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Guide **3**

Building partnerships with
healthcare professionals



Why collaboration with healthcare professionals matters

Healthcare professionals are often the first point of contact for people diagnosed with bladder cancer. Primary care doctors, urologists, oncologists and nurses not only treat patients but also connect them to information, support networks and the broader medical community.

Forging relationships with these professionals helps patient groups amplify tap into valuable networks and ensure more healthcare providers signpost patients and carers to support and information these patient groups provide.

What you will gain from this guide

This guide offers practical steps to help your patient group build effective partnerships with urologists, nurses and professional bodies. By following these steps, you will learn how to:

- ✓ **Identify and connect** with healthcare professionals who can champion your cause.
- ✓ **Explain your goals** clearly and respectfully so that professionals want to support you.
- ✓ **Develop collaborations** that produce tangible benefits for patients, professionals and your organisation.



Step 1

Understand your local landscape



In many cases, one of the most effective ways to engage healthcare professionals is through professional societies and associations. These may include urology associations, nursing organisations, oncology societies or primary healthcare networks.

These organisations often have large member bases and are generally open to collaborating with non-profit patient organisations. Working through these groups can help you reach a wider audience more efficiently than contacting individuals one by one.

Offering to deliver an educational session on bladder cancer for their members can be a good starting point. Many professional societies actively look for educational content that supports continuing professional development for their members.

Engaging individual hospitals or clinicians directly can sometimes be more difficult and time-consuming. However, when approaching professional societies or healthcare organisations, it can be helpful to already have the support of one or two respected medical professionals who can act as references. Their involvement can add credibility to your organisation and facilitate initial engagement.

Start by identifying the professionals and institutions involved in bladder cancer care in your region:

- ✓ **Hospitals treating bladder cancer**
- ✓ **Urologists and oncology specialists**
- ✓ **Specialist nurses**
- ✓ **Allied healthcare professionals**
- ✓ **Relevant scientific societies**

National urology associations and nursing organisations often publish congress programmes or expert directories. These can help you identify professionals with a specific interest in bladder cancer.

If you are a membership-based organisation, ask your members which clinicians they see and trust. A personal introduction is often more effective than a cold email.





Step 2

Prepare a clear and professional message

Your first contact should be short, structured and respectful. Include:

-  **1. Who you are:**
mission and key activities
-  **2. Who you represent:**
patients, carers, geographic reach
-  **3. What you are asking for:**
a meeting, collaboration, referral pathway
-  **4. What value you bring:**
patient perspective, educational tools, peer support



Avoid long explanations. Focus on how your work supports better patient care. Clinicians are more likely to engage when they see alignment with their priorities, such as timely diagnosis, shared decision making, treatment adherence, support survivorship care or patient education.

Step 3

Approach through appropriate channels

Many healthcare professionals are active in:

- **Scientific or medical societies**
- **Hospital networks**
- **Conferences/congresses and educational meetings**

Professional events can be valuable spaces to introduce yourself. After meeting someone, follow up with a short email summarising the conversation and suggesting next steps. Consistency and professionalism build long-term trust.



Step 4

Focus on mutual benefit

Effective partnerships are based on shared value.



Patient groups can offer:

- **Patient-friendly materials for clinics**
- **Access to peer support communities**
- **Insight into patient experience**
- **Participation in awareness initiatives and campaigns**
- **A strong and respected patient voice that can help highlight unmet needs and advocate for improved access to treatments and care**

Patient organisations can also play an important role in representing the patient and consumer perspective in discussions with pharmaceutical companies and in Health Technology Assessment (HTA) processes that influence access to new treatments.

Healthcare professionals can offer:

- **Referrals to newly diagnosed patients**
- **Medical input for events or materials**
- **Support for awareness campaigns**
- **Greater credibility and visibility**



Step 5

Create simple referral pathways

One of the most practical results of collaboration is a clear and simple referral system. This may include:



1. Printed information in waiting rooms



2. QR codes linking to your website or support group



3. Inclusion in discharge information packs



4. Direct introduction by specialist nurses or other healthcare professionals

Make it easy for clinicians to refer patients to you. When referrals are received, respond promptly and professionally. Periodically share impact updates to help professionals see the value of the partnership.

Offering free in-service educational sessions for hospital nursing teams, for example, through short Zoom sessions, can also be very effective.

Nurses often welcome opportunities for education, and these sessions can help them become more familiar with your organisation and resources. As a result, they are more likely to refer patients and share information across their teams.

Step 6

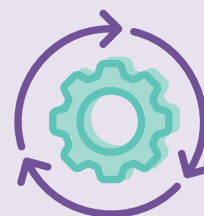
Support professional development

Another effective way to build trust is by contributing to continued education of healthcare professionals

Consider offering:

- **Short educational webinars on patients perspectives and needs**
- **Patient perspective sessions during hospital training days**
- **Co-developed informational materials**

When you contribute to professional education, you position your organisation as a partner in improving care quality, not simply as a recipient of referrals.





Explaining your goals effectively

When presenting your organisation: Tell your story clearly and briefly. Explain why your group was created and what gap it fills for patients and families.

Focus on outcomes. Worldwide, more than 614,000 people are diagnosed with bladder cancer each year and around 1.9 million people are living with the disease. Support beyond treatment is essential. Show how your work improves understanding, confidence and quality of life.

Offer practical tools. Translated materials, support groups and reliable information make clinicians' work easier. Always position your organisation as a collaborative partner working toward better patient care.



Top tips for better tracking:

- ✓ **Be prepared before you reach out. Know your message clearly**
- ✓ **Keep your communication short and professional**
- ✓ **Focus on shared goals, not only your organisation's needs**
- ✓ **Offer value first: education, materials or insight**
- ✓ **Respect clinical boundaries: never provide medical advice**
- ✓ **Protect independence and transparency**
- ✓ **Follow up consistently, but do not overwhelm**
- ✓ **Share impact results: numbers matter**
- ✓ **Think long term: trust takes time to build**

Collaboration in action: Case studies

Associazione PaLiNUro (Italy): Uro H Advisor

In Italy, many people diagnosed with bladder cancer face a difficult and emotional question: Where should I be treated?

Associazione PaLiNUro recognised that patients often lacked transparent, accessible information about hospital expertise. To address this, they developed Uro H Advisor, a digital platform designed to help patients better understand the hospital experience in bladder cancer care.

The initiative combines verified patient experience with structured information about hospitals, including surgical activity, multidisciplinary care, and overall patient experience. Reviews are carefully moderated before publication to avoid misinformation and protect credibility.

What makes Uro H Advisor particularly powerful is that it was not built against clinicians, but with them. PaLiNUro engaged healthcare professionals to help define meaningful indicators and ensure the tool reflected objective clinical standards. This collaboration transformed what could have been a controversial project into a respected national resource.

The added value:

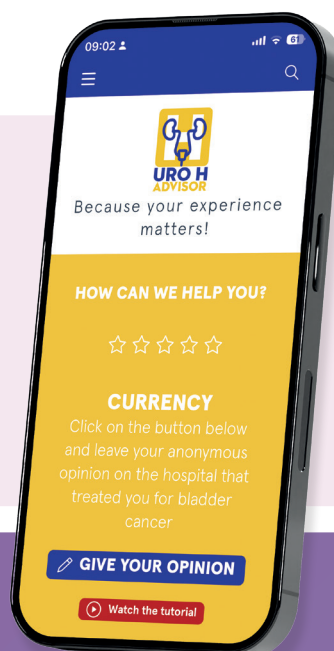
- **Patients feel more informed and empowered when choosing care**
- **Hospitals receive constructive feedback**
- **Dialogue between patients and clinicians improves**
- **The patient organisation becomes a credible stakeholder in quality discussions**



Laura Magenta,
Bladder cancer patient
advocate, Associazione
PaLiNUro

“We realised that many patients felt disoriented after diagnosis and did not know how to choose where to be treated. Our goal was not to judge hospitals, but to provide reliable information and encourage transparency.

By working with healthcare professionals from the beginning, we ensured that Uro H Advisor remained constructive, credible and focused on improving care. Collaboration made the project stronger and more trusted.”



CANVES (Spain): Clinical engagement from the beginning

When CANVES was created in Spain, the organisation faced a common challenge: how to be taken seriously in a healthcare environment where bladder cancer already had established clinical structures.

Their approach was clear from the outset. Healthcare professionals were not only involved in their first major initiative, the Bladder Cancer Patient Day, but were actively engaged in the creation of the association itself. Urologists and oncologists are part of CANVES' board and continue to play an active role in shaping its initiatives and projects.

For the Patient Day, clinicians helped design the programme, delivered presentations in accessible language, and encouraged their patients to attend. The event was carefully structured with clear objectives, a defined agenda and a strong patient-centred approach. Importantly, although financial support was secured from partners, content remained fully independent and led by patient needs and clinical expertise.

This model of collaboration demonstrated that CANVES was not operating separately from the healthcare system, but as a trusted partner within it.

The added value:

- Immediate credibility with hospitals and clinicians
- Strong referral pathways from specialists
- Trust from patients supported by medical engagement
- A solid foundation for long-term collaboration and joint initiatives



"From the beginning, we knew that credibility would be essential. We did not want to create something informal or disconnected from the healthcare system. By involving clinicians in the programme design and ensuring the event was structured and patient-focused, we built trust quickly. Healthcare professionals saw that we were serious about improving patient experience, not competing with medical care."



Laurent Gemenick,
Co-founder of CANVES

BEAT Bladder Cancer Australia: Education as partnership

BEAT Bladder Cancer Australia took a different approach to collaboration. Instead of focusing first on events or campaigns, they asked: **How can we support healthcare professionals directly?**

They developed accredited online education modules for nurses, one for primary healthcare nurses and another for urology and oncology nurses. These courses follow the patient journey from symptoms to survivorship, combine medical expertise with patient voice and provide recognised Continuing Professional Development (CPD) hours.

In addition, the organisation delivers structured in-service training sessions for hospital and community nursing teams. These sessions blend clinical information with lived experience and allow space for open discussion and questions.

By contributing to professional education, the organisation positioned itself as part of the healthcare ecosystem, not outside it.

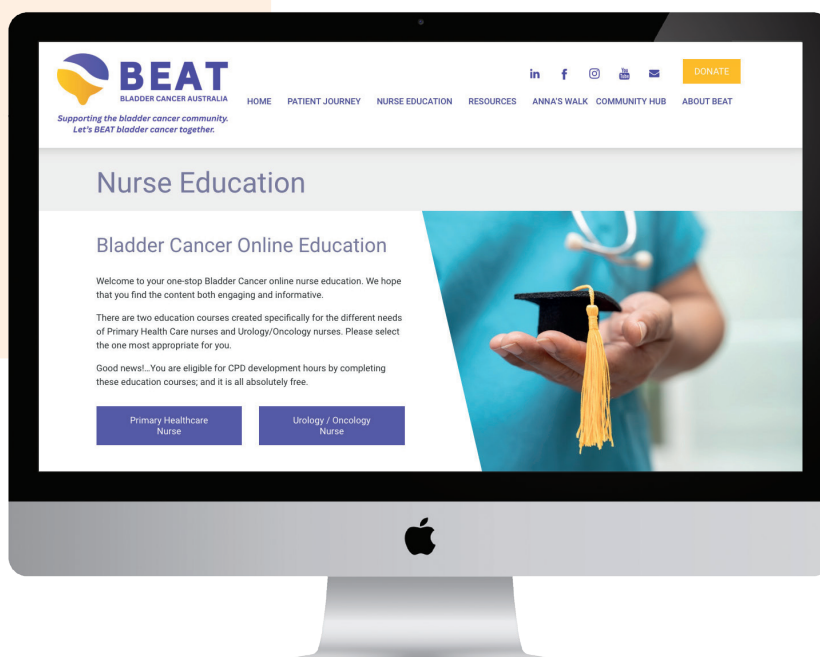
The added value:

- **Nurses gain practical, accredited knowledge**
- **Patients receive better-informed support**
- **Referral pathways strengthen naturally**
- **The organisation becomes a trusted educational partner**



*Adam Lynch, President
of BEAT Bladder Cancer
Australia*

"We realised that many nurses had limited bladder cancer-specific training, yet they are central to patient care. By investing in education, we were not simply asking for referrals; we were contributing to better standards of care. When healthcare professionals see that you are supporting their development and helping them serve patients better, real partnership becomes possible"



Bringing it all together

Building partnerships with healthcare professionals is not a one-time action. It is an ongoing relationship based on respect, clarity and shared purpose.

Strong collaboration can:

- ➡ **1. Improve patient referrals to support networks and patient groups**
- ➡ **2. Increase trust in your organisation and create visibility**
- ➡ **3. Strengthen advocacy efforts**
- ➡ **4. Contribute to better and more patient-centred bladder cancer care.**

When patient groups and healthcare professionals work together effectively, the result is a more connected and supportive system for everyone affected by bladder cancer.





World Bladder Cancer Patient **COALITION**

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