



Australian College of Nursing

Establishing a Nurse-led Palliative Care Service in Australia: An implementation toolkit

A WHITE PAPER BY ACN 2020

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ACKNOWLEDGEMENTS

The Australian College of Nursing (ACN) would like to acknowledge the ACN End of Life Care Policy Chapter 2019 for their development of this White Paper.

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And the ACN Policy Team for coordinating and preparing this White Paper for public dissemination.

PURPOSE OF THIS TOOLKIT

Registered and Enrolled Nurses are the largest group of health care professionals who provide care to people with life-limiting conditions across all settings. These nurses have a unique and central role in the team as they respond to the range of physical, emotional, social and spiritual needs of people with a life-limiting illness and promote continuity of care across the care trajectory. Given the demand for quality palliative care services in Australia is growing rapidly, urgent action is required to optimise the contribution of nurses in palliative care.

This Toolkit has been developed to support health service providers to optimise nurses' contribution to palliative and end-of-life care by providing guidance on how to develop, implement and evaluate nurse-led services as part of the broader range of multidisciplinary services required by people with life-limiting conditions. The Toolkit aims to support the implementation of recommendations outlined in the 2019 Australian College of Nursing (ACN) White Paper "*Achieving Quality Palliative Care for All: The Essential Role of Nurses*"¹. The White Paper concluded that there is a strong evidence base to support the multiple benefits of nurse-led models/interventions for patients, services and health systems. In particular, the evidence emphasised the importance of nurse-led models focused on promoting early palliative care intervention and on providing holistic, comprehensive care services. However, barriers exist to implementing such models and there are urgent areas for action for governments and health system managers to ensure nurse-led models are implemented to enable access to quality palliative care for all people with a life-limiting illness.

THE ROLE OF NURSE-LED MODELS IN HEALTH CARE

Nurse-led models of care and nurse-led clinics have been identified as one important solution to meeting the accelerating health care needs of individuals and communities² across acute and community care settings³. Nurse-led models of care are defined as an approach to practice in which nurses have an allocated patient caseload for whom they have primary responsibility, with appropriate partnerships with other health professionals, where required to meet the person's health care needs^{3,4}. Nurses working within a nurse-led model of care undertake assessment, provide education, support, treatment and monitoring, initiate admission and discharge and referral to other health professionals⁴. Such nurse-led models bridge traditional treatment silos in the provision of specialised and coordinated care, can reshape health services, improve the patient experience and address previous gaps in health care service delivery³.

Those requiring palliative care can have multiple, complex illnesses as they near the end of their lives. This requires the input of range of health, aged and social care from several care providers – so palliative care is everyone's business. Nurse-led models operate within this interdisciplinary context and are underpinned by effective coordination, communication and collaboration with various services and service providers.

Example - The contribution of a nurse-led models of care

In a regional health service, located on the mid-east coast of Australia, a nurse-led palliative care service provides an integrated service across community and aged care, and linked with the hospital palliative care service. Established more than 25 years ago, this nurse-led service is led by a Nurse Practitioner. The team consists of 4+ full-time nursing staff, who work in collaboration with a bereavement counsellor and social worker. Formal partnerships have been established with local rural doctors with specialist medical staff travelling from a major capital city to consult with terminally ill patients, at home or in a clinic setting, for one day every two months.

80% of terminally ill patients who access the service have a cancer diagnosis, however the service is available to any person with a terminal diagnosis.

KEY ELEMENTS OF NURSE-LED MODELS IN PALLIATIVE CARE

Available evidence identifies the key elements of nurse-led models in palliative care to be symptom management, patient and carer education, goals of care discussions and care coordination¹. This evidence demonstrates that nurse-led models which focus on ensuring early palliative care intervention positively impact on patient outcomes such as improved mood and wellbeing, health-related quality of life, and survival as well as health service use outcomes, such as reduced hospital admissions. Nurse-led models which reflect more comprehensive care delivery approaches also positively impact patient's end-of-life care planning, emotional function/mood, satisfaction with their care, hospital admissions, and costs for hospital or community care settings¹.

HOW TO USE THIS TOOLKIT

This toolkit provides an outline of how to plan, implement and evaluate nurse-led models in palliative care.

PLANNING

This section provides guidance for health service organisations who may be considering establishing a nurse-led palliative care service. The essential first steps are to consider the context and ways to identify service gaps in the provision of palliative care.

Understanding the context and service gaps

Models of palliative care service provision differ across Australia, according to state and federal legislation, public and private healthcare models, and local service delivery arrangements⁵. Irrespective of legislative and funding differences, access to palliative care services should be based on need, with equity in access for all people across Australia⁶.

Existing organisational data can assist in this assessment and build a case for a nurse-led palliative care service to address an identified service gap. Examples of types of organisational data that may be helpful in determining need, are shown in Table 1.

Table 1. Examples of organisational data

Organisational structure and policy
<ul style="list-style-type: none">• Existing palliative care services (inpatient and outpatient) and scope• Structure and size of specialist palliative care workforce
Referrals
<ul style="list-style-type: none">• Referral process• Referral rates and pattern, time from referral to review• Patient need (symptoms etc.) not manageable by other existing service
Inpatient Services
<ul style="list-style-type: none">• Admissions and Emergency Department (ED) presentations for patients with palliative care needs• Frequency of admission (e.g. over last 12 months) for patients with palliative care needs• Inpatient services used to address (wholly or in part) patient need• Access and availability of common/anticipatory medications prescribed in palliative or end-of-life care• Prevalence of Advance Care plans
Incident/Adverse Events
<ul style="list-style-type: none">• Use of Medical Emergency Team (MET) services by patients with palliative care needs• Adverse event data for patients with palliative care needs• Complaints
Consumer feedback
<ul style="list-style-type: none">• Informal feedback from patients, family, community service providers related to service gaps, limitations of existing services

(Adapted from the NSW Government, Clinical Excellence Commission (CEC) Last Days of Life Toolkit [7] and the Australian Commission on Safety and Quality in Health Care (ACSQHC) End-of-Life Toolkit [8])

Palliative care is typically provided by multiple service providers across settings of care. Mapping of other services within the local region of health service district is also important to enable appropriate transitions and integrated models of care. At the broadest level, such service mapping includes assessment of patterns of workforce and distribution of services across the region, characteristics of specific locations and service types, and locations or service types that are potential priorities (PHN Commissioning Guide). Box 1 describes elements of a service mapping activity which can help to build a comprehensive model of care to support a nurse-led service.

Box 1: Elements of Service Mapping

- Location – including but not limited to physical location, hours of opening, with consideration of identifiable gaps. For rural areas this would also include outreach services, for urban areas it may involve some consideration of services outside the region borders but accessed by people from within the region;
- Utilisation – including a range of hospital and community data, such as use of Emergency Departments and other measures of occasion of service, and with a consideration of under-utilisation, duplication and waste;
- Accessibility – including financial and cultural barriers and access to specialists and secondary referred services, access to services after hours;
- Responsiveness – such as wait times;
- Capability – such as skills and competence;
- Acceptability – such as cultural sensitivity, patient experience of and satisfaction with the quality of care; and
- Quality – such as level of service and quality data (such as Palliative Care Outcomes Collaboration Data).

(Adapted from PHN Commissioning Needs Assessment Guide^[9])

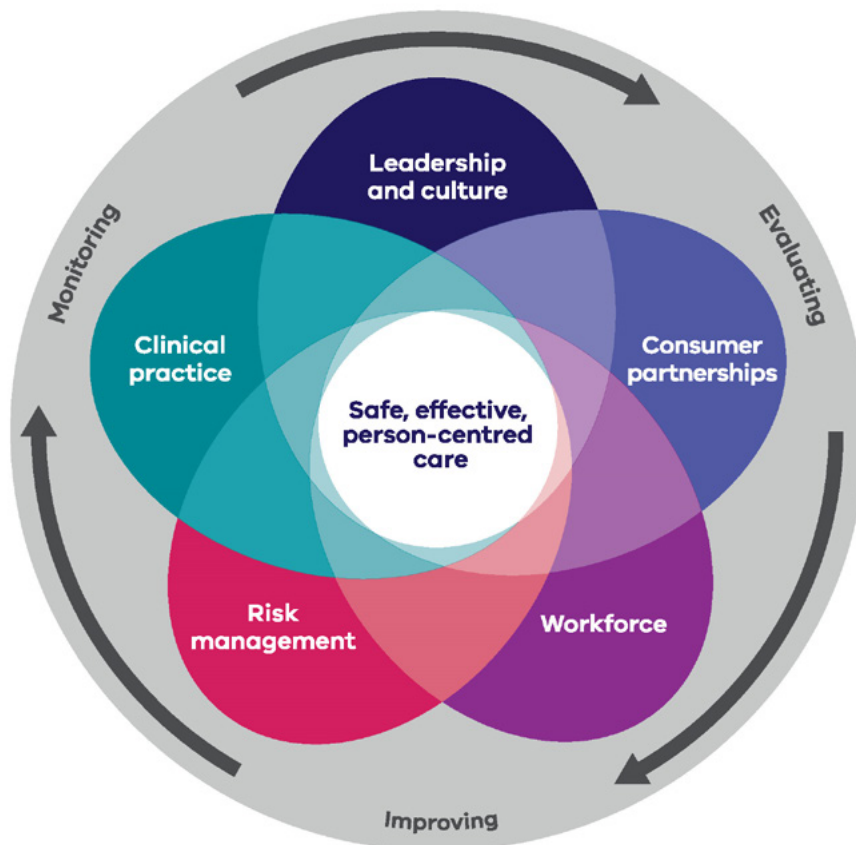
Mapping of patient journeys is also another useful activity that can be undertaken as part of a co-design process to developing a service centred around the person's needs. The NSW Agency for Clinical Innovation has developed a step by step guide to process mapping¹⁰.

Establishing effective clinical governance

Clinical governance is the set of relationships and responsibilities established by a health service organisation between the governing body, health professionals, patients and other consumers, to provide safe and quality health care¹¹. A nurse-led palliative care service must be designed to operate within existing corporate and clinical governance frameworks at the health service. Hence, early consideration of the governance requirements is essential. The Australian Commission on Safety and Quality in Health Care [ACSQHC] recommend that health services should consider how best to allocate resources within the context of the organisation's strategic plan to support the delivery and effective functioning of systems for providing end-of-life care¹². Organisational policy frameworks should outline the organisation's approach to governance, how specialist palliative care services are to be accessed, the interface between existing and newly established services, how the identified service gap is addressed and the interface between inpatient and community services¹². The roles and responsibilities of clinicians providing a palliative care service, their training and education requirements including clinical supervision, mentoring and debriefing must also be specified¹².

The five domains of clinical governance that are incorporated into the organisation's clinical governance structure are shown in Figure 2 below.

Figure 2. The five domains of good clinical governance¹³



ENGAGING STAKEHOLDERS

Engaging stakeholders is key to identifying local needs and resources, and to ensuring the feasibility and acceptability of a new nurse-led palliative care service to internal and external stakeholders. Stakeholders can include patients and families, clinicians, relevant advocacy and volunteer groups/agencies, other health care agencies or services involved in the care of people with life-limiting illnesses, not just people who are imminently dying, support staff, administrators, educators and government or regulatory bodies¹⁴.

Principles for stakeholder engagement include that engagement is purposeful, inclusive, timely, transparent and respectful¹⁵. Stakeholder engagement may involve varying levels of engagement, beginning with informing stakeholders, consulting stakeholders, involving stakeholders, collaborating with stakeholders and empowering stakeholders¹⁵. Irrespective of the level of involvement of stakeholders, it is important to recognise and understand the values, beliefs and perceptions of stakeholders in order to benefit from stakeholder engagement¹⁵.

Engaging stakeholders, perhaps in the form of a 'stakeholder reference group' can aid in ensuring a nurse-led palliative care service meets the needs of stakeholders and is supported by stakeholders. Tips for establishing a stakeholder reference group¹⁴ include:

- Aim for a mix of internal and external stakeholders, all of whom will be affected (directly or indirectly) by the establishment of the service
- Ensure stakeholders are able to commit to the reference group from inception of the nurse-led palliative care service, until early evaluation
- Establish clear and consistent communication channels with the key stakeholder reference group
- Carefully consider the number of participants in the key stakeholder group and whether the role of the group is to advise only or contribute to decision-making.

DEVELOPING THE NURSE-LED PALLIATIVE CARE SERVICE

An effective nurse-led palliative care service will be person and family-centred and collaborative in nature¹⁶, with the scope of the service determined according to the identified service gap, and in accordance with the National Palliative Care Standards, published by Palliative Care Australia¹⁷. In accordance with these Standards, it is an expectation that the registered nurse employed to provide the nurse-led palliative care service will be appropriately qualified, with recognised qualifications, credentialing and experience to meet the service requirements.

Job description

The title associated with the role will likely vary across jurisdictions. However, health service organisations should look to appoint a registered nurse who demonstrates sustained practice at an advanced level. Nursing at an advanced practice level is a type of practice rather than a role, designation or specific title¹⁸. A registered nurse who is operating at an advanced practice level, has developed their professional knowledge, clinical reasoning and judgement, skills and behaviours to higher levels of capability¹⁹. Nurses practising at an advanced level incorporate professional leadership, education and research into their clinically based practice. Their practice is effective and safe, with demonstrated ability to manage the care of people with complex healthcare requirements, including their physical, psychological, social, cultural and spiritual needs¹⁷.

Whilst the job description must consider the nuances and specific requirements of the health service, key components of a nurse-led palliative care service, that positively impact outcomes for care recipients and health services have been identified as:

- Symptom management
- Goals of care discussions
- Patient education
- Care co-ordination
- Psychological and spiritual support¹.

The incumbent should be expected to work both autonomously and collaboratively, engaging other members of the healthcare team as appropriate to meet the patient's goals of care. In larger teams, the incumbent may have direct responsibility for other team members, such as other registered or enrolled nurses working as part of the team. In this case, governance structures and job descriptions will need to clearly describe areas of responsibility and accountability.

Case Example – The role of education

An advanced practice nurse working as part of a specialist palliative care service in regional Western Australia describes the provision of education as a core feature of her role. As part of the direct care she provides to patients and their families, her focus is on educating and preparing families for managing medications, the dying process, the emotions of bereavement, and waiting for death. Within the local and surrounding hospitals, she visits, educating terminally ill patients, their families and clinicians is also key part of the service.

Clear processes for referral to the service are also necessary, supported by organisational policy and or procedure. The referral process should specify:

- Who can refer (e.g. clinicians, patients, family, external service providers)?
- How a referral is made (e.g. by telephone, email)
- Ideal service timeframes (i.e. time from receipt of referral to first consultation)

Formal agreements with memorandum of understanding (MOU) will require formalising if service provision is required within another organisation or in collaboration with another organisation.

An Example of Referral processes and outcomes

In a large regional acute care hospital on the eastern coast of Australia, a nurse-led end-of-life care service has been established to address a service gap identified in end-of-life care in the acute hospital setting. Anyone can refer to the service, including clinicians, terminally ill patients and their family. Once referrals are received, they are triaged according to urgency and need.

- *Referrals are most commonly received from clinicians who are seeking support for those identified as dying but also for advocacy and initiating difficult conversations with the terminally ill person and/or their family.*
- *Family members self-refer in order to seek support with recognising the signs of dying.*
- *Patients tend to self-refer to seek advice or support about their care options; 90% of whom have had not had any prior contact with a specialist palliative care clinician.*

DEVELOPING A BUSINESS CASE

A business case is a formal, structured written document submitted to those responsible for approving and/or funding a service development initiative or project²⁰. According to the UK HM Treasury 'five case model'²¹, a business case should contain evidence that:

- The intervention is supported by a compelling case for change that fits with other parts of the organisation and the wider public sector – the 'strategic case';
- The intervention represents best value for public money – the 'economic case';
- The proposed deal is attractive to the marketplace, can be procured and is commercially viable – the 'commercial case';
- The proposed spending is affordable – the 'financial case';
- What is required from all parties is achievable – 'the management case'²¹

Your health service may have its own business case template, which will require completion to establish your service. A standard template is also available at the Australian Commission of Safety and Quality website²².

IMPLEMENTING THE ROLE

Communication to Stakeholders

The provision of palliative care and utilising the palliative care tool kit will be improved through communication and collaboration with other services. Communication regarding introduction of the service can involve a range of strategies to ensure all stakeholders are prepared to optimise the role (See Appendix 1 – Stakeholder and Communication Plan). A range of communication methods can be used, including telehealth and modern visual and mobile technologies present opportunities.

Engaging Consumers

Enabling meaningful consumer engagement is an important area for planning and consideration, particularly when considering consumers with palliative care needs, their carers and/or bereaved carers. The National Framework for Consumer Involvement in Cancer Control (the Framework), written by Cancer Australia and Cancer Voices in 2011 is a useful reference document to inform clinicians and service planners²³. Although it is focused on cancer care, this work is relevant to people with non-malignant diagnoses also. Important aspects to think about in relation to consumer engagement in service planning, delivery and implementation include how you will recruit consumer representatives and who they might be (patients / carers / diverse populations etc.), what their role will be, training requirements to enable their full involvement and reimbursement strategies. There may well be local, jurisdictional or national consumer bodies who can assist in this thinking and planning. For example, Palliative Care Australia has a National Register of Palliative Care Consumers and Carers²⁴, most States and Territories have a consumer organisation and nationally the Consumer's Health Forum of Australia has tools and resources available to assist in planning work²³.

MONITORING AND EVALUATION

The aim of all healthcare service delivery is to provide high-quality, safe care that meets the needs of patients, their families/carers. Careful consideration of service delivery and how to measure its impact and effectiveness, is important to inform current care, foci for future improvement efforts, evaluation of care delivery and service design as well as performance relative to others²⁵⁻²⁷. Consideration of how a service will measure their performance, in a meaningful way, at the outset of service design is a great opportunity to embed this from service commencement – enabling a baseline understanding of care delivery and an ongoing method for identifying gaps in care provision or improvement requirements.

Established Australian palliative care services are well positioned to measure the work they do, supported by key national programs to inform measurement²⁸, self-assessment against national palliative care standards²⁹ and evidence use³⁰. In addition, careful consideration of the purpose of a new service is essential, to understand whether additional measurement metrics may be useful. For example, there may be important local data requirements to take into consideration, such as consideration of access to the new nurse-led palliative care service, and how it will fit with existing services, or there may be key levers to enable support and change into the future that should be considered³¹. Finally, working with consumers to design service monitoring and evaluation frameworks is an important step in maintaining focus on measuring what matters most to those we are providing care for²⁶. Key steps to consider when considering how a new nurse-led palliative care service should be monitored and evaluated, are provided below:

- Consider establishing an advisory group comprised of consumers, health professionals, service administrators and managers
- Use the National Palliative Care Standards¹⁷ and a clinical governance framework¹³, and existing health service governance and policy to guide service evaluation
- Just as how organisational data was used to build the case for a new nurse-led palliative care service, organisation data should also be used to monitor and evaluate the impact/efficacy of the service.
- Consider the consumer outcomes, such as patient experience data, complaints and satisfaction data, waiting times etc. that can be used in evaluation of the service
- Consider any mandatory reporting requirements, and what data is needed to meet these.

As a final step, consider how the outcomes of regular internal monitoring and evaluation may be used to evaluate the service against other similar services locally, nationally and internationally (where relevant).

Case Study – Service Evaluation

For an individual nurse, running a nurse-led end-of-life care service within a large acute care hospital, evaluation of the service is an ongoing process to ensure the service is meeting the needs of terminally ill patients, their families and carers, and addressing the identified service gap.

From the greater hospital perspective, the number of patients to utilise the service is an important metric. However, it is not the only one used to evaluate the service. The nurse providing this service set her own KPIs (key performance indicators), which included:

- *to respond to every referral received, within 24 hours, but usually within the same working day;*
- *to follow-up with every deceased person's family/carer within 4-6 weeks after the death to offer bereavement support, seek feedback about the service provided (from admission to death) and identify any other issues, problems or concerns.*

Even after death of the terminally ill person, families and carers are encouraged to remain in contact for further support if needed.

ADDITIONAL RESOURCES

A number of resources exist across Australia that may be useful in establishing and supporting a nurse-led palliative care service.

[Palliative Care Outcomes Collaboration](#) (PCOC) – provides services with standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. This national program supports tool implementation and use to inform clinical care as well as quality improvement locally, regionally and nationally³².

[Palliative Care Self-Assessment \(PaCSA\) Online Portal](#) (PaCSA) – provides palliative care services with resources to assist their self-assessment against the endorsed national Australian Palliative Care Standards³³.

[CareSearch](#) – This online resource provide quality evidence based resources in relation to palliative care for all Australians³⁴.

[Australian Commission for Safety and Quality in HealthCare](#) (ACSQHC) – led recent work in relation to safety and quality indicators for end-of-life care (hospital setting) as well as patient experience measures³⁵.

GLOSSARY OF TERMS

Advanced Practice Nursing Advanced practice nursing is the experience, education and knowledge to practice at the full capacity of the registered nurse practice scope. It is neither a title nor a role: it is a level of clinical practice that involves cognitive and practical integration of knowledge and skills from the clinical, health systems, education and research domains of nursing. The nurse practising at this level is a leader in nursing and healthcare. Advanced practice nursing is enabled through education at master's level⁴¹.

End-of-life That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown³⁶.

End-of-Life Care End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and their carers is higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the health care team is being delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care³⁷.

Nurse-led services Nurse-led services exist on a continuum and include the direct substitution of single medical tasks, through to advanced practice nursing models of care [38]. Core features include direct referral mechanisms, patient assessment and technical skills, freedom to initiate diagnostic tests, prescription of medications, scope of decision-making, and discharge³⁹.

Palliative Care Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life⁴⁰.

Patient The term used within this toolkit to refer to the person for whom care is required; equivalent to client and service-user.

Specialist palliative care services Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes, and hospices and palliative care units³⁶.

Specialist palliative care provider A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available. A palliative care specialist has specialist knowledge, skills and expertise in the care of people living with an eventually fatal condition and their families and carers, including in the management of complex symptoms, loss, grief, and bereavement³⁶.

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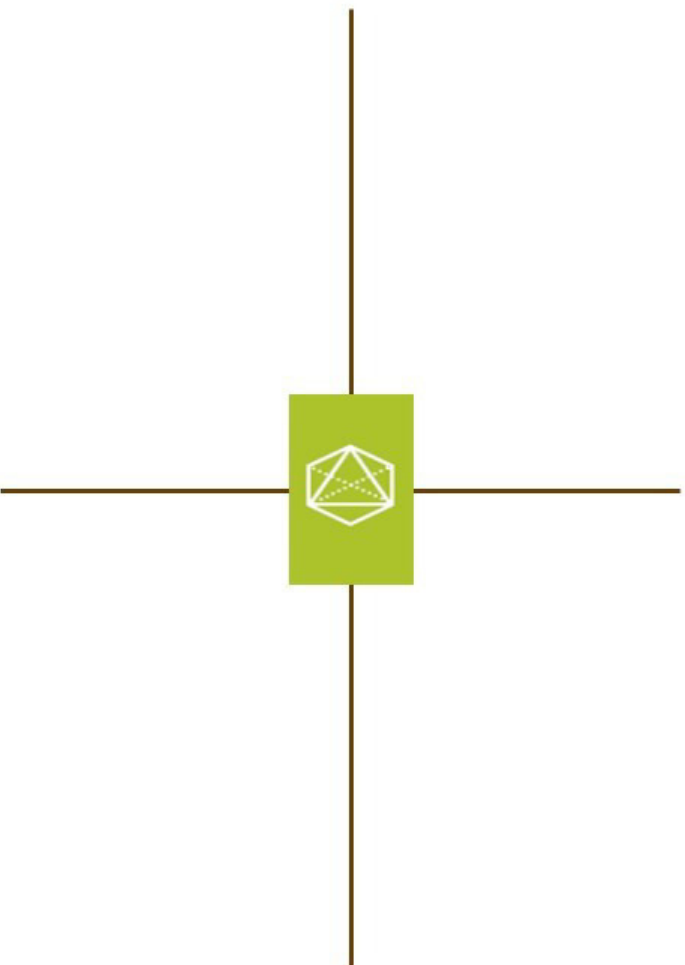
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Stakeholder mapping and communication plan

What are your key messages? (Remember the "why")

What's important for your stakeholders?



What modalities can you use to communicate?

What forums already exist?

How will you utilise your team?

