



NANYANG
TECHNOLOGICAL
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SINGAPORE

LEE KONG CHIAN SCHOOL OF
MEDICINE

CRIS 
Consortium for Clinical Research and Innovation Singapore

Roadmap for a National Guidance Document for Patient and Public Involvement in medical research, including clinical trials, in Singapore

Executive Summary

Patient and Public Involvement (PPI) is internationally recognised as a core component of high-quality medical research and clinical trials, improving research relevance, ethical standards, participant recruitment, public trust, and the translation of research into practice. Singapore has made important progress in patient advocacy and engagement in healthcare and health technology assessment. More recently, initiatives such as, Lee Kong Chian School of Medicine (LKCMedicine) Office of Patient Engagement (OPEN), Precision Health Research Singapore (PRECISE) PPI Advisory Panel, and a national PPI Community of Practice have begun to advance patient and public involvement in research. However, there is no national guidance document to support the consistent, high-quality implementation of PPI in medical research and clinical trials in Singapore. The absence of a national guidance may lead to uncertainty around expectations, roles, standards, remuneration, and evaluation, and may increase the risk of fragmented, uneven, or tokenistic PPI practices.

On 17 November 2025, Consortium for Clinical Research and Innovation, Singapore (CRIS) and OPEN convened a “Roadmap to PPI Guidance Document Workshop,” co-chaired by A/Prof Danny Soon and A/Prof Sanjay H Chotirmall. The co-creation workshop brought together patient partners, healthcare professionals, researchers, and international PPI experts, with patients and the public participating as equal partners. The primary purpose of the workshop was to establish a shared understanding of PPI in the Singapore context and to develop a practical roadmap for the creation of a national guidance document for PPI in medical research and clinical trials. Discussions were informed by a structured review of established international guidance documents from the United Kingdom, Canada, Australia, and Japan, and by a Key Discussion and Mapping Activity (KDMA).

Workshop participants reached strong consensus on the need for guidance that is clear, practical, culturally grounded, and aligned with Singapore’s regulatory, ethical, and healthcare systems. Key priorities identified included embedding PPI early across the research lifecycle; preventing tokenism; clarifying roles, responsibilities, and remuneration; ensuring inclusivity for under-represented communities; aligning with ethics and data protection requirements; and providing practical tools to support implementation, evaluation, and reporting. Participants emphasised the importance of adopting an explicit Singaporean lens, recognising multicultural, multilingual, and family-centred contexts.

This report synthesises the insights, discussions, and consensus outcomes from the workshop and presents a roadmap for moving from concept to development of the national PPI guidance document, with eight priority action areas identified. These were:

1. Broaden and deepen stakeholder engagement
2. Establish governance, structure and a clear roadmap to develop the guidance document
3. Adopt an inclusive, consensus-based development approach
4. Address key content priorities explicitly
5. Contextualise the guidance for Singapore
6. Prioritise accessibility of guidelines
7. Engage ethics and oversight bodies early
8. Plan for implementation, evaluation, and impact

Finally, this Roadmap represents a critical first step toward establishing a shared national standard for Patient and Public Involvement in Singapore. It provides a clear and actionable pathway to develop guidance that is credible, culturally appropriate, and usable across the research ecosystem, supporting meaningful partnerships between researchers, patients, and the public, and strengthening the relevance, quality, and impact of future medical and clinical trial research in Singapore.

How to cite this document:

This report should be cited as: “Office of Patient Engagement (OPEN), Lee Kong Chian School of Medicine & Consortium for Clinical Research and Innovation, Singapore (CRIS): Roadmap for a National Guidance Document for Patient and Public Involvement in Medical Research, including Clinical Trials in Singapore: Report of the Roadmap to PPI Guidance Document Workshop held on 17/11/2025, Singapore 2026.

Acknowledgements

We thank all participants of the Roadmap to PPI Guidance Workshop (listed in Table 1) for their valuable contributions and engagement. Their insights and discussions played a critical role in informing the priorities, direction, and recommendations outlined in this roadmap. We thank Mr. Prabu Naidu, an OPEN Voices Patient Partner and Master Facilitator, for his expert facilitation of the workshop. We also thank Tan Sock Hwee (CADENCE), Ritu Jain and Veronica Lim (patient and lived experience partners) who provided input and additional feedback on this document.

Table 1: Roadmap to PPI Guidance Workshop Participants

Category	Name	Organization / Affiliation
Patient/Lived experience Partners	Ellil Mathiyan	Patient Partner
	Hanin Hussain	Patient Partner
	Evelyn Yeo	Patient Partner
	Carol Tsang-Sandric	Patient Partner
	Serene Mai	Patient Partner
	Nicole Kay	Patient Partner
International PPI Experts	Gary Hickey	NIHR, UK
	Kazuto Kato	Osaka University, Japan
Academic Institutions	Jo-Anne Manski-Nankervis	LKCMedicine
	Ai Ling Sim-Devadas	LKCMedicine
	Konstadina Griva	LKCMedicine
	Sanjay Chotirmall (Co-chair)	LKCMedicine
	Emina Obarcanin	LKCMedicine
	Lutfi Bin Mohamed Zulnizan	NUS Medicine
	Laura Martinengo	NUS Medicine
	Laurie Goldsmith	NUS Medicine
	Ryan Man	Duke-NUS Medical School
Healthcare Clusters	George Goh	SingHealth
	Chang Sook Mei	SingHealth
	Xu Huiying	NHG Health
	Celine Ong	NHG Health
	Tracy Gan	NHGP
	Soh Lai Yee	NUHS
Research & National Agencies	Neena Modi	A*STAR
	Eugene Gan	SCRI / CRIS
	Danny Soon (Co-Chair)	CRIS
	Seow Shih Wee	PRECISE
	Koh Ming Shi	TRUST

Summary of Abbreviations

A*STAR	Agency for Science, Technology and Research
CADENCE	Cardiovascular Disease National Collaborative Enterprise
CRIS	Consortium for Clinical Research and Innovation, Singapore
GRIPP2	Guidance for Reporting Involvement of Patients and the Public (Version 2)
IRB	Institutional Review Board
KDMA	Key Discussion and Mapping Activity
LKCMedicine	Lee Kong Chian School of Medicine, NTU Singapore
NHGP	NHG Polyclinics
NHIR, UK	National Institute for Health and Care Research, United Kingdom
NUHS	National University Health System
OPEN	Office of Patient Engagement
PiiAF	Public Involvement Impact Assessment Framework
PIRIT	Patient Involvement in Research Impact Tool
PPEET	Public and Patient Engagement Evaluation Tool
PPI	Patient and Public Involvement
PRECISE	Precision Health Research, Singapore
SCRI	Singapore Clinical Research Institute
UK	United Kingdom

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Introduction

Patient and Public Involvement (PPI) in research refers to the active partnership of patients, carers, and members of the public in the design, conduct, and dissemination of research, rather than as participants or subjects of research.^{1,2} Individuals with lived experience contribute their perspective and expertise, which can lead to more relevant, effective, and impactful research outcomes.³⁻⁶ Over the past two decades, the integration of PPI has become a recognised best practice in many countries, with growing evidence highlighting its benefits across the research lifecycle, including in clinical trials. Internationally, PPI in clinical trials has been increasing, and recent guidance from the World Health Organization (WHO) has recommended that patient involvement should be the norm in all trials, and “not an optional extra.”^{7,8}

Benefits of PPI in Research

There are numerous benefits to embedding PPI in medical research, including clinical trials. PPI helps ensure that research questions and outcomes reflect the needs and priorities of patients and members of the public. By involving patients and the public, researchers can design studies that are more accessible, inclusive, culturally sensitive and ethically sound. Systematic reviews have identified key benefits of PPI for patients and members of the public and researchers, ranging from increased confidence and self-worth for the former to new insights and identification of barriers to research participation for the latter.^{3,4} A systematic review and meta-analysis has also demonstrated that PPI is associated with increased enrolment of participants in clinical trials.⁵ Meaningful collaboration between patients and the public and researchers is critical to help build trust between academics and the community, overcome waste in research and ensure that the investment made in research benefits both the patients and community members who contribute to funding and are the expected benefactors.

When patients and the public are engaged as partners, they can become advocates for research, helping to disseminate findings and facilitate the translation of evidence into policy and practice. Furthermore, PPI can empower individuals and communities, giving them a voice in shaping the research agenda and contributing to capacity building within the health ecosystem.^{3,9}

Current Status of PPI in Singapore

While the value of PPI in medical research and clinical trials is increasingly recognised globally, its adoption and integration in Singapore’s research landscape remain in the early stages.

There are approximately 160 patient organisations in Singapore, and there are well developed roles for patient advocates in Singapore’s healthcare system and health technology assessment.^{10,11} The interest in PPI in medical research is growing, demonstrated by the development of programmes such as the OPEN at LKCMedicine, a PPI Community of Practice with membership from healthcare and research institutions across Singapore, and the incorporation of consumers and patient advocates in governance committees and advisory groups in national research platforms, such as PRECISE and TRUST.¹²⁻¹⁴

Previous research in the Singapore context has indicated that consideration of social and professional hierarchies and cultural factors will be necessary to incorporate PPI successfully into medical research. Leveraging on communities with a motivation to support health outcomes and embracing novel PPI approaches such as “Hawker café” may be important to realise the potential of PPI.¹⁵⁻¹⁷

There is currently no national guidance for PPI in medical research and clinical trials in Singapore and awareness among researchers and the public alike is limited. Without clear guidance, researchers and PPI partners may lack the confidence and resources needed to implement effective PPI strategies.

The Need for a National Guidance Document for Singapore

Guidelines and frameworks for PPI involvement, assessment and reporting in research have been developed in countries such as United Kingdom (UK),^{18–21} Canada,^{22,23} Ireland,^{24,25} Australia,²⁶ and the United States.^{27,28} Whilst these documents are helpful to inform PPI in Singapore, they do not consider the cultural context. Roles and issues such as remuneration are yet to be clarified in Singapore. Without appropriate contextual guidance being available, any PPI initiatives risk poor reporting, unclear roles, confusion, administrative constraints and tokenism, amongst others.²⁹ A national guidance document could also address specific cultural, linguistic, and systemic factors unique to Singapore, ensuring that PPI approaches are sensitive to local needs and values.

Given the growing recognition of the value of PPI in Singapore, there is an urgent need for a national guidance document to inform and support local PPI activities, fostering a shared understanding of PPI among researchers, funders, institutions, and the public. By offering practical tools, case studies, and resources, the guidance would empower researchers to implement PPI effectively, while supporting patients and the public to participate with confidence. Ultimately, the development and adoption of national guidance will be essential for building a sustainable culture of PPI in Singapore, maximising the impact of research, and ensuring that health innovations reflect the needs and priorities of the community.

Developing a Roadmap for a National Guidance Document for Singapore

The Consortium for Clinical Research and Innovation, Singapore (CRIS) and OPEN at LKCMedicine have joined efforts to develop a National Guidance Document for Patient and Public Involvement in medical research, including clinical trials, in Singapore. On November 17, 2025, a dedicated workshop was convened to create a “Roadmap” for this important initiative. The workshop brought together key stakeholders from Singapore’s healthcare clusters, research institutes, medical schools and patient partners. Its primary objectives were to establish a shared understanding of the essential elements needed in the guidance document and to actively engage key stakeholders in the process of developing comprehensive guidance for PPI. The detailed outcomes and discussions from this workshop are presented in this report.

Structure and Aims of the Roadmap Workshop

The multi-stakeholder workshop “Roadmap to PPI Guidance Document” was held on Monday, 17 November 2025 at LKCMedicine. The objectives of the workshop were to:

- Establish a shared foundation for the collective development of PPI in medical research, including clinical trials, in collaboration with key stakeholders across Singapore’s healthcare and research ecosystem.
- Identify the needs, scope, and core components of a national PPI guidance document, including how it should be co-developed with stakeholders and translated into practice to guide researchers in Singapore.
- Develop a practical roadmap for the PPI Guidance Document project, including an outline of the proposed contents page to guide specification of requirements.

LKCMedicine and CRIS invited research leaders from medical schools, public healthcare clusters, and major research organisations in Singapore to nominate one person in their organization with experience and/or interest in PPI to participate in the workshop, to ensure broad institutional representation. Six patient and lived experience partners who were members of OPEN Voices, a patient partner network at LKCMedicine, were invited to participate. Two international PPI experts, one from the UK and the other from Japan, were invited to share their perspectives and lessons learned from establishing the PPI frameworks in their settings.

The workshop was designed as a co-creation workshop, bringing together patient and lived experience partners, researchers, clinicians, and healthcare professionals as equal partners to share experiences, generate ideas, and collaboratively shape the foundation and a roadmap for the Singapore PPI Guidance Document (see Appendix A: Workshop Agenda). The full-day co-creation workshop combined small and large group discussions with short presentations by the international PPI experts to enable shared learning and collaborative decision-making. The programme progressed from identifying key needs and priorities to developing content and discussing practical approaches for producing the guidance document.

Review of International Guidance Documents for PPI

National PPI guidance documents from the UK³⁰, Canada²² Australia²⁶, and Japan³¹ were selected as references to inform the development of a Singapore-specific PPI guidance document. The UK was included due to its long-standing leadership and extensive experience in PPI, providing well-established principles, governance models, and practical tools. Canada and Australia were chosen as comparable high-income healthcare and research systems with strong national commitments to patient and public engagement, offering practical insights into implementation and sustainability. Japan was included to provide an Asian perspective, offering regionally relevant lessons on adapting PPI approaches within cultural and healthcare contexts more closely aligned with Singapore.

During the workshop, participants engaged in structured small and large group discussions to review and compare the international guidance documents. Participants undertook a KDMA and identified and categorised elements of the reference documents into four areas (see Table 2).

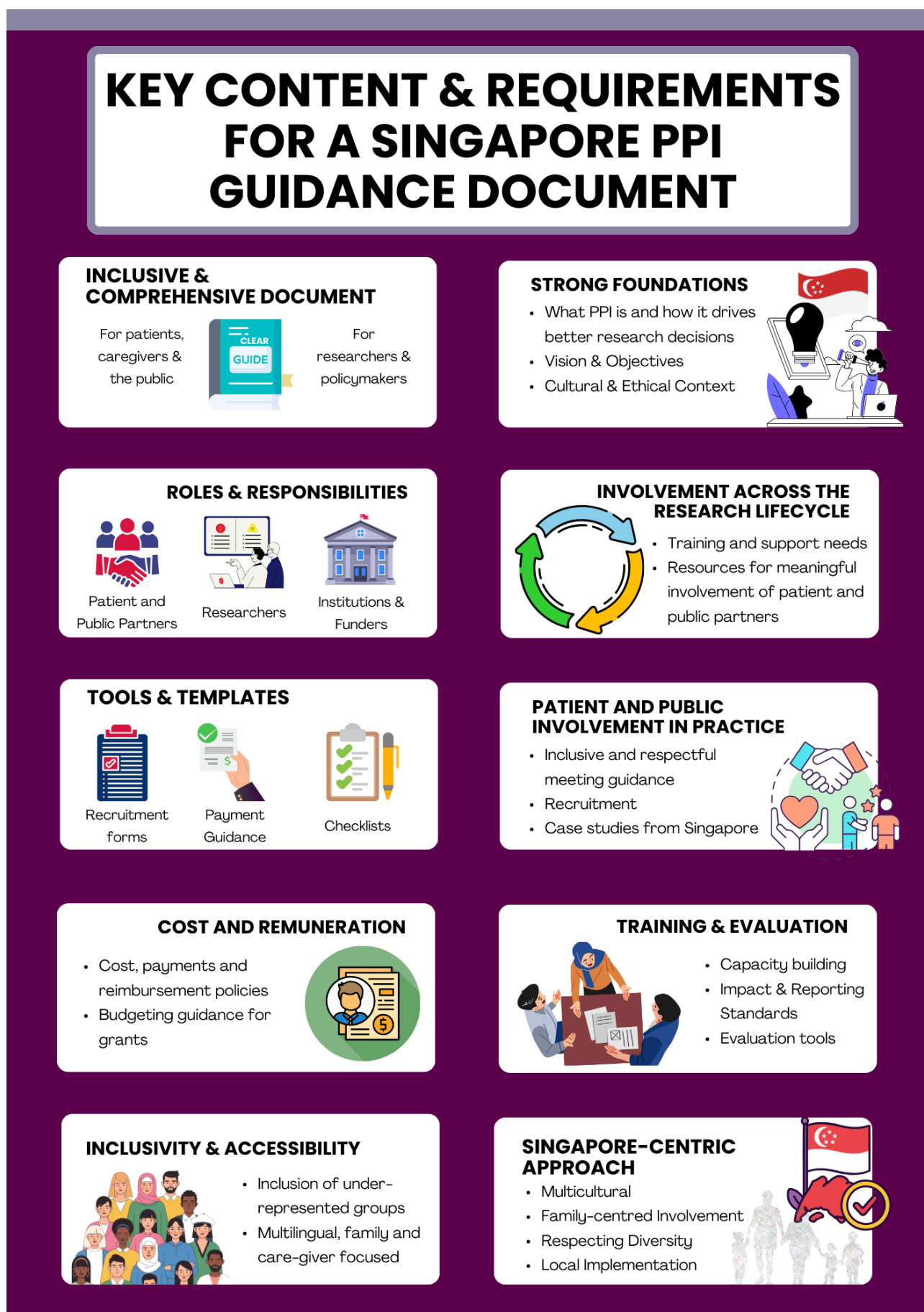
Table 2: Key Discussion and Mapping Activity (KDMA) - Traffic Light Document Summary

KEEP Elements to <i>keep</i> for the Singapore PPI Guidance Document	Transferable core PPI principles and practical features, including UK topic coverage and templates, Canada’s clear PPI vision and objectives, and the use of plain language, summaries, visuals and patient/lived experience stories across all guidance documents.
DROP Elements to <i>drop</i> due to limited relevance or feasibility	Repetitive content, highly prescriptive “how-to” instructions, non-transferable country-specific elements such as Australian First Nations governance frameworks and Canadian national infrastructure and governance structures.
MODIFY Elements to <i>modify</i> to better suit the local context	Document structure and terminology (e.g. consider avoiding the term “consumer” used in Australia), simplify flow, adapt payment guidance, alignment with Singapore regulatory requirements, incorporate Asian cultural norms such as family involvement and communication style.
ADD New elements to <i>add</i> , reflecting local priorities, cultural considerations, and system-specific needs	Singapore-specific content, evaluation and impact measures, locally relevant tools and forms (payment templates, checklists, conflict of interest declarations), differentiated guidance for lived experience/patient partners, researchers and institutions, training resources, multilingual materials, regional rationale for PPI.

Identifying Key Contents and Design Principles for Singapore

Key contents and design principles for a National PPI Guidance Document in Singapore were distilled from the large group discussions during the workshop (see Appendix B: Key Contents Page) and are summarised in Figure 1. A high-quality, locally relevant PPI framework should include a public-friendly explanations and practical implementation tools that cover topics including governance, ethics, training, and evaluation standards. Grounded in Singapore’s multicultural, family-centred context and regulatory environment, the elements shown aim to support meaningful, inclusive partnerships between the public, caregivers, researchers, institutions, funders, and policymakers across the full research lifecycle.

Figure 1: Key Content and Requirements for a Singapore PPI Guidance Document



Actions for Moving from Roadmap to Development

Participant feedback and workshop discussions led to the identification of eight key action areas.

1. Broaden and Deepen Stakeholder Engagement

To ensure the guidance document reflects comprehensive input and gains legitimacy and adoption, it is essential to actively expand engagement beyond the participants at the Roadmap Workshop. Priority stakeholder groups to involve include:

- Public sector organizations
- People with lived experience involved in PPI initiatives
- Patient and Community based organisations, including those representing under-represented groups to provide advice on PPI inclusion strategies and support requirements
- Research funders
- Institutional Review Boards (IRBs), Ethics Committees, and ethics experts
- International experts in PPI
- Researchers

2. Establish Governance, Structure, and a Clear Roadmap to Develop the Guidance Document

A clear, structured roadmap for writing the Guidance Document is required. A core writing team will be established, supported by working groups, to develop specific sections of the Guidance Document, with defined roles, timelines, milestones, and regular meetings. An expression of interest for four roles: workgroup member, advisory group member, consultation and to remain informed was obtained during the workshop and will be expanded through the stakeholder engagement process.

3. Adopt an Inclusive, Consensus-Based Development Approach

Use consensus-building methods to ensure all relevant perspectives are included, particularly those of researchers and people with lived experience. Targeted input from policymakers and funders should be sought for specific sections of the guidance. This approach will involve group and individual consultation and stakeholder workshops with ongoing feedback mechanisms maintained over the course of guidance development to build collaboration, trust and sustained buy-in.

4. Address Key Content Priorities Explicitly

Key requirements identified during the workshop (see Figure 1 on page 9) should be addressed in the Guidance Document. These include how to actively prevent tokenism in PPI, advice to embed PPI early in the research lifecycle (including when seeking research funding), and raising awareness of issues such as financial burden, stigmatisation, and barriers faced by under-represented groups.

In parallel to the Guidance Document, education and training for researchers, patients, caregivers and members of the public should be planned to support meaningful engagement and optimal PPI outcomes.

5. Contextualise the Guidance for Singapore

The guidance should be contextualised for Singapore, ensuring relevance to local healthcare systems, regulatory and ethical frameworks, and cultural considerations. This will enhance resonance and usability for local end-users.

6. Prioritise Accessibility of Guidelines

Accessibility and usability should be prioritised. One approach is the application of Universal Design for Learning principles, positioning the guidance as a learning document for all stakeholders. This could include multiple means of representation (e.g. clear language, visuals alongside text, and consideration of alternative formats such as audio), multiple means of action and expression (e.g. opportunities to provide feedback through discussions, meetings, workshops, and online platforms), and multiple means of engagement tailored to varying levels of knowledge, experience, and familiarity with healthcare research and PPI.

7. Engage Ethics and Oversight Bodies Early

Proactively consult Ethics Committees and IRBs during development to address ethical concerns, anticipate regulatory and risk-management issues and strengthen the credibility and feasibility of the guidance.

8. Plan for Implementation, Evaluation, and Impact

Evaluation frameworks and tools for PPI should be included in the document, such as GRIPP2¹⁹, PiiAF¹⁸, PPEET³², and PIRIT³³. Implementation strategies to maximise the impact of the guidance document should be developed in parallel with guidance development. Success should be defined not only by publication of the guidance but by its uptake and use, with indicators such as adoption by institutions and measurable metrics including the number of downloads. The Guidance Document should be a living document that is updated as PPI continues to evolve in Singapore.

Process for Developing the Guidance Document and Next Steps

The development and dissemination of the National Guidance Document for PPI will follow a phased, inclusive, and consensus-based approach over 24 months. Participation in the development of the National PPI guidance document will occur through clearly defined roles that reflect different levels of responsibility, authority, and engagement:

Strategic Leadership (Core Group) – will oversee overall strategy, coordination, analysis, and drafting. It will be responsible for synthesising inputs from all groups and producing successive versions of the guidance document.

Expert Co-creation (Workgroups) – a multi stakeholder group will provide specialised expertise on priority topics identified by the Core Group. They will co-develop and refine specific sections to ensure the guidance reflects diverse professional, cultural, and lived experiences.

Strategic Advice and Assurance (Advisory Group) – A targeted, multi-stakeholder body which will provide advice on this project convening approximately every six months. The Advisory Group will ensure the document aligns with the needs of each stakeholder group across the two-year development cycle.

Issue Specific Input (Consultation Contributors) – This involves reaching out to specific experts or community members via email, meetings, or workshops to gather feedback on individual chapters or complex issues that require a deeper level of external validation.

Ongoing Stakeholder Engagement (Inform) – All previous workshop participants and interested stakeholders will receive regular email communications regarding the project's progress, ensuring that the community remains connected to the development of the national guidance even if they are not part of the formal drafting groups.

Preliminary National Guidance Document Development Timeline

Phase 1: Governance Setup, Stakeholder Expansion and Content Framework Finalisation (Months 0–3)

Objectives

Establish governance and terms of reference.
Formalise Core Group, Workgroup and Advisory Group structures.
Expand stakeholder participation beyond the Roadmap Workshop.
Confirm the structure and scope of the National Guidance Document.
Agree on development principles and consultation methods.
First Advisory Group meeting scheduled to endorse priorities and regulatory alignment.
Disseminate the first progress update to the Inform group.

Phase 2: Drafting, Co-Creation, and Early Digital Planning (Months 2–15)

Objectives

Assign chapter leads and drafting responsibilities.
Conduct multiple rounds of stakeholder consultation.
Conduct additional workshops.
Ensure consensus-building and cultural contextualisation.
Initiate website development planning and scoping.
Complete full first draft of National Guidance Document.

Phase 3: Final Drafting and Website Development (Months 16–20)

Objectives

Complete final revisions of the National Guidance Document.
Develop and populate the project website.
Prepare materials for dissemination and implementation.

Phase 4: Dissemination, Outreach, and Impact Monitoring (Months 20–24)

Objectives

Disseminate the report nationally.
Deliver outreach activities and training.
Monitor uptake and inform future revisions.
Collection of feedback for future updates.

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Appendices

Appendix A: Workshop Agenda

Date: Monday, 17 November 2025

Time: 9.00 am – 5.00 pm

Venue: HQ Seminar Room (Level 2), HQ Building,
Lee Kong Chian School of Medicine, 11 Mandalay Road, Singapore

Time	Session
9.00 am – 9.30 am	Welcome and Introduction
9.30 am – 11.10 am	Co-creation Conversation 1: What do we need in the Singapore PPI Guidance Document? Small group discussions
11.10 am – 11.30 am	Tea Break
11.30 am – 11.50 am	Presentations: Experiences with PPI Guidance Documents in the UK and Japan
11.50 am – 12.45 pm	Co-creation Conversation 1 (continued): What do we need in the Singapore PPI Guidance Document? Large group discussion
12.45 pm – 1.30 pm	Lunch
1.30 pm – 3.30 pm	Co-creation Conversation 2: Developing the Content Framework for the Singapore PPI Guidance Document Small group and large group discussions
3.30 pm – 3.45 pm	Tea Break
3.45 pm – 4.30 pm	Co-creation Conversation 3: How should we develop the Singapore PPI Guidance Document?
4.30 pm – 5.00 pm	Next Steps and Wrap-Up
5.00 pm	End of Workshop

Appendix B: Key Contents Page

This appendix outlines the proposed key content areas for the National Guidance Document for PPI in Singapore. These sections were derived from the Roadmap Workshop discussions and Expressions of Interest and informed the Eight Key Areas for Action. The framework will guide drafting by the Core Group, Workgroups and Advisory Group and will be refined through ongoing consultation with patients and the public, researchers, funders, policymakers, ethics committees, and other stakeholders. Proposed Key Contents are:

1. Vision and Objectives

This section will articulate the purpose, scope, and intended outcomes of the national guidance, including its role in strengthening meaningful, ethical, and inclusive PPI across the research lifecycle in Singapore.

2. Patient and Public Involvement

This section will present foundational definitions, principles, and the scope of PPI in medical research, including clinical trials, drawing on international standards while contextualising them for Singapore.

3. Involving Patients and the Public Across the Research Lifecycle

This section will provide guidance on when and how to involve patients and the public at different stages of research, from priority-setting and study design to dissemination and implementation.

4. Planning and Preparing for Patient and Public Involvement

This section will address considerations for readiness, governance structures, roles and responsibilities, training and support needs, and resourcing required to enable meaningful involvement.

5. Patient and Public Involvement in Practice

This section will outline practical approaches to implementing PPI in real-world research contexts, including illustrative examples relevant to Singapore's healthcare and research systems.

6. Practical Advice for Involvement

This section will provide operational guidance and good practice examples for researchers and PPI partners, including communication strategies, meeting structures, conflict resolution, and sustaining engagement.

7. Templates and Tools for Patient and Public Involvement

This section will include proposed templates, checklists, and practical tools to support the planning, delivery, and reporting of PPI activities.

8. Cost, Payment, and Remuneration

This section will address financial considerations related to PPI, including remuneration, reimbursement policies, budgeting guidance for grant applications, and transparency in financial arrangements.

9. Evaluating Patient and Public Involvement

This section will outline proposed approaches to evaluating the processes and impacts of PPI, drawing on established frameworks and tools such as GRIPP2, PiiAF, PPEET, and PIRIT.

10. Engagement and Involvement of Under-Represented Groups

Identify strategies to improve inclusion and participation of under-represented groups in medical research, including clinical trials, in Singapore.