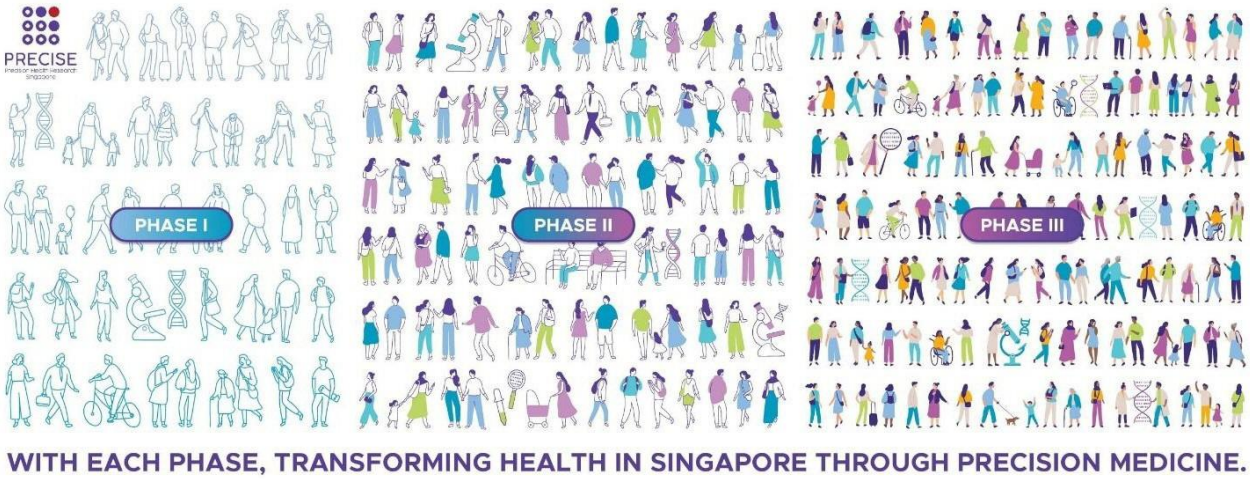


Our Promise

Patient, Public Involvement and Engagement for socially acceptable and patient-centred innovation in precision medicine research and healthcare in Singapore

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Foreword

Through Singapore's National Precision Medicine (NPM) programme, we envision a future where healthcare informed by genetic information advances patient health outcomes so every Singaporean can thrive regardless of the genetic hand they inherited.

We recognise that precision medicine is more than science alone. To succeed, it must also earn trust, reflect public values, and improve health in ways that matter to people. Therefore, we have chosen to invest in Public and Patient Involvement (PPI).

This document is a declaration of our intent, lays out our thoughts on what involvement looks like and invites you to join us on this journey. It reflects our commitment to making PPI a core part of how precision medicine is developed, implemented, and governed in Singapore.

Background

Our genes can affect our health, including our risk of developing certain conditions and how we respond to medicines. By studying genetic information alongside health information, researchers can learn how to improve disease prevention, diagnosis, and treatment, helping to make healthcare more personalised and effective.

SG-INSIGHT is the flagship research cohort of Phase III of Singapore's National Precision Medicine (NPM) Programme. The NPM programme aims to explore how genetic information can be used responsibly to improve healthcare and support better treatment and care in the future. SG-INSIGHT will enroll up to 450,000 Singapore residents into the study and participants will contribute a DNA sample and health information to help researchers better understand the health needs of Singapore's population.

To ensure that patients and members of the public have a voice in this national project, PRECISE established the **Public and Patient Involvement Advisory Panel (PPIA)** in 2024. The panel reviews evaluates, and makes recommendations on areas of the programme that affect patients and the public.

PPI is Important to PRECISE and NPM

The NPM programme represents a significant national investment in understanding the genetic and environmental factors that influence health and disease in Singapore's diverse population. For this ambitious initiative to succeed and deliver meaningful benefits, it must earn and maintain the trust and support of Singaporeans. PPI is fundamental to achieving this and reflects the values that should define how precision medicine is done in Singapore.

a. **Trust** is essential for people to feel confident about taking part in research. Through PPI, researchers will work with PPI contributors to ensure that their personal and genetic

information will be handled responsibly, protected, and used in ways that reflect their values and expectations.

b. **Partnership** recognises patients and members of the public as active partners in research, not just participants. Their lived expertise in health can highlight insights that researchers may not see. PPI ensures that the research reflects the realities of communities it serves.

c. **Equity** means that everyone should have the opportunity to benefit from precision medicine. PPI helps us understand the barriers that different communities may face and identify ways to make participation and future benefits more accessible and inclusive.

d. **Accountability** demands PRECISE to be responsive to people who contribute their time, and data. PPI creates opportunities for the public to provide feedback and influence decisions, ensuring that the research remains answerable to the communities it serves.

e. **Benefits sharing** should be delivered to people across Singapore. PPI helps ensure that research priorities, programme design, and future applications are informed by public needs, so that the value created through participation can be shared as widely and fairly as possible.

Our Beliefs

We believe that the future of precision medicine depends on public trust and acceptance, and meaningful partnership with the people whom the programme is intended to serve. Our beliefs guide PRECISE to cultivate the capability to listen, learn, and build together with patients and the public.

a. We believe people affected by research should help shape it.
b. We believe lived experience is expertise.
c. We believe precision medicine must benefit as many communities as possible.
d. We believe trust must be continually earned.
e. We believe participation should be meaningful and sustained through the research.

Our Commitment

PRECISE is committed to making PPI an integral part of how research is done. We envision a precision medicine programme that is truly co-created with the people of Singapore - one where diverse voices are heard, valued, and influential at every stage.

To do that, PRECISE commits to:

a. Listening with openness and humility:

- Create platforms and avenues for participants to raise questions and concerns directly.

- Seek perspectives from a diverse range of communities, including those who may be less familiar with research.

b. Explaining research clearly and honestly

- Use plain language when developing participant-facing materials.
- Explain how data and samples are collected, used, stored, and accessed.
- Be open about the opportunities, limitations, and uncertainties of precision medicine.

c. Responsible handling and use of data

- Explain how participant data is protected and who can access it.
- Share information about the safeguards and oversight processes that govern data use.
- Address public concerns and incorporate feedback about data governance and consent.

d. Supporting contributors with training and fair recognition

- Provide learning resources to help contributors understand precision medicine research.
- Recognise contributors' time, expertise, and effort through appropriate acknowledgement and reimbursement, where applicable.

e. Continuously improving based on feedback

- Ask participants and contributors about their experiences of being involved in PRECISE.
- Share how public input has influenced decisions, priorities, or programme activities.
- Refine our engagement approaches based on lessons learned and community feedback.

Working Together to Shape Precision Medicine

Patients and members of the public bring valuable perspectives that can help ensure precision medicine is developed in ways that are relevant, responsible, and beneficial for the people it is intended to serve. PRECISE is committed to involving patients and the public in areas where their experiences, expectations, and values can meaningfully inform decisions.

However, we recognise that not every activity requires the same depth of involvement. We also want to be respectful of participants' time and ensure that the right support and training are provided. To guide our approach, PRECISE draws on the principles of the IAP2 Spectrum of Public Participation, recognising that people can be involved in different ways at different stages of the programme.

Our aim is to provide meaningful opportunities for involvement that are appropriate to the issue being considered and supported by the resources and training needed to participate effectively:

a. **Understanding public perspectives on precision medicine and genomics**: We will work with patients and members of the public to better understand their perspectives, concerns, expectations, and priorities regarding precision medicine and the use of genomics in

healthcare. including their concerns, what people hope to gain, and what outcomes matter most to them.

- Exploring what people hope precision medicine can achieve for patients and families.
- Understanding concerns about genetic testing and the use of genomic information.
- Identifying outcomes that matter most to patients and the public.

b. **Shaping responsible use of personal and genetic data**: We will involve patients and members of the public in discussions about how personal and genetic information is collected, used, protected, and governed.
   - Provide information about data governance and safeguards.
   - Seek feedback on privacy, consent, access to data, and data sharing.
   - Work with public contributors to help inform policies and approaches that maintain public trust.

c. **Helping to shape how precision medicine is implemented:** We will involve patients and members of the public in discussions about how precision medicine can be integrated into healthcare in ways that are meaningful, acceptable, and accessible to Singaporeans.
   - Identifying barriers that different communities may face in accessing future precision medicine services.
   - Co-designing patient-facing resources and educational materials.
   - Providing input on how genetic information and research findings should be communicated.
   - Helping to identify priorities and considerations for future implementation.

d. **How you may be involved**: Depending on the topic and decision being considered, patients and members of the public may be involved in different ways, including by:
   - Receiving information and updates about the programme.
   - Providing feedback through consultations and engagement activities.
   - Participating in advisory groups, workshops, or working groups.
   - Collaborating with PRECISE on specific projects or priority areas.
   - Contributing to the co-design of selected policies, materials, or programme activities.

e. Demonstrating impact: We will show contributors how their input has influenced our work and explain our decisions openly.
   - Publish summaries of feedback received and actions taken.
   - Report back on changes made because of public input.
   - Explain where suggestions cannot be adopted and the reasons why.

Our Aspirations – The Future We Are Building Together

We envision a Singapore where precision medicine is something built with people as partners. Where Singaporeans — across every community, background, and generation — feel a genuine sense of ownership over the NPM programme, because they helped shape it from the beginning.

In this future, genomic research is trusted because trust has been earned through transparency, inclusion, and a consistent record of keeping promises. Participation in research is seen as a meaningful act of contribution to something larger than oneself.

Patients are partners in this future — not subjects to be studied, but collaborators whose experiences and insights make science better and the outcomes more human. Their voices inform which questions get asked, how research is designed, and how findings are communicated and applied.

Research findings translate into real improvements in prevention, diagnosis, and treatment — improvements that are accessible across Singapore's diverse communities. The programme actively works to close gaps rather than widen them.

When the next generation inherits this healthcare system, they will inherit one that was shaped with public input at every stage — a system that reflects Singapore's values, honours its diversity, and demonstrates what is possible when science and society move forward together.

This is the future PRECISE is working towards, and it is a future none of us can build alone.

We Invite You to Join Us!

Precision medicine will only fulfil its potential if it is built with the people it is meant to serve.

PRECISE invites patients and their families, healthcare professionals, researchers, community leaders, and Singaporeans from all walks of life to help shape this journey. Whether you contribute your data, your experience, or your perspective — your involvement enriches the programme.



https://for.sg/sginsightcommunity

Scan the QR code to be part of the SG-INSIGHT community and embark on the PPI journey with us. To find out more, visit our website at Precision Health Research, Singapore (PRECISE) or email us at contact@precise.cris.sg.

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Transforming Health in Singapore through Precision Medicine

