

ADVOCACY

How to produce and use a White Paper

ADVANCED

→ THE WHITE PAPER IS A COMPREHENSIVE REFERENCE DOCUMENT THAT SERVES AS A POWERFUL ADVOCACY TOOL FOR PATIENT REPRESENTATIVES, AIMED AT ADDRESSING THE IN-DEPTH CHALLENGES FACED BY THE PID COMMUNITY IN YOUR COUNTRY TO POLICYMAKERS.

OBJECTIVES:

- **Highlight Patients Issues:** Address specific health, social, financial, and other challenges faced by the PID community in your country, providing evidence-based insights into their causes, effects, and potential solutions.
- **Support Policy Making:** Inform healthcare policies and practices by presenting data and expert opinions that guide decision-making at institutional or governmental levels.
- **Propose Solutions or Innovations:** It can propose new treatments, therapies, or technologies, detailing their potential benefits, risks, and how they compare to existing options.
- **Facilitate Collaboration:** White papers can foster collaboration between researchers, clinicians, and organisations working on related issues.

ADVANTAGES:

- **In-depth Analysis:** Provide a thorough analysis of complex issues, presenting detailed information and evidence that lead to a deeper understanding of the topic.
- **Credibility and Authority:** By presenting well-researched and expertly written content, white papers help establish the author or organisation as an authority in the field, enhancing their credibility.
- **Informed Decision-Making:** They offer valuable insights and data that assist stakeholders, such as policymakers and healthcare professionals, in making informed decisions based on evidence.
- **Support for Policy Development:** White papers can provide the evidence and rationale needed to shape or reform policies and guidelines.
- **Attracts Funding:** Use to attract funding when raising interest from other stakeholders

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STEP BY STEP:

1

ASSEMBLE A TEAM

- **Form a Core Team** that includes your medical/expert advisers, patient advocates, and communication specialists to distribute the tasks and develop a realistic project timeline.
- **Engage with patients and caregivers** to understand their perspectives and ensure the white paper addresses their concerns.

2

DEFINE YOUR GOAL AND SCOPE

- **Clearly determine what you aim to achieve**, e.g. improved diagnosis and better treatment.
- **Understand your target audience** – whether politicians, policymakers, or other stakeholders.

3

CREATE A COMPELLING PROPOSAL & OBTAIN FUNDING

- **Develop a project summary** including its goals, benefits, and impact.
- **Demonstrate the need** for your white paper.
- Outline the specific **objectives** of your white paper and the expected **outcomes**.
- Include a detailed **budget & timeline** that explains how the funds will be allocated and when the white paper is expected to be completed.

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STEP BY STEP:

4

GET TO THE DOCUMENT

- **Develop, Write & Review** the challenges being addressed, their significance, and the purpose of the white paper.
- Do not hesitate to **seek help and guidance** from IPOPI.
- Verify all data, citations, and references for **accuracy**. Ensure claims are **evidence-based**. Patient stories offer compelling, credible support.
- Have the draft **reviewed** by colleagues or field experts for feedback and credibility.

5

PUBLISH, STRATEGISE AND ADVOCATE

- Ensure the white paper is professionally designed with a clean layout, clear headings, and visually appealing elements (e.g., charts, graphs).
- **Engage** with relevant stakeholders, and policymakers to present your white paper.
- **Keep advocating for the white paper's recommendations** by participating in policy discussions, submitting to relevant committees, or organising further educational events.

TIPS

- Prepare an **Executive Summary**: Policymakers often have limited time. Prepare a concise executive summary that highlights the main findings and recommendations.
- **Build Relationships**: Establish connections with policymakers and healthcare leaders early on to increase the likelihood of your recommendations being considered.
- **Leverage Media**: Use media channels and social platforms to raise awareness of the White Paper and its recommendations.
- **Follow Up**: After initial meetings or presentations, follow up with stakeholders to keep the momentum going and ensure continued engagement with the White Paper's proposals.