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Glossary

**Activism** – use of action or involvement to achieve political or social change

**Advocacy** – an activity that is used to gain public support for a particular cause or policy

**Campaigning** – a way to work together in an organized way toward a particular goal

**Chromosome** – an organized structure found inside of the cell nucleus that contains genetic information in the form of genes

**Deoxyribonucleic acid (DNA)** – a molecule that carries genetic information in the cells of living organisms

**European LeukemiaNet** – a research network funded by the European Union with a goal of curing leukemia

**Gene** – a segment of DNA that is transferred from a parent to offspring and determines some characteristics of the offspring

**Karyotype** – the number and visual appearance of chromosomes in a cell nucleus

**Lobbying** – the act of attempting to influence leaders, such as politicians or public officials, on a particular issue

**Policy** – a plan or procedure of action adopted or proposed by a government, party, business, or individual

**Polymerase chain reaction** – a laboratory technique used to make multiple copies of a piece of DNA

**Progression-free survival** – the length of time during and after the treatment of a disease that a patient lives with the disease but it does not get worse

**National Comprehensive Cancer Network** – a network of cancer centers in the United States that is focused on improving the quality of cancer care
Abbreviations

- **BCR-ABL**\textsuperscript{IS}, BCR-ABL transcripts measured on the International Scale
- **CCyR**, complete cytogenetic response
- **CF**, conversion factor
- **CML**, chronic myeloid leukemia
- **DNA**, deoxyribonucleic acid
- **ELN**, European LeukemiaNet
- **IRIS**, International Randomized Study of Interferon vs STI571
- **IS**, International Scale
- **LDT**, laboratory-developed test
- **MMR**, major molecular response
- **NCCN**, National Comprehensive Cancer Network
- **PFS**, progression-free survival
- **PCR**, polymerase chain reaction
- **Ph+ CML**, Philadelphia chromosome–positive chronic myeloid leukemia
- **TB**, tuberculosis
- **TKI**, tyrosine kinase inhibitor
What is the My PCR initiative?
My PCR (MyPCR.org) is a community-driven initiative conducted in partnership with chronic myeloid leukemia (CML) patient advocacy organizations around the world. It is designed to raise awareness among people living with CML, caregivers, advocates, and physicians about the importance of regular, standardized CML diagnostics and monitoring. Our partners share a common mission to educate their communities about the importance of PCR testing and improve access to PCR testing for people living with CML.

Why a PCR advocacy toolkit?
As a community-driven initiative, My PCR seeks to provide resources that address needs identified by the CML community. The My PCR partners expressed a need for clear and simple educational resources about how to advocate effectively for access to PCR testing. In response to this request, My PCR initiated the process of creating the My PCR Advocacy Toolkit. The content in this toolkit was generated through an iterative co-creation process that involved feedback from the CML community and strategic guidance from a steering committee composed of partner advocates from Asia, Africa, South and Central America, and North America.

This toolkit is a resource for advocates that provides educational information about PCR testing and the importance of regular PCR monitoring for patients with CML and provides guidelines on how to strengthen advocacy efforts to bring better access to PCR testing to your local community.

Who can benefit from using this toolkit?
The PCR Advocacy Toolkit is for advocates who want to campaign for better access to quality PCR testing for patients with CML in their communities. It is a tool for those who wish to develop a deeper understanding of the subject area and of how to create a successful advocacy strategy.

How can one make the most of this toolkit?
There is no one way to conduct advocacy, and one’s approach to advocacy will vary widely depending on local political and social context and access needs. This toolkit is a practical guide to help advocates understand PCR testing and adapt the suggestions in the toolkit to implement an advocacy strategy that makes sense within a local context. It is divided into 2 sections. Section I provides background information about PCR testing in the diagnosis and management of CML. Section II provides guidelines and tools for developing an advocacy strategy. Readers can also access additional information on related topics at the end of the toolkit.
Philadelphia chromosome–positive chronic myeloid leukemia (Ph+ CML) is a cancer of the white blood cells that is associated with an abnormal chromosome. A chromosome is an organized structure found inside a cell that contains genetic information known as DNA. The abnormal chromosome is called the Philadelphia chromosome. Ph+ CML is caused by BCR-ABL, an abnormal fusion gene that is formed when a piece of chromosome 9 and a piece from chromosome 22 swap places. The abnormal BCR-ABL gene creates a protein called BCR-ABL. The BCR-ABL protein causes changes in cells that lead them to become cancerous.
What is PCR?

PCR stands for polymerase chain reaction. It is a blood test used to diagnose CML and to measure the response to treatment in patients who are on tyrosine kinase inhibitor (TKI) treatment. PCR is not only used in CML; it is also used in other conditions and is generally one of the most accurate ways to detect the presence of a substance. For example, PCR testing can detect anthrax on a mailed letter or evidence of a specific virus in a person after bone marrow transplant.

- PCR is a laboratory technique that is used to amplify, or make multiple copies of, a segment of DNA.
- In CML, PCR is used to measure the amount of genetic material that is present.
- PCR is a very sensitive method that can detect very low levels of BCR-ABL.
Why is PCR testing necessary for patients with CML?

Prior to 1960, very few treatment options existed for patients with CML. Once it was understood that BCR-ABL played a role in Ph+ CML, targeted therapies known as tyrosine kinase inhibitors, or TKIs, were invented to specifically inhibit the progression of CML. The introduction of TKIs has allowed many patients to remain in chronic phase for years without progression to advanced phase or blast crisis, leading to an increased life expectancy for patients with CML. Because CML is a disease that usually requires lifelong treatment, consistent access to PCR testing is critical for patients to monitor the disease. Testing is recommended every 3 to 6 months depending on a patient’s level of response to treatment.¹⁴

Despite its importance for people living with CML, many patients do not have appropriate access to PCR testing. The primary challenges are that (1) PCR testing requires expensive diagnostic equipment that is not available in all countries, (2) not

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Measuring molecular responses relies heavily on the ability of a technique to achieve the necessary precision, accuracy, sensitivity, and efficiency³:

- **Precision** – the closeness of two measurements to each other
- **Accuracy** – how close a measurement is to the true result
- **Sensitivity** – the smallest amount of change that can be detected in a measurement
- **Efficiency** – the ability to perform well without wasted resources
all physicians are properly trained on PCR testing for CML patients, and (3) many CML patients do not understand what PCR testing is and why it is so critical to their health.

PCR testing is important for patients with CML because it can be used to diagnose the disease and also to evaluate how well a patient’s treatment is working. By monitoring the level of BCR-ABL over time, a physician can compare results and make informed decisions. Regular PCR testing will give physicians the information they need to decide whether a patient is responding effectively to their treatment and whether or not it is necessary to change treatment to better treat the disease.

Other tests are available for patients with CML, such as a bone marrow test. Links to additional resources on bone marrow tests can be found at the end of this toolkit.

International recommendations for PCR testing

The ELN and NCCN research networks have developed recommendations for how frequently patients should receive molecular testing.

<table>
<thead>
<tr>
<th>ELN and NCCN Recommendations for Molecular Monitoring</th>
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<tbody>
<tr>
<td><strong>Baseline</strong></td>
</tr>
<tr>
<td>ELN-recommended monitoring</td>
</tr>
<tr>
<td>NCCN-recommended monitoring</td>
</tr>
</tbody>
</table>

The ELN has recommendations for achieving certain treatment goals, or milestones, at different times after starting treatment for CML.
Understanding PCR results

The first important treatment milestone is early molecular response, or EMR, at 3 months after the start of treatment. EMR means that BCR-ABL level is ≤ 10% of baseline. Another important treatment milestone is a complete cytogenetic response (CCyR). CCyR is equivalent to a 2-log, or 100-fold, decrease in BCR-ABL level. A major molecular response (MMR) is a 3-log, or 1000-fold, decrease in BCR-ABL level compared to a standardized baseline. MMR is an important goal for patients being treated for CML because achieving MMR is associated with a reduction in the risk of losing response and with lower risk of disease progression. Some new therapies allow patients to achieve deeper responses, such as MR4 (4-log decrease) or MR4.5 (4.5-log decrease).

Benefits of PCR testing

Monitoring BCR-ABL levels over time can help physicians make clinical decisions. PCR testing is more sensitive than other techniques used to monitor CML. PCR can be performed using a blood sample, so it is less invasive than tests that require a bone marrow biopsy.

A monitoring frequency of 3 to 4 times a year has been associated with:

- Reduced risk of disease progression
- Longer progression-free survival (PFS)
- Increased adherence to treatment
- Fewer inpatient hospital visits
- Reduced financial burden to patients

The log scale is a way of looking at values that uses factors of 10 in order to show very large differences in numbers on a smaller scale.

1-log decrease is equivalent to a 90% reduction
2-log decrease is equivalent to a 99% reduction
3-log decrease is equivalent to a 99.9% reduction
4-log decrease is equivalent to a 99.99% reduction
5-log decrease is equivalent to a 99.999% reduction
Considerations for proper testing

Several considerations are important for obtaining reliable PCR results. For reliable PCR results, at least 10 mL of blood should be used for the test, and the blood sample should arrive in the laboratory and be processed within 24 hours of the blood draw.

Different types of PCR tests are available, including laboratory-developed tests (LDTs), commercially available kits, and automated systems, and each has advantages and disadvantages.

Several factors can contribute to differences in results, such as the instrument and materials used, the protocol, and the experience of the technologists performing the assay. Since not all laboratories use the same tests, the same level of leukemia could result in different test results in 2 different laboratories. To improve the accuracy and decrease the variability of molecular monitoring, an International Scale (IS) was developed in 2005 to allow alignment of BCR-ABL values by different laboratories. The IS uses a standardized baseline BCR-ABL level that was established from the IRIS clinical trial, which compared the TKI imatinib with older treatments that were commonly used to treat CML. Blood samples from patients in this trial were tested to establish a typical baseline level of BCR-ABL.

This baseline level was defined as 100%. A 3-log reduction in BCR-ABL level, or 0.1%, was defined as MMR.

Laboratories can become standardized to the IS by using a sample exchange process or by using secondary IS calibrators that are traceable to the WHO reference panel in order to establish a laboratory-specific conversion factor (CF). Laboratory results that are not standardized to the IS can be useful in showing the trend in an individual patient’s response but cannot report whether a patient ever achieved a response of MMR or deeper; reporting MMR requires the use of a laboratory-specific CF that is aligned to the IS.

<table>
<thead>
<tr>
<th>Type of PCR Test</th>
<th>Cost</th>
<th>Validation</th>
<th>Platform</th>
<th>Expertise Required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laboratory-developed tests</td>
<td>Low cost</td>
<td>No independent validation</td>
<td>Compatible with multiple platforms</td>
<td>High level</td>
</tr>
<tr>
<td>Commercially available kits</td>
<td>Higher cost</td>
<td>Defined protocols and robust validation by the manufacturer</td>
<td>Compatible with multiple platforms</td>
<td>High level</td>
</tr>
<tr>
<td>Automated systems (eg, GeneXpert)</td>
<td>Highest cost</td>
<td>Independently validated</td>
<td>Specific instrument required</td>
<td>Lower level</td>
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What is advocacy?

Advocacy is an activity carried out to gain public support for a particular cause or policy. A human rights approach to advocacy focuses on the rights of patients, barriers to the enjoyment of those rights, and the ways in which the actions of individuals in power influence these barriers. Advocates seek to influence individuals in power to break down the barriers.

How to advocate effectively

There is no one way to conduct advocacy, and the approach will vary depending on local access needs and the political and social context. There are several important considerations for successful advocacy, including appropriate government policies, education of policy makers and the public, adequate test availability, and implementation of services. Regardless of the specific considerations, the best way to advocate effectively is to develop and follow a plan by following the steps above.
Develop an understanding of the subject matter

The first step in successful advocacy is understanding the subject matter with which you are working. Having an understanding of what PCR is, why it is important, and what the specific needs are for patients in your community will enable you to establish an effective goal and develop an impactful campaign.

Part I of this toolkit provides background information on the importance of PCR in CML. Readers can access additional information on related topics at the end of the toolkit.

It is important to have a clear understanding of the unique challenges and barriers that exist within the local context of your country. There may be patient-related challenges, physician-related challenges, or health system–related challenges. Examples of common barriers to accessing high-quality PCR, particularly in resource-poor settings, are:

<table>
<thead>
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<th>Patient-related challenges</th>
<th>Physician-related challenges</th>
<th>Health system–related challenges</th>
</tr>
</thead>
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<tr>
<td>Availability of PCR testing</td>
<td>Lack of understanding about the importance of PCR testing for the management of CML</td>
<td>Poor supply chain infrastructure</td>
</tr>
<tr>
<td>Cost of testing</td>
<td>Lack of consistent access to tests (inconsistent supply)</td>
<td>Lack of financial support from the local Ministry of Health for procuring automated systems and tests at government hospitals</td>
</tr>
<tr>
<td>Cost of travel</td>
<td>Poor-quality testing facilities</td>
<td>Private clinics that are unaffordable for patients</td>
</tr>
<tr>
<td>Travel time</td>
<td>Inability to use automated systems that are in place for testing in other diseases (eg, tuberculosis)</td>
<td></td>
</tr>
<tr>
<td>Education about the need for PCR testing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding where to receive tests</td>
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Advocacy Case Study, Step 1: Develop an understanding of the subject matter

**Challenge:** No access to PCR testing for CML patients in your country

As a patient advocate who wants to bring access to PCR testing to CML patients in your country, you already have a strong grasp of what PCR is and why it is important in the management of CML. In order to better understand the local barriers to testing, you research the following:

1) What are the key barriers to PCR access in your country (eg, funding, technology)?

2) What efforts, if any, have been conducted in the past to bring PCR testing for CML patients to your national hematology center?

3) What is the cost of a PCR machine, machine maintenance, and tests?

4) Are there assistance programs for PCR machines and tests?

5) Is there a laboratory at the national hematology center that can support PCR testing for CML patients?

6) Are there physicians who are willing to advocate to the hospital administration for access to PCR for CML patients?

7) How educated are patients in your country about the importance of PCR testing in the monitoring of their CML disease levels?

Through your subject matter research, you develop a good relationship with the hematologists in the local hospital, and you discover that a PCR machine is currently in operation in the tuberculosis (TB) laboratory. The hematologists are aware of the PCR machine, but they have not been able to use it for CML patients because the laboratory technician does not believe it is safe and effective to run both TB and BCR-ABL tests on the same machine.

You also discover that one of your advocate partners, The Max Foundation, has a collaborative agreement with the company that manufactures the PCR machine and BCR-ABL tests to provide discounted pricing on PCR instruments and tests. They also offer occasional donations of tests to qualifying institutions. The Max Foundation is able to put you in contact with a local representative from the company that manufactures the instruments and tests to provide you with additional information about how the tests work. The contact confirms that both TB and BCR-ABL tests can be safely run on the same machine without compromising the test results.
Advocating for PCR Testing: Tips for Implementing a Successful Campaign

Before establishing an advocacy goal, you should research several key questions to help understand PCR testing in your area. Some key questions include:

- Is PCR testing available anywhere in the country, and if so:
  - Where is it available?
  - Are there gaps in access due to the geographical location of the machines?
  - What types of instruments are used for testing?
  - What is the quality of the PCR testing, and is the laboratory on the IS?
  - What percentage of CML patients have access to PCR testing?
  - How frequently do these patients receive PCR testing?

Establish an advocacy goal

After developing an understanding of the subject matter and researching the local barriers to PCR testing, it’s time to set a goal(s). A goal is an overarching principle that will guide decision making, and it should be developed based on the need(s) you identified in step 1 when researching your subject matter within your local context. A broad range of goals will be available for advocates based on the needs of the patients in each community. For example, goals could include educating patients, educating the community, or campaigning to bring an instrument to a local laboratory.

After establishing a goal(s), it’s important to assess available resources (e.g., financial resources) and create objectives that are realistic. Objectives are specific and measurable steps that can be taken to achieve the advocacy goal. The specific objectives of the campaign should be SMART:

- **Specific**
- **Measurable**
- **Achievable**
- **Relevant**
- **Time bound**

Planning is key for successful advocacy. Advocates should assess manpower, time, finances, availability of a spokesperson, and other resources to help determine how big or small a campaign will be. If there are any gaps identified, they can be addressed prior to beginning the campaign.

**Advocacy Case Study, Step 2: Establish an advocacy goal**

**Goal 1:** Get the TB laboratory technician to agree to run both BCR-ABL tests and TB tests on one machine.

**Objective:** Organize a training between the laboratory technician and a trainer from the company that manufactures the PCR machine and BCR-ABL tests, in which the laboratory technician can run several sample tests to check the accuracy of the tests and to check for cross contamination.

**Goal 2:** Provide BCR-ABL tests to CML patients at an affordable price.

**Objective:** Work with the hematologists to establish a payment plan for BCR-ABL tests that is affordable for patients and raises sufficient funds to procure additional tests after an initial donation.
**3 Map your stakeholders**

Stakeholders are the individuals and/or organizations that are interested in your advocacy efforts and/or have the power to help make your efforts successful. It’s important for advocates to understand the roles of the different stakeholders they are engaging, whether they are decision makers, facilitators, potential partners and allies, or potential opponents of change. One way to understand this landscape is to perform a stakeholder analysis. A stakeholder analysis is a qualitative method used to gather information to help identify and understand needs of different stakeholders.

Using a stakeholder map is a way to break stakeholders into different categories based on several factors, including their knowledge of the policy area, levels of influence (primary stakeholders have a direct interest, while secondary stakeholders have an indirect interest), beliefs regarding the issue (whether they are supportive or not supportive of the issue), and ability to mobilize resources. Some examples of stakeholders are Ministries of Health, hospital administrators, patients and caregivers, physicians, companies that provide donations or services to your organization, and laboratory technicians.

After identifying all relevant stakeholders, a stakeholder prioritization grid can be used to determine the best way to engage with each of the stakeholders by classifying them by their influence over and interest in the campaign. Influence indicates the ability of a stakeholder to impact a goal, while interest indicates how concerned a stakeholder is about a particular goal.14

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**Advocacy Case Study, Step 3: Map your stakeholders**

After establishing your goals and objectives, you identify your key stakeholders as follows:

- **Encourage and influence**: lab technician, hematologists, manufacturer of PCR machine and BCR-ABL tests
- **Keep informed**: patients and caregivers
- **Keep satisfied**: The Max Foundation
- **Monitor**: hospital administrators

Once the different stakeholders have been identified and prioritized, it’s time to plan when and how different stakeholders will participate in the projects.

Engaging with a constituency, or a group of supporters, and creating partnerships is important. A variety of partners can strengthen a campaign and increase reach. After identifying and engaging potential partners, you can work together to define possible areas of collaboration. When establishing partnerships, several steps should be taken to help avoid potential pitfalls:

- Make sure to be as clear about the issue as possible so that everyone is on the same page and clearly understands the goals and objectives of your advocacy efforts
- Clearly define the roles and expectation of each of your partners so that everyone understands how best to maximize their impact
- Periodically assess progress by holding meetings or phone conferences
- Maintain open communication with all partners
Advocacy Case Study, Step 4: Develop your message

The messages that you develop will be tailored for the different audiences that you will be engaging.

To the laboratory technician: The message you present to the laboratory technician should be scientific in nature and should come largely from the company that produces the BCR-ABL tests. A company representative who is trained in running BCR-ABL tests will best be able to speak to the laboratory technician’s concerns.

To the hematologists: In this case, the hematologists are already eager to improve access to PCR testing for their CML patients. Your message to the hematologists needs to clearly convey what you need from them in order to make that dream a reality (e.g., the development of an affordable fee schedule for patients that will secure the procurement of future tests, and internal advocacy to the hospital administrators and TB laboratory technicians to encourage collaboration in this effort).

To the manufacturing company: To this stakeholder, you would convey the need in your country (number of patients) and then explain the potential access pathway that you have identified through a possible collaboration with the TB laboratory. You would conclude your message with a request for a training session with the laboratory technician locally.

To patients and caregivers: Your message should clearly and simply articulate the importance of PCR testing in the monitoring of CML. It should also inform patients about the possible access pathway, transparently conveying that a small fee would be collected to ensure the sustainable procurement of tests. This messaging should come from both physicians and patient advocates.

To The Max Foundation: It is important that you keep The Max Foundation informed on the progress of both the TB laboratory collaboration and the development of the pricing plan. Doing so will inform them of whether you are ready to receive a starter donation of BCR-ABL tests.

To the hospital administration: If the hospital administration is not closely involved in the decision making of the TB laboratory, your messaging may be as simple as keeping them informed on the progress of the advocacy through the hematologists. If the hospital administration is more engaged, you should convey to them the benefits that access to PCR testing brings to CML patients, with a focus on patient outcomes and adherence to ELN guidelines.

Example messages for targeted audiences:

Ministries of Health and Government officials:
Consider creating an economic argument for your advocacy goal. Governments work within the confines of a limited budget and are often most concerned with how cost effective a treatment or diagnostic test might be.

Hospital Administrators:
Consider creating an argument for the safety and affordability of your advocacy goal, as well as the health benefits that it will bring to patients. Hospital administrators are concerned with cost as well as the quality of the treatments their facilities provide.

Physicians:
Make sure that your physicians have access to the scientific research supporting the use of quality PCR testing in the diagnosis and monitoring of CML. They will want to understand the research related to PCR as well as the guidelines for proper testing to ensure the best possible outcomes for their patients.

Develop your message

After an advocacy goal has been established, key messages should be developed. These messages should provide a short summary of your advocacy goal and should be tailored for the different audiences that you will be engaging. Messages should describe why your advocacy goal is important. Messages will have to be repeated often and should be consistent.

When delivering messages, identify specific characteristics of the audience, and focus the messages to that audience. Consider the audience and think about the best medium to use when sending the messages.
**Take action!**

Create an Advocacy Campaign

After creating an advocacy goal and building a team of stakeholders and influencers, it’s time to take action and create a campaign by developing your communications and activities. A campaign is an action or set of actions used to work toward a particular goal, and does not necessarily require a lot of resources. A successful campaign can include one well-planned action, such as arranging training meetings with laboratory technicians, or it can involve a larger long-term set of activities aimed at improving access to PCR testing.

Make a case to decision makers

Public policy plays an important role in an advocacy campaign because laws, policies, and allocation of resources are all important for access to care within a country. Making a case to decision makers, such as politicians, is important because they have an impact on local and national policies and can make direct changes to laws and policies. Influencers, such as respected community members, have the power to influence decision makers. In order to create change on a national level, it may be necessary to change the minds of politicians and decision makers. The best method or methods of communication will vary based on the advocacy goals and the target audience, and may change throughout the course of the campaign to align with the goal.

Reaching out to decision makers and stakeholders

Several possible avenues are available for contacting and communicating with politicians, decision makers, and stakeholders, including letters and email, face-to-face meetings, press and media releases, and public speaking. It is important to choose the most relevant and effective method of communication based on the local political and social context.

Advocacy Case Study, Step 5: Take action!

To achieve your 2 goals, you design an action plan that consists of 3 parts:

1. Arrange an in-person training with the TB laboratory technician and company trainer to address any questions or concerns that he or she has. Provide the TB laboratory technician time to run sample BCR-ABL tests with TB tests on the same machine to check the integrity of the results.

2. Arrange a meeting with the hematologists to develop a test pricing plan that is affordable for patients but that can cover future procurement of tests.

3. Share the results of steps 1 and 2 with The Max Foundation when requesting the initial seed donation of tests.

Write letters

Writing a letter or an email can be a great way to get a message across to government officials or health authorities. Generally, short letters that are printed or neatly handwritten will have the most impact. Including an example of the personal effect that different legislation will have on you is helpful. After writing your first letter to an individual, trying to keep up regular correspondence or following up with a meeting is a useful way to engage an individual.

- General tips for letter writing include:
  - Keep letters brief and to the point
  - Stick to 1 issue per letter
  - Use bullet points to highlight arguments
  - Include supporting facts to back up your case
  - Ask for a reply

Email can also be effective tool to get supporters involved in an advocacy campaign. Advocates can help to organize supporters to send emails to a policy maker in an effort to increase awareness of a particular topic.
Advocating for PCR Testing: Tips for Implementing a Successful Campaign

Advocacy

SECTION 2

Use Social Media

Social media are web-based applications that can be used to build networks and share information with large groups of people. There are several advantages of using social media in advocacy. Using social media sites is a useful way to reach mass audiences and can be a good route for getting into mainstream media.

Social media have several uses in advocacy, including raising interest about an event or developing an online community with which to engage. Developing a strategy for use of social media is a helpful way to stay organized and ensure that you are reaching the right audience.

Choose the best social media platform, such as Facebook or Twitter, to spread your message and achieve your goal. Different social media platforms have very different user demographics. In order to have the greatest impact, determine which platform or platforms will reach your intended audience and consider some tips for using Facebook and Twitter for advocacy.

Facebook
- Keep it short
- Make it visual with photos/images
- Post regularly

Twitter
- Use hashtags
- Tweet regularly
- Use images

Engage the media

Media coverage is a valuable way to increase awareness or change public opinion about an advocacy issue. Media engagement can involve press releases, press conferences, or interviews. Regardless of the type of media, it is important to define your story. The story should be relevant to the audience and should include new or interesting information to get their attention. Putting a human face on the issue can make the story more emotionally engaging for an audience.

A press release should be localized and adapted for the audience. Press releases should be short and simple and should ideally focus on 1 key message.

The best way to secure media attention is to learn about different types of media and to decide which types of media will provide the best access to your audience. The next step is to identify different journalists who report on the issue that you focus on and compile their contact information. Reach out to different journalists to establish relationships with them.

You can establish a spokesperson who can speak to the media on behalf of your campaign. A spokesperson should be articulate, well informed about the issue, and familiar with your messages.

Host an event

When planning an advocacy event, there are several factors to consider in order to raise awareness of the event. Factors to consider when planning an advocacy event include:

WHO? Decide the audience for the event (e.g., influential local business leaders)
WHERE? After identifying the audience and the number of attendees, find a venue that can accommodate everybody
WHEN? Timing of the event is important for attracting the right audience
WHY? Ensure that the goals of the event are clearly articulated to the attendees in a way that is relevant to them
WHAT? Ensure that attendees understand the message by preparing a talk or printed materials that attendees can take with them; ensure that printed materials include contact information so that attendees can follow up after the event.
Advocacy follow-up and evaluation

It is important to follow up with your supporters after implementing a campaign to keep them informed, so be sure to collect their contact information. After your initial campaign, you should evaluate whether the actions taken have been successful and whether you are on the right track. If not, it may be time to modify the course of action. It’s also important to maintain enthusiasm over time by continuing to engage with supporters using different methods, such as social media.

Advocacy Case Study, Step 6: Advocacy follow-up and evaluation

Because the outcome of your advocacy is an ongoing program that provides affordable PCR tests to CML patients, you decide to check in with the physicians every other month to identify:

1) How many patients are electing to get PCR tests?
2) How many additional tests have been procured through the test fees?
3) Is the pricing plan still sustainable, or should it be re-evaluated?

You also determine that it will be important to check in with the TB laboratory technicians to make sure that they are able to keep up with the testing workload and that the machine continues to operate efficiently.

All of this information should be shared periodically with stakeholders who have an interest in the success of the program, such as hospital administrators and donors.
Additional resources

Preferential Pricing for GeneXpert IV System and Xpert BCR ABL Assay through The Max Foundation - Cepheid Collaboration Agreement:
https://www.themaxfoundation.org/what/treatment/genexpert/

Guidelines for Setting Advocacy Priorities:

Guidelines for developing messages for stakeholders:

Additional Information about Stakeholder Analysis:

Social Media Guidelines:
http://www.aauw.org/resource/how-to-use-social-media-for-advocacy/

Press Release Template for Nonprofit Organizations:

My PCR Downloadable FAQs:
http://mypcr.org/frequently-asked-questions/

Patient Friendly ELN Guidelines:
http://www.cmladvocates.net/education/eln-recommendations

The CML Guide for Patients and Caregivers:

International Scale PCR Webinars:

International Scale PCR FAQ for Physicians:
References


My PCR is facilitated by The Max Foundation. For questions, contact us at news@themaxfoundation.org.