



Starting and Maintaining a Successful End-of-Life Coalition

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Starting and Maintaining a Successful End-of-Life Coalition

Introduction

A coalition is an alliance of parties or people created to work toward a common cause. Coalitions can be powerful agents for creating social change and calling attention to issues that affect communities. Membership in coalitions may range from individuals and organizations working at the heart of the coalition's cause, to diverse members with personal, special, or political interests. What matters is that a group of distinct members has joined to create and support efforts toward a common goal.

End-of-life coalitions may form in order to increase the community's awareness of relevant issues, to support community initiatives, to help change public policy, or for a wealth of other reasons. Individual agencies may be working toward many of these same goals. So, why start an end-of-life coalition? Here are some good reasons:

- Coalition members can educate one another about programs and services in your community.
- A coalition extends the assets of organizations by pooling resources.
- A coalition can increase credibility in the community by including key stakeholders in your process.
- Coalition members can work together to identify community needs and develop potential solutions from multiple perspectives.
- A coalition can convene a cross section of individuals and agencies with a shared mission to improve access to quality end-of-life care and services.
- A coalition can expand the ability of a single organization to promote interest in and awareness of end-of-life activities.
- A coalition can empower underserved segments of the community to participate in creating change.
- A coalition can address identified needs that cannot be addressed by any single organization or agency.

Building an end-of-life coalition is an art and a science. It takes a commitment from the founders to invest in the process. The **Caring Connections** program of NHPCO can provide resources, mentoring, and support to assist you in building a self-sustaining coalition working to improve end-of-life care and services in your community.

Getting Started

The following steps will help guide you through the coalition development process. Your coalition may choose to skip certain steps or approach them in a different order -- this need not be a linear process.

1. Gather a working group
2. Select an area of focus
3. Identify initial resources
4. Assess community needs
5. Identify potential coalition members
6. Invite members
7. Develop coalition leadership
8. Conduct the first meeting
9. Develop a vision/mission
10. Develop a strategic plan

1. Gather a working group

The first step in starting an end-of-life coalition is to find others willing and interested in the issue who can help you in the initial phases. Having a working group in the beginning of this process can help you widen your access to potential coalition members, deepen your initial resource pool, and demonstrate to the community the shared interest in end-of-life issues. Think of your professional and personal contacts, those working in end-of-life care, those whom the issue affects, and "people who know people." You may be surprised at how quickly this working group comes together!

2. Select an area of focus

The next step is to brainstorm the kind of changes your coalition can bring to your community. Your working group members will likely be aware of some of the community's needs through their personal and professional experience. It may help to consider questions such as the following:

- What do you know about end-of-life care in your community?
- Who in your community cares for your dying?
- What end-of-life resources are you aware of in your community?
- Where do people die in your community?
- What barriers to accessing end-of-life care are you aware of in your community?
- What positive and negative end-of-life experiences have working group members had?

- What gaps in end-of-life services are you aware of in your community?
- What new information about end-of-life care or legislation is available?

In identifying the focus of your coalition, it is important to develop broad initial goals aimed at achieving community change. These initial goals can be used to identify stakeholders (or people with a vested interest) and potential coalition members and invite them to participate in the process. For example, if your coalition's focus is on professional education, you may want to recruit representatives from the professional development and education departments of local hospital and nursing facilities. If your coalition's focus is on identifying gaps in end-of-life service provision, you may want to recruit people from end-of-life service organizations and those who represent the underserved.

One of the primary reasons for identifying an area of focus is that coalition development is enhanced when members agree on goals and measures of success. Remember that your group's focus may change as the coalition grows and matures, and as you learn about and work with your community.

3. Identify initial resources

Your working group will have resources – some more easy to recognize than others. Resources can be anything from available funds to extra time. Access to office machines, networking contacts, the ability to cover printing costs, a volunteer pool and Internet-savvy individuals are all useful resources. It is important to determine what resources you have available in the initial stages of starting a coalition. A coalition member resource assessment is provided in the Exercises and Samples Section below to help your group determine your available initial resources. You can use this assessment tool again later when identifying potential coalition members to expand your working group. The status of your resources will help you identify potential coalition members who can add to your resource pool, and determine the methods by which your group can address some of the steps in the coalition development process.

4. Assess community needs

In step 2, your working group members identified an area of focus for the coalition based on their experience and knowledge. Since your working group represents a small portion of the community, it is important to perform an assessment of needs related to your coalition's area of focus as perceived by a diverse cross section of the community.

This process can often seem overwhelming and costly. There are multiple ways to begin the community assessment process, many of which are not complicated or expensive.

- Review Existing Data
Your coalition can gather existing information about the community from various sources. There are many free sources of service utilization, demographic and other information available on the Internet and from governmental agencies.

Sources of Secondary Data

Local and State Data

- Local or state health departments
- Community organizations
- Universities
- Census bureau (<http://www.census.gov>)
- US aggregate statistics (<http://www.prb.org>)

National Data

- **National Center for Health** (<http://www.cdc.gov/nchs>; phone: 301-458-4636): Studies and surveillance data including the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the National Survey of Family Growth
- **National Health Information Center** (<http://www.health.gov/nhic>; phone: 301-565-4167 or 800-336-4797): Referrals to appropriate federal clearinghouses and information centers as well as other organizations serving as resources for a particular topic
- **Centers for Disease Control and Prevention** (<http://www.cdc.gov/scientific.htm>): Online links to research data, including large-scale health surveys and the *Morbidity and Mortality Weekly Report*
- **Roper Center for Public Opinion Research** (<http://www.ropercenter.uconn.edu>; phone: 860-486-4440): Database of thousands of public opinion poll questions from 1936 to the present (fee charged to access this information)
- National organizations (e.g. American Cancer Society, Alan Guttmacher Institute)
- Academic journals
- Private marketing research firms
- Foundations
- Professional associations

Source: Hands-on Social Marketing: A Step-by-Step Guide by Nedra Kline Weinreich (Sage Publications, 1999)

The community assessment sources listed above can provide you with a limited snapshot of community needs related to your coalition's area of focus.

- **Written Survey**
Your group can create a simple written survey with a few key questions to assess community attitudes, expectations and needs related to end-of-life care and service delivery. You may select people randomly from the phone book, or mail the survey to consumers of the services provided by organizations in your coalition. To cut costs, volunteers from coalition member agencies can help stuff envelopes, or a coalition partner can donate the cost of the mailing.
- **Focus Groups/Feedback Sessions**
Informal focus groups or feedback sessions provide an opportunity to hear community members discuss end-of-life issues and identify needs in their own words. This process can take many forms. Consider different methods your coalition might use to invite community members, possible locations for your session and the kind of agenda that would best suit your purposes.

5. Identify potential coalition members

Coalition founders need to identify potential coalition members to join them. Ideally, the people invited should directly or indirectly have information about, influence over, or be consumers of the focus and goals identified in step 1. The following types of questions can assist you in this process:

- Who influences how people die in our community? Include direct involvement and peripheral involvement.
- What organizations and key people must we partner with to ensure "buy-in" and a demographically representative cross-section of our community?
- What other organizations in our community are providing end-of-life care/services?
- Where do people learn about end-of-life issues in our community/society?
- What are the biggest barriers to increasing access to end-of-life care and services? Who can help break down those barriers?
- What resources will our coalition need to be effective in promoting change?

It is important to include gatekeepers in your coalition to ensure credibility. Gatekeepers are the leaders in parts of the community who, officially or

unofficially, grant or deny entry into that part of the community. To earn acceptance in a community of which you are not a member, it is often necessary to demonstrate to the gatekeeper that you have a non-judgmental, non-threatening attitude and a genuine respect for the community. This can happen by including multiple gatekeepers in your coalition and actively seeking their input as you plan events and programs. Refer to the *Community Map* in the Exercises and Samples section below to assist you in identifying potential groups of stakeholders to invite to join your coalition.

When building a coalition, it is important to determine potential members' reasons for wanting to belong to the coalition. This can defuse problems before they appear. In addition to the benefit of promoting an individual agency, it is vital that all coalition members have global reasons for belonging to the coalition and are able to contribute to the greater good.

Ask coalition members why they are there and what resources they can commit to the process. Resources can include money, staff time, volunteers, space, food, in-kind donations, etc. Use the coalition member resource assessment provided in the Exercises and Samples section below to facilitate this process. Determining the coalition's resources can also be very useful as you develop a strategic plan.

6. Invite members

Initially, you may decide to keep the coalition small until you determine how it will be structured, or you might decide to "cast the widest net" and invite everyone who has an interest in your cause. As your coalition matures, you may decide to add members or to let attrition lead to a smaller working group.

Before you invite potential members to join you, you must be able to articulate the general purpose and goals of the coalition. If multiple people are issuing in-person invitations to potential members, you might want to develop a one-page information sheet stating the coalition goals, any membership requirements or expectations, current members and other pertinent information. You can follow-up with a letter inviting new members to their first meeting.

Your coalition information sheet can be updated periodically to reflect changes to the membership, add the vision/mission statement, etc. An example of an information sheet for the Pinellas Partnership for End-of-Life Care coalition is provided in the Exercises and Samples section, below.

7. **Develop coalition leadership**

The reason your coalition comes together may influence which person or individual will initially become the leader. If a single organization has put forth the effort to form partnerships with others and convene a coalition, a representative from that organization might take an initial leadership role. If the coalition is convening around a specific issue or event, the group convening the coalition should select a leader or lead organization familiar with the topic before the first meeting. Regardless of the reason for starting the coalition, it is important to identify a leader who can speak on behalf of the group.

Ideally, coalitions also have leaders who can communicate a broader vision of end-of-life issues and inspire active participation in the coalition. In addition, coalitions need someone to manage the following responsibilities:

- Facilitate coalition meetings
- Develop meeting agendas (with input from members)
- Ensure that follow up meetings are scheduled
- Welcome new members to the coalition
- Maintain the membership roster
- Participate in developing and maintaining an operating budget

Coalition leaders also need to have an understanding of group process and dynamics to help the coalition evolve through the normal stages of group development. As new members are added and structure evolves, leadership may need to change to best meet the needs of the coalition.

8. **Conduct the first coalition meeting**

The first meeting of the coalition can set the tone for the ongoing work of the group and the ability to complete projects aimed at improving end-of-life services in the community.

It is likely that coalition members will have varying degrees of expertise regarding the local, state and national end-of-life movement. You may opt to provide background materials to coalition members to give individuals a common set of information and to give them a context for understanding the need for the establishment of a coalition. [Information](#) on coalition building is available at www.Caringinfo.org.

You may choose to spend time during the first coalition meeting having group members share their professional and/or personal experiences with end-of-life issues, care delivery systems, cultural norms, etc. This will help

coalition members learn more about each other and the expertise in the group.

At the first meeting, make sure to set a date, time, and place for the next meeting and identify the topic to be addressed. At subsequent meetings, members may leave with tasks or projects to work on, and can report on their progress. Meetings are most productive when the leader or a designated member plays an active role in facilitating the process.

9. Develop a vision/mission

Vision and mission statements drive the efforts and spell out the beliefs and principles of your coalition for the greater community and coalition members. A vision is the picture or dream of what you want to achieve. Visions typically focus on long-range goals.

A mission statement spells out the “what and why” action steps to reach your vision. Mission statements are more concrete, short-term objectives and strategies. Community coalitions striving to improve access to end-of-life care and services must have a broad vision and mission. In order to encompass the broad range of end-of-life issues, be sure to take time to have your draft vision/mission reviewed by a broad range of constituencies.

End-of-life coalition **vision** statements:

- Every person has timely access to quality end-of-life services.
- People in this community die where they want.
- The community cares for caregivers.
- Every grieving person is offered support.

End-of-life coalition **mission** statements:

- Increase access to end-of-life services by eliminating barriers, enhancing services and reaching out to the community.
- Promote end-of-life conversations through community education, outreach and dialogues.
- Create a community network of caregivers and support systems for those at the end of life.
- Support caregivers with education and support to care for those at the end of life.
- Increase awareness of available grief support services through education and outreach.

10. Develop a strategic plan

In step 2 of our process, we discussed the initial goals or rationale for starting your coalition. Once you've developed your vision and mission, it is time to translate your broad goals into specific objectives for your coalition. You should be able to link each goal/objective with the vision and mission statement of your coalition. Often goals change over time as new coalition members are added, community needs assessment data is analyzed and you learn more about the availability and quality of end-of-life services currently available in your community.

A coalition's objectives offer specifics of *how much* of *what* will be accomplished *when*.

For example, end-of-life coalition **objectives** related to advance care planning might be:

- Distribute 500 advance care planning packets by year end.
- Conduct twenty community forums on advance care planning by year end.
- In 2002, increase percentage of advance directives completed for people admitted to XYZ hospital.
- Sixty percent of people in XYZ retirement community will document their end-of-life wishes by December 2003.
- Twenty large employers (more than 200 employees) will include information about advance directives in their paycheck envelopes.

Once the vision, mission and objectives are developed, the final steps in developing a strategic plan are to develop the strategies by which your coalition will achieve the goals, and an action plan to implement them. A strategy is a way of describing *how* you are going to get things done.

For example, strategies related to the advance care planning objectives above include:

- Distribute advance directive packets at all Speaker's Bureau presentations, health fairs, libraries and other public events/venues.
- Conduct the community forums at easily accessible locations in the community, develop an agenda for the forums and determine the options for publicizing the events.
- Provide education for hospital admissions staff regarding advance care planning and assure that advance directives are easily accessible during the admissions process.
- Conduct educational sessions for residents and staff at XYZ retirement community about advance care planning, distribute advance care planning documents to all residents, and provide opportunities for individual assistance completing the documents.

- Contact the fifty largest employers in the community regarding opportunities to distribute information to employees and develop a one page flyer on advance care planning to be inserted in paycheck envelopes

The last step in your strategic planning process is to develop the action plan. The action plan outlines the activities the coalition will undertake to implement the strategies. According to the Community Tool-Box Center (<http://ctb.ukans.edu/tools/corecompetencies.jsp>), an action plan documents:

- *What* actions or changes will occur
- *Who* will carry out these changes
- *When* they will take place, and for how long
- *What resources* (i.e., money, staff) are needed to carry out these changes
- *Communication* (who should know what?)

Once the action plan is developed, your coalition is well on the way to implementing strategies to improve end-of-life care and services in your community. Refer to the Community Tool-Box Center (website listed above) for more information about the elements of developing a strategic plan.

Evaluation

The success of a coalition is often measured by the outcomes of the work it undertakes. However, measuring the outcome of coalition efforts is not always the same as measuring social change. Much of the success of a coalition can be seen in the ways in which it helps to shape and transform the community it serves. Creating social change is not always directly linked to coalition activities.

Because social change is a dynamic process, evaluating it is like trying to evaluate a subtle shift in the wind or tides. Small changes may be detected, but it is difficult to determine the cause. While you can never know for certain that a particular coalition event resulted in lasting social change, thorough evaluation can help to determine whether any change occurred after the event or activity. Your coalition can use focus groups, questionnaires, telephone surveys, or other data collection methods to measure outcomes. The method your coalition chooses will depend upon what you want to measure, what kind of data was initially collected, and the resources available to perform your evaluation. In order to obtain the most accurate and useful measure of change, you will need to use the method that best suits what you are trying to

achieve, and trying to measure. Your coalition may choose to have a research consultant help with the evaluation process.

One important component of evaluating social change is identifying other factors in the community that may or may not have had an influence. For example, if you are trying to determine whether a coalition event on advance directives was responsible for increasing completion of advance directives in your community, the coalition might ask, "What other activities in the community might be responsible for this? What organizations/agencies were conducting advance directive activities at the same time as the coalition? Was there media attention on advance directives during the time in question?" If there are no other factors that might have had an influence, then the coalition can make a stronger case that their activity or event was largely responsible for the change. This kind of evaluation process will be important as your coalition completes initiatives and implements the strategies developed.

Even in the initial stages of building a coalition, it is possible to measure progress. This early evaluation of coalition building success can be achieved by looking at internal aspects of the coalition such as:

- Level of ongoing participation by coalition members
 - Attendance at meetings
 - Participation in coalition activities
- Support of coalition activities from coalition members
 - Financial support
 - In-kind support (including donated services)
- Productivity of coalition meetings – what you are able to accomplish
- Ability of new members to become involved – how quickly this happens
- Completion of action steps identified in the strategic planning process

You may decide to have the coalition periodically complete a self-evaluation. You can develop this using the above indicators and questions related to specific coalition activities and goals.

Conclusion

Starting a coalition is a time-consuming process that requires planning and organization to ensure that the time invested is well spent. The benefits of partnering with others to foster change through a community coalition are worth the "front-end investment." Coalitions can multiply the power of individuals and organizations to promote social change, can heighten visibility and awareness of community issues, and can focus the community's available resources toward improving end-of-life care and services.

Just as no two people and no two communities are identical, no two coalitions will look exactly the same. Assessing and understanding your community allows your coalition to reflect, in membership and focus, the community's diversity, current end-of-life care delivery systems, and most pressing needs. With active members, knowledge of the community, awareness of your resources, effective leadership, viable goals, and a solid plan, you have all the elements of a strong coalition. Social change is possible.

Exercises and Samples

Coalition Resource Assessment

You can facilitate this as a group discussion or ask members to complete this form and return it to the coalition leader.

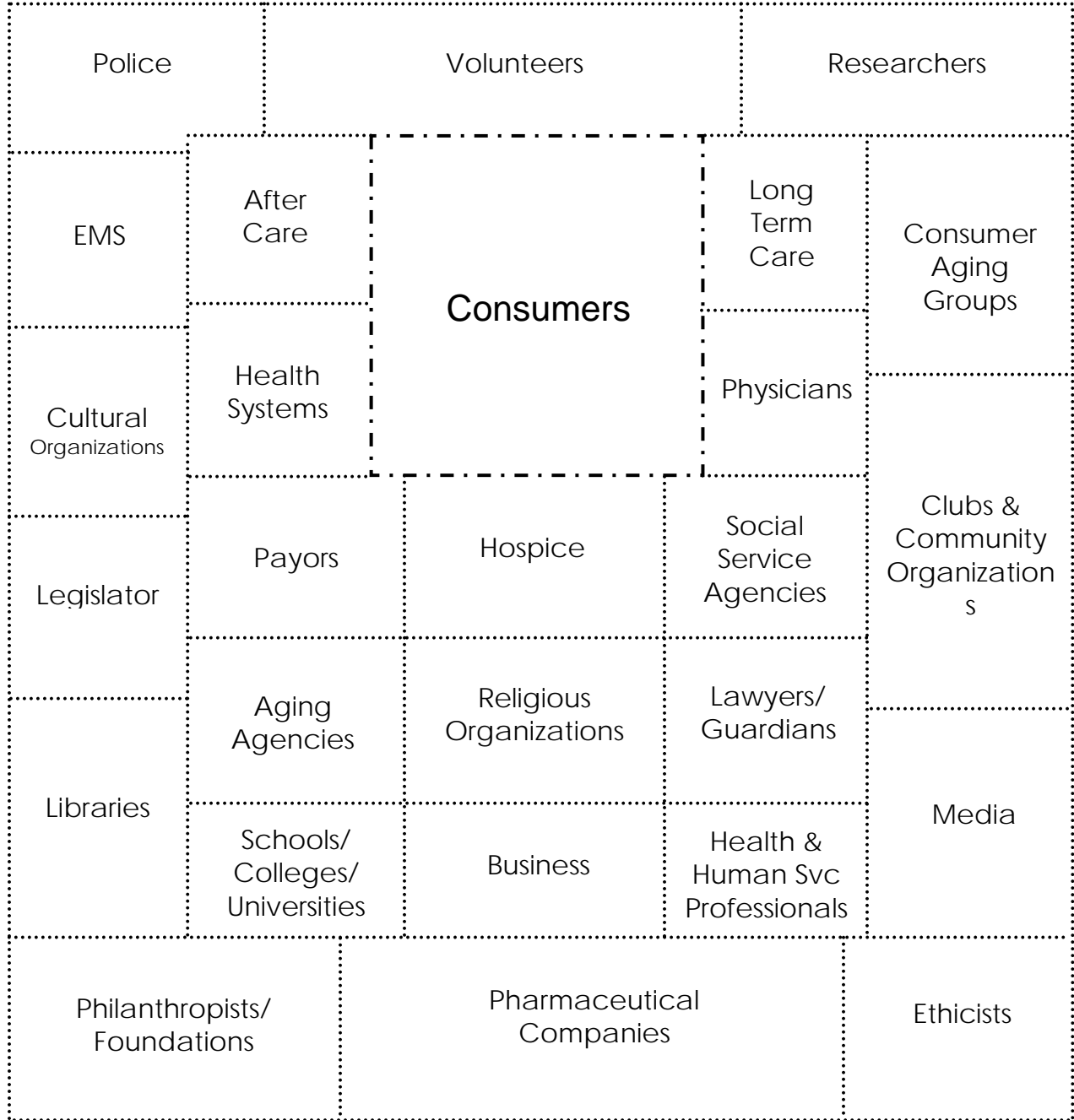
Coalition Member/Agency _____

Primary Customers (e.g. hospice/palliative care patients, elderly, caregivers, grieving parents): _____

Resources to Share with the Coalition - put a check in the box next to each resource you can provide. In the space provided, note any other relevant information (meeting room location or space, amount of financial support available, etc).

Resource	✓	Additional Notes
Coalition meeting space		
Conference/event space		
Annual contribution		
Periodic financial donations		
Volunteers		
Mailing list		
Newsletter for PR		
Speakers bureau		
PR/marketing staff (list skills)		
Contact hour provider (CEUS)		
AV equipment		
Other (list)		

Community Map





The Pinellas Partnership for End-of-Life Care is a community coalition of individuals and groups that share the common goal of enhancing access to quality end-of-life education, information and services. Committed to comfort and compassion when it's needed most, the coalition encourages the development of new ideas and solutions, seeks to strengthen collaborative initiatives, enhances networking opportunities and promotes quality end-of-life care for all Pinellas County residents. The coalition is a community-based affiliate of the Florida Partnership for End-of-Life Care.



For more information, contact Mike Bell, Pinellas Partnership Coordinator, at (727) 586-4432 or Mikebell@thehospice.org.

Vision

A community prepared to experience the end of life with dignity, meaning and respect.

Mission

The mission of the Pinellas Partnership for End-of-Life Care is to:

- Create opportunities for public dialogue;
- Encourage conversation about end-of-life issues as a natural part of community life;
- Enhance consumer understanding and participation in end-of-life decision making;
- Engage diverse communities through culturally sensitive initiatives;
- Advance palliative care and pain management initiatives through community and professional education;
- Issue a "call to action" for our community to influence public policy related to end-of-life issues; and,
- Encourage provider partnerships which ensure that all individuals receive exceptional end-of-life care and services.

Pinellas Partnership Members:

Area Agency on Aging of Pasco-Pinellas, Inc. • Bon Secours Maria Manor
Moss Feaster Funeral Homes • Project GRACE • St. Petersburg College
St. Petersburg General Hospital • The Hospice of the Florida Suncoast

Pinellas Partnership for End-of-Life Care

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