer referrals.

One way to improve relations with medical doctors and nurses would be to work through the doctor network that currently supports the group to identify doctors and nurses that don’t know the organization but who might be willing to speak at group education sessions on a topic within their technical expertise. This provides the opportunity to sensitize these doctors and nurses to the group’s activities and opens the possibility for dialogue and a future relationship.

Managing and developing a volunteer organization

The leadership reported being heavily involved in the group’s administration, and less able to focus on developing and managing the organization and its volunteer staff. Other issues identified were the small number of volunteers and the lack of financial resources. Although it was clear that these challenges are significant, they are the same type of challenges faced by most non-profit, volunteer-based organizations.

The organization is dependent on the president and a small group of volunteers who are dedicated and passionate about their work. During our discussions, the members were invited to identify solutions to the challenges they faced, but were unable to identify a comprehensive approach to expand the organization and overcome the financial and administrative challenges. The only proposed “solution” was to hire an administrative staff member, but this was not feasible because of lack of funds.
It is important to take into account that the organization has grown from eight volunteers at its creation in 1993 to 17 active volunteers in 2006 – a growth rate of just over 100% in 12 years. The current volunteer base in Zagreb is only sufficient to cover the University Hospital for Tumours, but in the meantime the number of breast cancer cases is growing, placing high demands for volunteers serving even a single hospital. Opportunities to expand the organization’s impact across Croatia are compromised by the small number of volunteers.

Our recommendation is that the leadership undertake training on developing and implementing a strategy for building a volunteer organization. The training would provide much needed management skills and assist the leadership in formulating a specific strategy for developing Reach to Recovery Croatia.

Partnerships and stakeholder development

With respect to partnerships, Reach to Recovery Croatia identified strong ties with RRI, and reported that they systematically reach out to potential international partners through conference attendance. For instance, volunteers attended the UICC RRI breast cancer support conferences in Athens (2005), Lisbon (2003) and Grado (2000), the Europa Donna conference in Milan (1998), the National Congress of Breast Cancer Patients in Budapest (1994), and the first two World Conferences on Breast Cancer Advocacy in Brussels. The contacts made at these events could be useful in providing support on addressing some of the challenges currently faced by Reach to Recovery Croatia.

During our interviews, the leadership emphasized the need for better connections and more joint activities between the local groups, and cited Europa Donna, the Croatian Senologic Society, the Breast Cancer Club and other cancer groups as potential partners. Joint training and advocacy events were identified as two opportunities for greater collaboration. Both ideas have merit: joint training promotes closer connections between groups, allows training resource materials to be pooled, and may reduce costs, while advocacy events have the potential to attract media attention and provide publicity opportunities for the participating organizations and their causes. We recommend working on developing both these opportunities.

The local government and the University Hospital for Tumours were named as the most important stakeholders. The local government funds the organization, and the University Hospital is important because of the work performed there with patients and the long-standing relationships with a small core of health professionals.

During our discussions, interviewees acknowledged that Reach to Recovery Croatia needed to work with other hospitals in Zagreb, but did not have the resources to do so. Given the limited resources, we recommend choosing one additional hospital and slowly building up the relationships and activity there.

Financial management and fundraising

The organization reported that it is dependent on local government for 100% of its funding. This reliance on a sole source of funding places the group at risk should the local government change its funding priorities and scale back or eliminate its contributions. It is therefore critical to develop new sources of funding.

Interviewees also identified their meeting rooms as in-kind contributions from the city, and reported that pharmaceutical companies had occasionally provided sponsorship for a group member to attend a conference of interest.

The discussions concerning funding centred on the global need for more resources, rather than funds for specific needs, with the exception of the need for a paid administrator. We observed a lack of ability to analyse and communicate financial needs in a structured way that might appeal to donors requiring accountability.

Based on the information provided, our conclusion was that the organization had a passive approach to raising funds. In addition, there was an evident lack of understanding of how to identify and approach potential donors.

The leadership of the organization needs to develop some expertise in fundraising for non-profit volunteer organizations. We recommend finding international sources of information on this topic that can be used to generate ideas and options for constructing a funding plan for Reach to Recovery Croatia. Attending fundraising training sessions held by international organizations is another option to consider, but may be less attractive due to the costs of travel and attendance.

Media and promotion

Reach to Recovery Croatia does not have its own website but is included in the Croatian League against Cancer’s site www.hlpr.hr. Should Reach to Recovery Croatia seek funding from international organizations, it would be advisable for them to establish a site with English and Croatian versions. This would provide them with an opportunity to communicate to a wider
audience the priorities, activities, challenges and results that the organization faces. Establishing an independent site is not an immediate priority but should be undertaken when and if the organization pursues international funding sources.

Reach to Recovery Croatia reported that it did not actively seek out opportunities for free local media press coverage, but did take advantage of publicity opportunities that were sometimes offered at major events. We recommend that the organization take a more active approach to providing public information on its work and seek out publicity opportunities in the local media.

The organization places a strong emphasis on direct contact with patients and health professionals to promote their services, with the majority of this activity in Zagreb taking place in the University Hospital for Tumours. As mentioned earlier, we recommend making direct contact with patients, doctors and nurses in other hospitals, and building the relationships and activity over time.

**Educational and information resources**

As an affiliate of RRI, the Croatian group has access to peer support training, bi-annual international conferences and the Bloom newsletter. In addition, RRI provides information and fact sheets through its section on the UICC website. These services are provided at no cost to all interested groups.

The materials, including Bloom, are published in English and available for translation into local languages. Bloom is published twice a year and provides a current source of information for newly diagnosed breast cancer patients, long-term survivors and coordinators of breast cancer support groups. The recommendation is that Reach to Recovery Croatia organize translations of additional selected materials to distribute to patients and health-care professionals.

Europa Donna Hrvatska periodically offers training to Reach to Recovery Croatia members on advocacy topics, a service greatly appreciated by the Reach to Recovery members interviewed.

**6.2.2. SWOT Analysis**

The following analysis identifies the internal strengths and weaknesses of the patient group or organization in seven key capacity areas. The external environmental factors are identified when they impede or prevent the organization from building on their strengths or addressing internal weaknesses. The results of this analysis are used to identify and prioritize the recommendations.
## Analysis of Reach to Recovery Croatia’s strengths and weaknesses in seven key areas

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Strengths</th>
<th>Weaknesses</th>
<th>Comments</th>
</tr>
</thead>
</table>
| **Mission and governance**                | • Psychologist on the board  
• Cancer survivors drawn from the volunteer base present on the board | • The board is too internally focused and lacks members with expertise in medical/nursing oncology and business or organizational development | Add two board members – one with expertise in oncology and one with business or organizational development experience |
| **Service delivery**                       | • Focused set of services offered to new patients in hospital  
• Strong relations with University Hospital for Tumours and a small group of doctors there  
• Well-trained and dedicated volunteers delivering the support services | • Underdeveloped local partnerships  
• Small pool of volunteers and difficulties identifying new volunteers  
• No relations with health-care staff in hospitals other than the University Hospital for Tumours in Zagreb | Hold a support group for discharged patients  
Revise the criteria for post-diagnosis survival time to expand potential volunteer pool  
Target one additional hospital, slowly build relations with medical/nursing staff and begin offering limited services to patients |
| **Partnerships and stakeholder development** | • International partnership with RRI  
• Small pool of supportive health-care professionals in the University Hospital for Tumours | • Lack of supportive health-care professional network in hospitals other than the University Hospital for Tumours  
• Weak links with other local associations and groups | Develop relations with a broader network of health-care professionals, including those in hospitals other than the University Hospital for Tumours  
Strengthen collaboration with local groups and associations through joint training and joint events |
<table>
<thead>
<tr>
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</tr>
</thead>
</table>
| Managing and developing a volunteer organization | • Small group of 17 well-trained and committed volunteers  
• Nationwide organization with 47 groups | • Size of volunteer group not keeping pace with growing opportunities for services  
• Funding levels inadequate to support expansion of activities  
• Management capabilities in strategy and planning for volunteer organizations | Leadership should source information and attend training on management and organizational development for volunteer organizations |
| Financial management and fundraising   | • Limited but regular pharmaceutical company sponsorship of members attending conferences | • Reliant on single government source for 100% of funds | Diversify funding base to reduce risk |
| Media and promotion                    | • Web pages on the Croatian Coalition against Cancer site  
• Good materials available through RRI in Geneva  
• Some experience in media related to large events and ad hoc | • Lack of dedicated website in Croatian and English  
• Reactive approach to media opportunities  
• Infrequent exposure in local press and on radio and TV | Develop media contacts and pursue a more focused and planned approach to generate publicity |
| Educational and information resources  | • High-quality training sessions and materials offered through RRI  
• All volunteers have undertaken training  
• Volunteers participate in training offered by Europa Donna Hrvatska | • Scope to improve use of RRI materials with patients and network volunteers  
• Underutilization of training materials available through international organizations on building and managing a volunteer organization | Increase use of translated RRI and other materials – e.g. Bloom articles, fact sheets – with cancer patients, healthcare professionals and other patient groups/associations  
Need to seek out and apply information on building and managing a volunteer organization |
The strength and weakness profile above shows that Reach to Recovery Croatia has significant work to do in each of the seven capacity areas.

One of the group’s strengths is the well-trained and highly motivated group of 17 core volunteers, six of whom are located in Zagreb. The organization has a very strong relationship with the University Hospital for Tumours and has been delivering services to cancer patients at that hospital since 1994.

However a fundamental problem for the organization is the difficulty it has finding and recruiting volunteer candidates who meet the time requirement of 4+ years post cancer diagnosis, in addition to the psychological and physical health criteria. The practical impact of this is that the organization has been unable in to expand its activities to other hospitals in Zagreb and is also approaching the limit of its ability to meet patient needs at the University Hospital for Tumours.

We suggest that a new approach is required in order to attract suitable volunteers and allow the organization to grow. Only then will Reach to Recovery Croatia be able to meet its goal of serving other hospitals in the Zagreb area, where 45% of the breast cancer patients in the area are cared for.

A critical recommendation offered is that of increasing the leadership’s managerial and organizational development skills. This requires an ongoing commitment to attend training on how these skills can be applied to volunteer organizations, and to make regular attempts to approach management and organizational challenges in new ways.

In the governance, educational and financial management capacity areas, Reach to Recovery Croatia has an opportunity to achieve “quick wins”. Expanding board membership to include stakeholders from the health-care and business communities is an important step. With respect to the financial area, the Reach to Recovery Croatia leadership has an opportunity to develop in-kind contributions with a focused appeal for specific resources.

### High-priority recommendations

<table>
<thead>
<tr>
<th>Capacity area</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service delivery</td>
<td>• Expand the potential pool of volunteers by reducing the criteria for post-diagnosis time of survival from four years to one or two years, while retaining the strict criteria for physical and mental health.\n• Pilot a support group for discharged patients, which may in time provide volunteer candidates.\n• Ask the volunteers to team up in pairs and approach one additional hospital to introduce the organization and make an initial contact. Build on these initial meetings by offering to establish a weekly meeting at the new hospital.\nThe three initiatives above do not require substantial additional resources at first and would pave the way for expanding services in line with the recruitment of new volunteers.</td>
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### Capacity area Recommendations

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<td><strong>Mission and governance</strong></td>
<td>Add two members to the board of directors – one with expertise in oncology and one with business or organizational development experience. This is a good start to build further links with the medical stakeholder community and gain access to management expertise.</td>
</tr>
</tbody>
</table>
| **Educational and information resources**  | • Increase use of translated RRI and other materials – e.g. relevant Bloom articles, fact sheets, etc. – with cancer patients, health-care professionals and other patient groups/associations.  
  • Locate information sources on fundraising for volunteer organizations and use this to stimulate ideas for increasing the funding base. These ideas can be part of a longer-term effort to reduce the financial risk of sole reliance on the government for funding. |
| **Financial management and fundraising**   | • Arrange a meeting with the volunteers to identify specific in-kind contributions that would benefit the organization, including training for volunteers and materials for patient visits, and a list of possible donors for each contribution.  
  • Using this list of contributions needed, recruit volunteers to contact the potential donors and request the contributions.  
  This will not solve the issue of administrative support that was raised by the president, but could provide additional resources needed by the group. |

### “Quick Win” recommendations

<table>
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<th>Recommendations</th>
</tr>
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| **Partnership and stakeholder development**| • Strengthen collaboration with local groups and associations through joint training and joint events. This initiative can build stronger links among local patient groups, lower the cost of training activities and generate media opportunities.  
  • Build on any inroads made with health professionals and other hospitals in the “service delivery” initiative above. |
| **Managing and developing the organization**| The leadership should source information and attend training on management and organizational development for volunteer organizations. Some specific skills and areas that should be included in the training are:  
  • Basic management skills;  
  • Assessment of organizational needs and planning;  
  • Developing a strategy for the organization;  
  • Identifying the key skills required to deliver the various services provided by the organization; and  
  • Recruiting and training volunteers to support the administrative and service delivery needs of the organization. |
7.1. References

1. World Health Organization, Core Health Indicators (page accessed 1 February 2008)
   www.who.int/whosis/database/core/core_select_process.cfm

   www.who.int/countries/rou/en

   www.who.int/countries/hrv/en

4. World Health Organization, Core Health Indicators (page accessed 1 February 2008)
   www.who.int/whosis/database/core/core_select_process.cfm

5. The Independent Newspaper, “Jeremy Laurance: The NHS should think twice before rationing care,”
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   www.independent.co.uk/opinion/commentators/jeremy-laurance-the-nhs-should-think-twice-before-rationing-care-447922.html
7.2. Acknowledgements

We wish to acknowledge the large number of people and organizations whose participation in interviews and discussions provided the content for this report. First and foremost we thank the patients, volunteers, advocates, health-care staff, and the researchers and staff at the cancer associations in Romania and Croatia for the time spent answering our questions and the valuable insight they gave us into the functioning of their organizations, groups and cancer care, and their lives:

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- Corina Alexandru, president, Oncologic Romanian Association
- Amazonia Association
  - Victoria Asanache, president
  - Lucia Barbot, coordinator
- Dr Paul Becheanu, CEO, Casa Nationala De Asigurari De Sanatate A Judetului Brasov (CNAS)
- Olga-Rodica Cridland, president, Association P.A.V.E.L.
- Ana Maria Dragomir
- Marlene Farcas, director, Romanian Society of Cancer
- Renasterea Foundation
  - Mihaela Geoana, president
  - Adina Bitoleanu
  - Adina Malan
- Ramona Gotteszman, partnership coordinator, World Learning for International Development
- Cesar Irimia, president, and Simona Ene, projects and programme coordinator, Association of Cancer Patients from Romania (ABC)
- Adela Ratiu, Department of Medical Statistics and IT, Institute of Oncology “Prof. Dr. Al. Trestioreanu”, Bucharest

In Croatia
- Reach to Recovery Croatia, Croatian Breast Cancer Care Voluntary Society, Croatian League Against Cancer
  - Vjekoslava Borosa, president
  - Dr Rozica Loncaric, medical oncologist, Klinika Za Tumore
  - Barbara Valicevic, volunteer
- Clinical Hospital Osijek
  - Dr Marjana Bras, psychiatrist
  - Dr Boris Belev, internal medicine
  - Dr Zoran Loncar, anaesthetist
- Invalid Society ILCO Karlovac – Stoma Klub Croatia
  - Visnja Druzak
  - Marijana Kruljac
- Croatian League against Cancer
  - Dr Damir Eljuga, president
  - Dr Damagoj Eljuga
- Dr Magdalena Grce, board member, European Cervical Cancer Association (ECCA), Rudjer Boškovic Institute
We are also very grateful to the following group of experts who assisted UICC with their important comments, feedback and advice throughout the project:

- Dr Jeff Dunn, UICC’s strategic leader for capacity building
- Patricia Allen, founder and vice president, English Speaking Cancer Association Geneva
- Angela Grezet-Bento de Carvalho, Association Savoir Patient, Geneva
- Silvana Hertz, vice president, Breast Cancer Net, Geneva
- Dr Tezer Kutluk, president, Turkish Association for Cancer Research & Control
- Thea Marais, psychologist, English Speaking Cancer Association, Geneva
- Isabel Mortara, executive director, UICC

In memoriam: Professor Charles-Henri Rapin, who was a member of our advisory group, passed away suddenly on 10 July 2008. As a medical doctor, a teacher, a cancer patient and an advocate, he made a great contribution to patients’ quality of life. His passion, knowledge and sense of humour were an inspiration to many.

A special word of thanks to Daniele Alesani who served as a consultant, and to the following UICC staff for their coordination work and assistance throughout the project: Ella Nkanagu, Ana Olivera, Páraic Réamonn and Anna Maria Vandelli.

UICC gratefully acknowledges Novartis for their financial support, and Dr Susanna Leto di Priolo and Gloria Stone and for their valuable contributions.
APPENDIX: CANCER PATIENT GROUP SURVEY

A project of the International Union Against Cancer (UICC)

This survey tool is designed to assess patient group needs and capacity building requirements.

This instrument is intended to be used as part of a semi-structured interview process with patient group managers and representatives.

There are five sections to the questionnaire:

• **Section 1** determines the profile of the patient group.
• **Section 2** focuses on how the patient group is currently organized and managed.
• **Section 3** explores how the patient group approaches and manages the relationship with its main beneficiaries.
• **Section 4** profiles how the patient group is financed and in particular what support it receives from other agencies or people in the local area.
• **Section 5** addresses partnerships and networks the patient group is currently part of and requests insights on the level of involvement of the affiliated patient groups within the local care networks.
• **Section 6** asks about what might help the patient group in the future.
SECTION 1
This section determines the profile of the patient group

1. In what year was your group formed? ____________________________________________

2. The geographical base of your patient group is:
   - [ ] Local
   - [ ] Regional
   - [ ] National
   - [ ] International (specify) __________________________________________

3. Does your association have a written statement of purpose? [ ] Yes [ ] No
   (If YES, request a copy)

4. What are the main goals of your group? Please prioritize your main goals with 1 being the most important
   - [ ] Emotional support
   - [ ] Peer-education and information spreading
   - [ ] Improvement of continuity of care
   - [ ] Offering services to other patient groups (administrative services, knowledge based services, training, etc.)
   - [ ] Other (specify) __________________________________________

5. How effective do you think you are overall in meeting these goals? ________________

6. What do you need to improve your effectiveness? ________________________________

7. How many people are on the mailing list of your group? _____
   Of these how many are:
   i. Cancer patients
   ii. Cancer patients’ parents or relative
   iii. Health professionals
   iv. Healthy people with an interest in cancer
   v. Other patient groups __________________________________________

8. How often does your group meet? ____________________________________________

9. On average, how many people usually attend your group meetings? ________________
SECTION 2
This section focuses on how the group is organized and managed:
• activities and services provided by related organizations
• governance and internal organization
• profile of people working for the organization

Activities
10. What services or activities does your group currently provide? Please tick the appropriate boxes.

- Group general discussion meetings
- Group education sessions with guest lecturers
- One to one visits by specially trained members
- One to one visits by members with no special training
- One to one telephone support by specially trained members
- One to one telephone support by members with no special training
- Email or internet support in group or chatroom
- Email or internet support between individuals on a one to one basis
- A regular newsletter about the group
- Fundraising
- Lobbying for better services for cancer patients
- Advertisement and lobbying activity towards institutional stakeholders
- Knowledge management services to other patient groups - standardization of practices and tools to use during activities and meetings, database management, guidelines for practice, etc.

Specify _________________________________________________________________________________

- Training for patient groups or for other subjects - health-care professionals, others

Specify _________________________________________________________________________________

- Administrative services to other patient groups - mailing, advertisement of services offered by member groups, etc. (specify) _________________________________________________________________________________

- Other (Please describe) _________________________________________________________________________________

11. Identify the top three services your group provides from the ones you previously listed

1. _____________________________________________________________________________________________

2. _____________________________________________________________________________________________

3. _____________________________________________________________________________________________

12. What do you think is the utilization level and satisfaction level of your participants with your main services and what resources do you need for improving services in the future?
### Service line Utilisation level Satisfaction level Resources to improve

<table>
<thead>
<tr>
<th></th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
<th>High</th>
<th>Medium</th>
<th>Low</th>
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</tbody>
</table>

13. What services currently **not provided** by your group do you think your membership would be happy to receive?

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______________________________________________________________________________
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______________________________________________________________________________

14. Please list the topics or activities addressed at your group meetings over the past 12 months.

______________________________________________________________________________
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______________________________________________________________________________
Services provided by the patient groups’ associations

15. Provided that you are affiliated with other patient group/groups providing your organization with services, what is your level of satisfaction with these services and how could providers improve the service level?

<table>
<thead>
<tr>
<th>Service line</th>
<th>Utilisation level</th>
<th>Satisfaction level</th>
<th>Improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>...</td>
<td>High</td>
<td>High</td>
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<tr>
<td></td>
<td>Medium</td>
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<td></td>
<td>Low</td>
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<td>...</td>
<td>High</td>
<td>High</td>
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<td>Medium</td>
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<td>Low</td>
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<td>...</td>
<td>High</td>
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<td>Medium</td>
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<td></td>
<td>Low</td>
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<tr>
<td>...</td>
<td>High</td>
<td>High</td>
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<tr>
<td></td>
<td>Medium</td>
<td>Medium</td>
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<tr>
<td></td>
<td>Low</td>
<td>Low</td>
<td></td>
</tr>
</tbody>
</table>

Governance and internal organization

16. How is your group currently governed?

☐ President
☐ Board of trustees (composition)
☐ Steering committee (composition)
☐ Committees dedicated to specific topics (specify) ________________________________
☐ Other (specify) ________________________________________________________________

17. How is your group internally organized?

☐ By geographical base
☐ By topic – e.g. external relations, relations with patient groups, fundraising, etc.
(specify) ______________________________________________________________________
☐ Other (specify) __________________________________________________________________
18. What is the background of the person who has the main responsibility for the overall management of your group? Please tick one box only

- [ ] Health professional
- [ ] Cancer survivor
- [ ] Partner or family member of cancer survivor
- [ ] Shared between a health professional and a cancer survivor
- [ ] Other (Please describe)_______________________________________________________________

19. What is the background of the person who has the main responsibility for leading group meetings?

- [ ] Health professional
- [ ] Cancer survivor
- [ ] Partner or family member of cancer survivor
- [ ] Shared between a Health professional and a cancer survivor
- [ ] Other (Please describe)_______________________________________________________________

Profile of people working for the group

20. What are the main profiles of people working for your patient group? Please describe the areas of activity they are engaged on:

- [ ] Health-care professionals
  - [ ] Nurses
  - [ ] Doctors
  - [ ] Technicians (specify)______________________________________________________________

- [ ] Cancer survivors
- [ ] Partner or family member of cancer survivor____________________________________________
- [ ] Others (specify)_____________________________________________________________________

____________________________________________________________________________________
SECTION 3
This section explores how the patient group approaches and manages the relationships with its main beneficiaries

21. Provided that your organization offers services to other patient groups, how do you manage the relations with them?

- Periodic meetings held:
  - Monthly
  - Annually
  - Other (specify)_______________________________________________________________

- E-mail

- Periodic public events

- Other (specify)_______________________________________________________________
  ________________________________________________________________________

22. Provided that your organization offers services to other patient groups, who are the main contact people in your affiliated patient groups?

- Patient group manager

- People holding meetings with patients

- Other people administering the group (specify)_____________________________________
  ________________________________________________________________________

23. Provided that your organization offers services to other patient groups, does the association have direct contacts with participants in the affiliated patient groups?

- Yes

- No

If you answered YES to the previous question, please describe the scope and the frequency of these contacts

_____________________________________________________________________________
_____________________________________________________________________________

24. What are the main phases of contact with patients of your group?

- After the cancer diagnosis, before the hospitalization

- During the hospitalization period

- After the hospitalization period
25. How do you advertise the activities of your group? Please tick the appropriate boxes.

- Local radio
- Local newspapers
- Website
- Contacting health professionals
- Contacting existing members
- Contacting other community groups
- Contacting patients directly during the hospitalization period
- Other (please describe) __________________________________________________________

____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

26. Do you record personal details, such as names or contact numbers, about who attends group meetings?

- Yes
- No

27. In what ways do you update or maintain your mail list/list of participants? Please describe.

___________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
SECTION 4
This section profiles how the patient group is financed and in particular what support it receives from other agencies or people in the local area

28. How is your patient group financed?
- Donations from NGOs
- Contributions from other patient groups
- Contributions from governmental organizations
  - Local/regional government
  - Public hospitals
  - National Government
  - International/Supranational Institutions
  - Others (specify) __________________________________________________________

- Fees from participants
- Other (specify) ____________________________________________________________

29. Please indicate the percentage of the total income relative to each source of funding or if not possible prioritize, according to size, the sources of funding you currently utilize

<table>
<thead>
<tr>
<th>%</th>
<th>Source of funding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Donations from NGOs</td>
</tr>
<tr>
<td></td>
<td>Contributions from governmental organizations</td>
</tr>
<tr>
<td></td>
<td>Local/regional government</td>
</tr>
<tr>
<td></td>
<td>Public hospitals</td>
</tr>
<tr>
<td></td>
<td>National government</td>
</tr>
<tr>
<td></td>
<td>International/Supranational Institutions</td>
</tr>
<tr>
<td></td>
<td>Fee from participants</td>
</tr>
<tr>
<td></td>
<td>Contributions from other patient groups</td>
</tr>
<tr>
<td></td>
<td>Other (specify) ____________________________________________________________</td>
</tr>
</tbody>
</table>

30. From the external sources that you utilize most often, what type of support do you receive? (Please tick the appropriate boxes)
- Meeting rooms
- Photocopying and postage
- Funds
- Health professional to help as a group leader
- Special training for group members
- Other (please describe)
SECTION 5
This section explores partnerships and networks the group is managing/is part of

31. Who do you perceive to be your most relevant stakeholders?

- Local/regional governments
- Public hospitals – local health-care organizations
- Health-care professionals’ associations–representative bodies
- International/supranational institutions
- NGOs operating in the area of health-care promotion (specify)

- Health-care professionals
  - Nurses
  - Doctors
  - Technicians (specify)

- Other patient groups
- Others (specify)

32. What other kind of resources do you think you can obtain in the future from your stakeholders/do you think you can increase the amount of resources you currently receive from them?

<table>
<thead>
<tr>
<th>Subject</th>
<th>Resources/benefits</th>
<th>Possible improvements</th>
</tr>
</thead>
<tbody>
<tr>
<td>International/supranational Institutions</td>
<td>- Funds</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Political support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Guidelines and standards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Other (specify)</td>
<td></td>
</tr>
<tr>
<td>Ministry of Health</td>
<td>- Funds</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Political support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Other (specify)</td>
<td></td>
</tr>
<tr>
<td>Local/regional governments</td>
<td>- Funds</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Political support</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Other (specify)</td>
<td></td>
</tr>
<tr>
<td>Public hospitals – local health-care organizations</td>
<td>- Funds</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Integration of patient groups in health-care networks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Other (specify)</td>
<td></td>
</tr>
<tr>
<td>NGOs operating in the area of health (specify which area)</td>
<td>□ Contributions</td>
<td>□ Other resources</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
<td>----------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Other groups</td>
<td>□ Improvement of network/institutional contacts</td>
<td>□ Improvement of association’s business practices</td>
</tr>
<tr>
<td>Health-care professionals’ associations</td>
<td>□ Improvement of patient groups practices</td>
<td>□ Integration of patient groups in health-care networks</td>
</tr>
<tr>
<td>Others (specify)</td>
<td>____________________________</td>
<td>____________________________</td>
</tr>
</tbody>
</table>

33. From your experience, how often do doctors refer cancer patients to your group?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Sometimes</th>
<th>Very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

34. In what ways does working with the doctors benefit or help your group? Please describe.

35. Are there any ways your group would like to work more closely with these doctors? Please describe.
36. How closely do you work with the other stakeholders in health-care sector?

<table>
<thead>
<tr>
<th></th>
<th>Not at all closely</th>
<th>Somewhat closely</th>
<th>Very closely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local health-care units</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Public/private hospitals</td>
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<td></td>
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<tr>
<td>Nurses</td>
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<tr>
<td>Technicians</td>
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<tr>
<td>Others (specify)</td>
<td>__________________</td>
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</tbody>
</table>

37. How closely do you think your group should work with the other stakeholders in the health-care sector to be more effective in its activity and how do you think it is possible to keep them on board?

<table>
<thead>
<tr>
<th></th>
<th>Less closely</th>
<th>No changes</th>
<th>More closely</th>
<th>How to get stakeholders on board</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local health-care units</td>
<td></td>
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<td></td>
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<tr>
<td>Public/private hospitals</td>
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<tr>
<td>Nurses</td>
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<tr>
<td>Technicians</td>
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<tr>
<td>Others (specify)</td>
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</tbody>
</table>

38. How do you think other stakeholders in the health-care sector can/could be successfully integrated in your group’s activities?

<table>
<thead>
<tr>
<th></th>
<th>Local health-care units</th>
<th>Public/private hospitals</th>
<th>Nurses</th>
<th>Technicians</th>
<th>Other (specify)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group’s meetings organization and management</td>
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<tr>
<td>Referral to patient groups</td>
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<tr>
<td>Information/Training to patient group members</td>
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<td></td>
</tr>
<tr>
<td>Others (specify)</td>
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</tbody>
</table>
SECTION 6
This section asks about what might help the patient group in the future.

39. From your experience, what things make it more difficult to run your group? Please describe.

40. What changes or developments would help you to run your group more effectively or easily? Please describe.
About UICC

Founded in 1933, the International Union Against Cancer (UICC) is the leading international nongovernmental organization dedicated exclusively to the global control of cancer. Its vision is of a world where cancer is eliminated as a major life-threatening disease for future generations.

UICC is a non-profit organization. Its objective is to advance scientific and medical knowledge in research, diagnosis, treatment and prevention of cancer and to promote all other aspects of the campaign against cancer throughout the world. Members are voluntary cancer leagues and societies, cancer research and treatment centres and, in some countries, ministries of health.

UICC focuses on cancer prevention and control, tobacco control, knowledge transfer, capacity building, and patient advocacy and support. It organizes the World Cancer Congress held every two years, and annual symposia, workshops and training courses with extensive expert networks. It launched a World Cancer Campaign in 2005 and coordinates World Cancer Day on 4 February each year.

UICC fellowships help train researchers, clinicians, health professionals and cancer workers across the world. Between them, GLOBALink (the online tobacco control community) and the Global Cancer Control Community service over 7,000 researchers and professionals.

UICC publishes the International Journal of Cancer, books in the TNM and prognostic factors series, a calendar of international cancer conferences, and technical reports, newsletters and manuals.

UICC is governed by its members through a general assembly, which meets every two years, and an elected board of directors. With over 300 members in more than 100 countries, UICC is a resource for action and a voice for change.