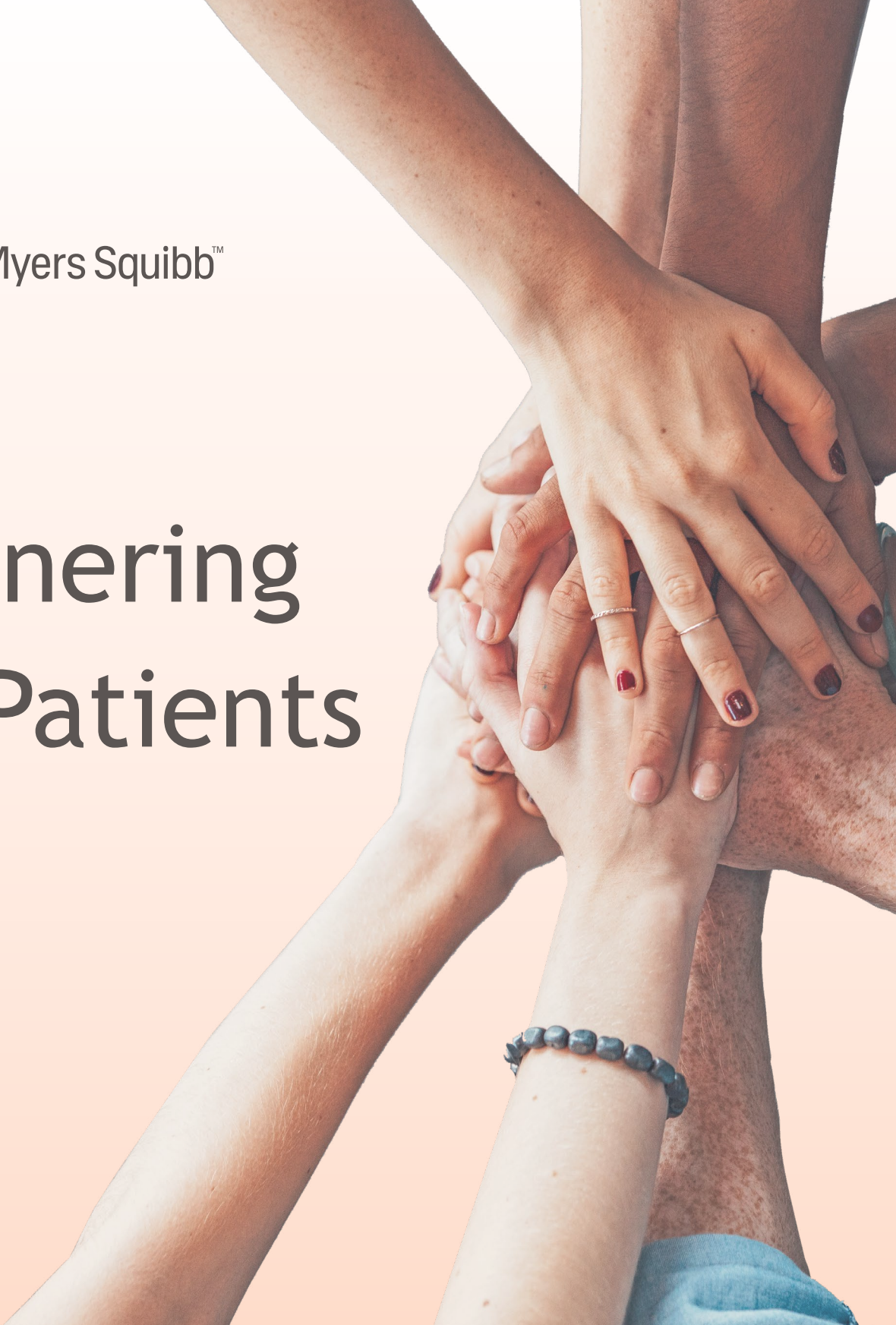




Partnering for Patients



2024 Patient & Parliament Summit

Summary

Partnering for Patients

Bristol Myers Squibb Australia (BMSA) is committed to working with patients and their representatives with the goal of shaping healthcare decisions and health policy that will best serve Australian patients. We are committed to working together to drive initiatives and changes that will improve our healthcare ecosystem and ultimately provide improved outcomes for Australian patients.

The third annual Patient & Parliament Summit convened this November in Canberra brought together patients, ranging from those with cancer to those with chronic diseases, representatives from patient organisations, the pharmaceutical industry, the Department of Health and Aged Care and parliamentarians to discuss key issues in health.

The theme of the 2024 Summit was *Partnering for Patients*; reflective of the critical role patients have in their own healthcare, as well as the critical role of the **patient voice** in our healthcare system. We focused on the importance of **early and continuous engagement** of patient communities, particularly in health technology assessment (HTA) following the recent release of the HTA review and Enhance HTA reports.

The Summit provided a platform to discuss plans for prioritisation and implementation of report recommendations related to embedding the patient voice across the lifecycle of HTA and supporting improved access to innovative medicines. The Summit included two key events; the Shaping Healthcare Together roundtable (for patient organisation representatives) and the Patient Showcase at Parliament House hosted by several Parliamentary friendship groups, as well as meetings with ten individual Members of Parliament, with further meetings scheduled in electorates outside of the sitting period for some MPs who were unable to accommodate a meeting in the busy final fortnight of parliament.

Throughout the Summit we heard from patients and patient organisation representatives about the need for progress to ensure healthcare decision making is underpinned with consideration of the patient voice and lived experiences and that Australian patients receive timely access to medicines. The Honorable Mark Butler, Minister for Health and Aged Care, announced the members of the HTA review Implementation Advisory Group (IAG) at the Patient Showcase, representing an important step towards positive HTA reform.

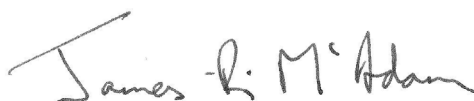
In a rapidly evolving, dynamic environment all healthcare stakeholders need to collaborate to build upon the existing momentum for change and deliver positive healthcare reform that best serves Australian patients.

We look forward to continuing to work with you to that end!

Yours Faithfully,



Hayley Andersen
Director, Patient
Advocacy & Policy



James McAdam
Director, Government Affairs,
Policy & Advocacy



Owen Smith
General Manager









Partnering for Patients








The Patient & Parliament Summit took place in Canberra with a series of events across 2 days, on November 19 and 20, 2024.

Presenters



Rosie Yeo	Director Public Affairs Network
Janelle Bowden	Managing Director AccessCR
Jo Watson	Deputy Chair Pharmaceutical Benefits Advisory Committee (PBAC) Chair HTA Consumer Consultative Committee
Kieran Gilbert	Chief Political Reporter Sky News
Professor Richard Scolyer AO	2024 Australian of the Year Co-Director Melanoma Institute Australia
Hon Mark Butler MP	Minister for Health and Aged Care
Dr Mike Freeland MP	Parliamentary Friends of Medicine – Co-Chair
Hon Dr David Gillespie MP	Parliamentary Friends of Medicine – Co-Chair

Summit Participants

	Health Care Organisation	Patient representative
	<p>AccessCR Pty Ltd</p> <p>Dr Janelle Bowden Managing Director and Consultant</p>	<p>Deborah Robins</p>
	<p>ausEE Inc</p> <p>Sarah Gray Chief Executive Officer</p>	<p>Isabella Gray</p>
	<p>Australian Patient Advocacy Alliance</p> <p>Deidre Mackechnie Executive Officer</p>	
	<p>Australian Patients Association</p> <p>Stephen Mason Chief Executive Officer</p>	<p>Jodie Guerrero</p>
	<p>BEAT Bladder Cancer Australia</p> <p>Adam Lynch Chief Executive Officer</p>	<p>Christine La Rose</p>
	<p>Breast Cancer Network Australia</p> <p>Vicki Durston Director Policy Advocacy and Support Services</p>	
	<p>Cardiomyopathy Australia New Zealand</p> <p>Leigh Bell President</p>	<p>Dionne Essenstam</p>
	<p>Crohn's & Colitis Australia</p> <p>Leanne Raven Chief Executive Officer</p>	<p>Hon Lisa Neville</p>

	Health Care Organisation	Patient representative
	CreakyJoints Australia Rosemary Ainley	Annie McPherson
	Heart Foundation Josh Hodges Head of Advocacy	
	Heart Support Australia Dr Christian Verdicchio Chief Executive Officer	Murray Chenery
	Hearts4heart Tanya Hall Chief Executive Officer	Sonia Spatino
	Inherited Cancers Australia Robyn Smith Programs and Advocacy Manager Lisa Caterina Community and Partnerships Manager	
	Kidney Health Australia Chris Forbes Chief Executive Officer Lydia Lauder National Advocacy and Policy Manager	Grace Woodford
	Lung Foundation Australia Dr Lily Grigsby-Duffy Policy and Project Officer	Vivienne Van Dissel

	Health Care Organisation	Patient representative
	Lymphoma Australia Sharon Winton Chief Executive Officer	
	Melanoma & Skin Cancer Advocacy Network (MSCAN) Tamara Dawson Chief Executive Officer	Pauline Ryan
	Melanoma Institute Australia Dianne Mason Corporate Engagement and Partnerships Manager	
	Melanoma Patients Australia Ross Kyrwood Acting Chief Executive Officer	Audrey Colbert
	MS Australia Katie Snell National Policy Manager	Ebony Moffat
	Pancare Foundation	Megan Verry Nicholas Verry
Patient Voice Initiative	Patient Voice Initiative Ann Single Chief Executive Officer	
	Psoriasis Australia Murray Turner Chief Executive Officer	

	Health Care Organisation	Patient representative
	<p>Rare Cancers Australia</p> <p>Sarah Benger Head of Policy and Public Affairs</p> <p>Cathy Slattery Head of Patient Programs</p>	<p>Danielle Pudovkin</p>
	<p>So Brave - Australia's Young Women's Breast Cancer Charity</p> <p>Rachelle Panitz Managing Director and Founder</p>	<p>Mary-Jane Logan</p>

Summit Supporters



Bristol Myers Squibb Summit Participants

Hayley Andersen	Director, Patient Advocacy & Policy
Greg Cook	Senior Director, Access, Policy & Advocacy
Lara Donovan	Associate Director, Market Access
Matthew Douglas	Associate Director, Market Access
Meredith Edwards	Country Medical Director
James McAdam	Director, Government Affairs, Policy & Advocacy
Owen Smith	General Manager



Parliamentary Participants

9 parliamentary friendship groups co-hosted the Patient Showcase:

- Parliamentary Friends of Arthritis
- Parliamentary Friends of Autoimmune Diseases
- Parliamentary Friends of Cancer Care and Cure
- Parliamentary Friends of Heart and Stroke Foundations
- Parliamentary Friends of Kidney Health
- Parliamentary Friends of Lung Health and Lung Cancer
- Parliamentary Friends of Medicine
- Parliamentary Friends of Melanoma and Skin Cancer Awareness
- Parliamentary Friends of Multiple Sclerosis



Meetings with the following Members of Parliament were convened across the Summit

Hon Warren Entsch MP	Member for Leichhardt (QLD)
Mr Garth Hamilton MP	Member for Groom (QLD)
Mr Jerome Laxale MP	Member for Bennelong (NSW)
Office of Hon Richard Marles MP	Member for Corio (VIC)
Hon Clare O'Neil MP	Member for Hotham (VIC)
Ms Alicia Payne MP	Member for Canberra (ACT)
Mr Henry Pike MP	Member for Bowman (QLD)
Mr David Smith MP	Member for Bean (ACT)
Mr Andrew Wallace MP	Member for Fisher (QLD)
Mr Tony Zappia MP	Member for Makin (SA)





Background

- In September 2024 the Commonwealth Government released the Health Technology Assessment (HTA) Policy and Methods Review Report which includes 50 recommendations¹, together with the Enhance HTA report² from the Co-Designed Enhanced Consumer Engagement Process with a further 10 recommendations.
- HTA is the system by which Australia determines whether a medicine³ is safe, effective and cost effective to be listed on the Pharmaceutical Benefits Scheme (PBS).
- Both reports recognise the value consumers' (patients') diverse health care experiences, needs, preferences and perspectives bring.
- Both reports include recommendations that support consumers' engagement with HTA processes across the HTA system and all relevant processes.
- Government responses to the recommendations in both reports remain outstanding.
- There have been growing calls for earlier and more consistent engagement with consumers across the lifecycle of medicines^{4,5} as the value of patient input and evidence to therapeutic product development and health technology assessment (HTA) processes is increasingly acknowledged.
- There are more than 7,800 products in clinical development globally⁶. We are on the precipice of a new frontier of medicine which provides hope for better treatments and technologies for conditions ranging from cancers to rare diseases.
- We must act upon the opportunities for policy reform to ensure the patient voice is embedded in the Australian Health System, so that the system meets the changing needs of the environment and that it best serves Australian patients.

1 Health Technology Assessment Policy and Methods Review - Final report | Australian Government Department of Health and Aged Care

2 Enhance HTA - Enhance Consumer Engagement for Australian HTA - Final report

3 HTA for Australian Government subsidy | Australian Government Department of Health and Aged Care

4 Recommendations to improve the patient voice in health technology assessment in Australia, 2019. Patient Voice Initiative Incorporated (NSW Association). <https://www.patientvoiceinitiative.org/wp-content/uploads/2019/09/Patient-Voice-Initiative-Recommendations-to-Improve-Patient-Voice-in-Health-Technology-Assessment-in-Australia.pdf>

5 Hoos, A., Anderson, J., Boutin, M. et al. Partnering With Patients in the Development and Lifecycle of Medicines: A Call for Action. *Ther Innov Regul Sci* 49, 929-939 (2015). <https://doi.org/10.1177/2168479015580384>

6 https://phrma.org/-/media/Project/PhRMA/PhRMA-Org/PhRMA-Org/PDF/G-I/Innovation_in_Biopharmaceuticals.pdf

HTA plays an important role in Australia’s world-class healthcare system

- Australia has one of the earliest, most robust and well regarded HTA systems in the world.
- However, the average time it takes for an innovative medicine to go from TGA registration to PBS reimbursement, through the HTA process, is 466 days.⁷
- Patient input is welcomed in HTA assessment, though more is needed to ensure “consumers and consumer organisations are: *informed and engaged, supported and knowledgeable, included in HTA processes and methods, and equal partners.*”⁸

Partnering for Patients – Ideas to Actions

To deliver upon the Australian National Medicines Policy vision (published in 2022) to achieve the world’s best health, social and economic results for all Australians, policy reform that prioritises the patient voice and faster access to innovative medicines for Australian patients is needed.

Policy reform relies on Government focus on two key actions:

1

Implementation of **recommendations from the Enhance HTA report** to deliver engagement processes that prioritises patient needs, preferences and values and provides meaningful opportunities for patients to participate in and influence the reimbursement decision making process.



2

Implementation of **recommendations from the HTA methods and policy review report and the Enhance HTA report** to support the patient voice in healthcare and deliver faster access to innovative medicines.



7. <https://www.medicinesaustralia.com.au/wp-content/uploads/sites/65/2023/04/Medicines-Matter-2022-FINAL.pdf>

8. <https://www.health.gov.au/resources/publications/conversations-for-change-report-2023?language=en>

Partnering for Patients Summit Overview

The Summit included:

- The **Shaping Healthcare Together** Roundtable was convened with representatives from 27 patient organisations together with representatives from the Pharmaceutical Benefits Advisory Committee (PBAC), Department of Health and Aged Care Consumer Evidence and Engagement Unit (DoHA CEEU) and Medicines Australia. BMS recognises the immense knowledge within the patient community and has convened an annual roundtable since 2018 with the aim of bringing together key healthcare stakeholders to discuss shared issues. At this year's roundtable, facilitated by **Rosie Yeo** (Public Affairs Network), we explored themes important to earlier and continuous engagement of patient communities in Health Technology Assessment (HTA) processes. The discussions were informed by an overview delivered by **Janelle Bowden**, Managing Director of AccessCR of a paper prepared for the roundtable on this topic. We also heard from **Jo Watson**, Deputy Chair of the PBAC who shared insights on the opportunities for collaboration in HTA and highlighted that policy and process changes will be shaped by consumer expectations and ongoing demands of scientific and technology advances on government systems. Roundtable participants workshopped three key themes selected for their impact on early and continuous engagement (a summary of the workshop is included on page 19):
 - ▶ Access & Transparency of Information
 - ▶ Legal & Compliance Considerations
 - ▶ Trust & Rules of Engagement
- A **welcome dinner** for patient organisation attendees and their patient representatives. The evening included a presentation from **Kieran Gilbert**, Chief Political Reporter, Sky News who discussed the current political environment with particular focus on Australia and the recent US elections. This provided important political context for patients and patient representatives ahead of their individual meetings and the patient showcase the next day.
- The **Patient Showcase** hosted by several **Parliamentary Friendship groups** provided an opportunity for patient organisations, together with their patient representatives to share their experiences and their organisation's mission with MPs and senators. The **Hon Mark Butler** provided an address that included the announcement of the Implementation Advisory Group (IAG) for the HTA review as well as recognition of the important role of patient organisations in Australia (full transcript below). Co-Australian of the Year, **Professor Richard Scolyer AO**, provided a moving keynote address reflecting on his personal experience as a cancer patient and the importance of hope. **Dr Mike Freeland** and **Hon Dr David Gillespie**, co-chairs of the **Parliamentary Friends of Medicine**, also provided remarks.
- Meetings with **Federal Members of Parliament** were convened for each patient (where possible), together with their patient organisation representative and a BMS representative to discuss the importance and value of the patient voice and lived experience in shaping healthcare and healthcare systems. MPs were provided with information about the HTA review and Enhance HTA reports and the importance and need for HTA reform.



Transcript of Minister Butler’s speech at BMS Patient & Parliament Summit, Parliament House about health technology assessment reform (20 November 2024).

My thanks to BMS for bringing everyone together today, including - of course - the one and only Professor Richard Scolyer - our 2024 Australian of the Year - a man who knows what it’s like to be both clinician and patient. It is humbling to be among representatives from so many incredible organisations and some of the countless patients you have supported. Thank you all for the work you do as researchers, support services and advocates.

To the patients here - thank you for being brave enough to share your stories and to use your experience to help others.

Australia has some of the most confident and most effective patient groups in the world - and particularly when it comes to engaging with government and with policymakers. I don’t just say that as Health Minister - though that is certainly my view. Just this month, a global survey of more than 11 hundred patient organisations found that - out of 19 countries - Australia’s patient groups lead the world in confidence that they have influence. Influence on government and policymakers, influence on drug approvals and reimbursement, influence on the provision of healthcare, and influence on access to medicines.

The global survey by ‘PatientView’ concluded that *“Only Australian patient groups appear to exert the most influence in all four spheres of activity within healthcare systems - policymaking, healthcare provision, healthcare education and pharma R&D”*.

That is testament to the effort and experience of everyone in this room, and so many more besides, who contribute their time to organisations from the largest national charities to the smallest groups, run by volunteers from spare rooms and kitchens.

Upon coming to government and since returning to the Health portfolio, a key focus of my time as Minister for Health and Aged Care, has been to elevate the voice of patients in the health sector.

We have done that through investments that build the capacity of established groups like the Consumers Health Forum, and other investments that fund the creation of new groups in areas of need, like mental health, or culturally and linguistically diverse communities.

We have also ensured that the patient perspective is always represented - and represented strongly - on key advisory bodies and expert groups.

Today, I can announce, that we continue that approach in the composition of the implementation group for the Health Technology Assessment Review Report.

We are living in a supercharged period of discovery, and the velocity of that change is stress testing every part of the health sector, from clinical practice to business models, to our systems for health technology assessment - or HTA.

HTA is the review process that emerging health technologies and treatments go through before they are funded or subsidised by government. It looks at the quality, safety, efficacy and value for money of those treatments.

The HTA Review Report generated 50 recommendations that are both far reaching and wide ranging. Some are small, focused prescriptions for change that are limited in scope, and eminently sensible. Others are wide ranging and visionary and call for changes in legislation and new investment.

As with all recommendations that require significant investment, they need careful consideration by government. We're starting that process through an Implementation Advisory Group - an IAG - which I am pleased to announce today. The IAG will be chaired by renowned cardiologist and former Chair of the Pharmaceutical Benefits Advisory Committee, Professor Andrew Wilson. Professor Wilson is currently the Co-director of the Menzies Centre for Health Policy at the University of Sydney.

The Report was a critical piece of work that brought together governments, health experts, patients and industry, and it is important that every one of those perspectives are represented in taking forward the reforms that come out of it.

We'll have industry represented by:

- Elizabeth de Somer - Chief Executive Officer, Medicines Australia, and
- Anne Harris - Deputy Chair, Medicines Australia Board.

Clinical expertise will be provided by:

- Dr Lorraine Anderson - Medical Director, Kimberley Aboriginal Medical Services, and
- Dr Richard Mitchell - Head of Clinical Services, Kids Cancer Centre.

Importantly, we will have patient voices represented thanks to:

- Nicole Millis - Chief Executive Officer, Rare Voices Australia, and
- Kirsten Pilatti - Chief Executive Officer, Breast Cancer Network Australia

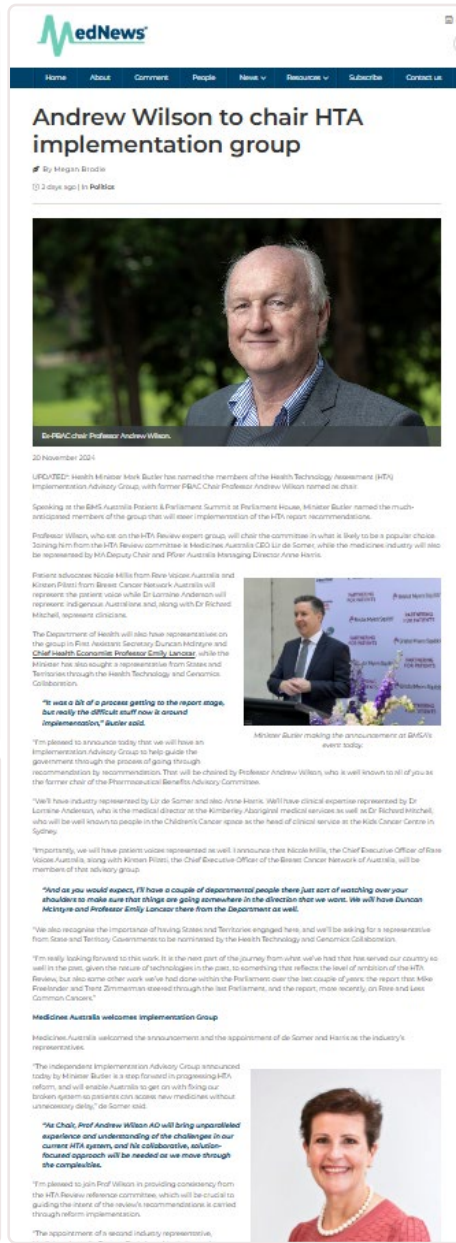
The Australian Government will be represented by Professor Emily Lancsar and Duncan McIntyre from my department. And a member to represent states and territories will be nominated by the Health Technology and Genomics Collaboration.

The IAG deliberately includes a robust mix of representatives, so all voices are heard and consensus can be reached on these important reforms. The IAG will co-design a draft Government response to the HTA review. These reforms will take time, but it's important we get them right.

I want to thank Professor Wilson and every member of the implementation group for taking on this important project. I look forward to working with them to realise a future of better health, better health technologies and better health technology assessment.

A future where all Australians can access effective, safe and affordable health technologies in an equitable and timely way.

Thank you. (Transcript end)



Amplification of voices

Social media provided the opportunity for messaging on the importance of the patient voice in healthcare and healthcare systems to be shared with a wide audience.

Wendy Askew LP
Senator for TAS | Chief Opposition Whip in the Senate

Senator Wendy Askew on Monday

I was glad to participate in the annual Patient and Parliament summit in my capacity as co-chair of the Parliamentary Friends of Heart and Stroke Foundations group last week.

This annual event is hosted by Bristol Myers Squibb which brings patients, industry organisations and politicians together to share their lived experiences and discuss the role they can play when engaging with policy makers.

The centrepiece of the summit was the patient showcase and it was wonderful to... See more



Rare Cancers Australia
5,654 followers
14h

Patients are at the heart of everything we do at Rare Cancers Australia.


That's why we were proud to attend the Patient and Parliament Summit in Canberra this week, hosted by **Bristol Myers Squibb (BMS) Australia**.

The event connected patients, patient organisations and parliamentarians, allowing people to share their lived experience and discuss strategies to ensure the patient voice is reflected in healthcare and systems.

Danielle Pudovkin joined us, sharing her experience of advocating for treatment and care access for her seven-year-old son Xavier, who is living with childhood cancer, neuroblastoma.

We also heard from Prof Richard Scolyer, Australian of the Year who was diagnosed with glioblastoma, a rare brain cancer, 18 months ago. He reminded us that no one knows what it is like to be a patient until they are one, and shared openly about his own 'scanxiety' and the mental health impact of living with cancer.

Thank you to BMS for bringing us together and highlighting the critical role of patients and patient organisations in healthcare delivery and reform.



Melanoma Institute Australia
8,000 followers
15h


The patient voice is critical in the Australian healthcare system.

MIA is pleased to have participated in the third annual Patient and Parliament Summit in Canberra yesterday, hosted by Bristol Myers Squibb Australia. Prof Richard Scolyer AO was an inspiring guest speaker, and the event was attended by Di Mason, our MIA National Advocacy Lead.

The theme of the summit, 'Partnering for Patients', explored the value patients bring to healthcare systems, with a spotlight on the importance of early and continuous engagement of patient communities.

The summit connected patients and over 25 patient advocacy groups directly with parliamentarians, to share their lived experience and discuss strategies to embed the patient voice in healthcare and healthcare systems.

#PartneringForPatients #BMSAustralia #ProfRScolyer Australian of the Year Awards




sobraveofficial • Follow
Original audio


sobraveofficial Alone we can do so much... Together we can do so much more.

This week in Canberra advocating for young women with breast cancer working together with so many fabulous organisations and representatives in the space all working towards our shared goals to improve outcomes for patients has been incredible.

Many thanks to @bristolmyerssquibb team for leading the Patient Engagement Workshops, @inheritedcancersaus and novartis fear of recurrence event and @bcnapinklady and @breastsurganz for leading the conversation around prophylactic and risk reducing mastectomies in managing risk.

Inherited Cancers Australia
1,654 followers
1d


This morning, our team attended the Bristol Myers Squibb Patient & Parliament Summit: Partnering for Patients, an annual event bringing together patients, patient organisations, and policymakers to emphasise the critical role of the patient ...more



BEAT Bladder Cancer Australia
141 followers
13h

The patient voice is at the heart of everything we do at BEAT Bladder Cancer Australia.

Thank you **Bristol Myers Squibb (BMS)** for hosting the Patient and Parliament ...more

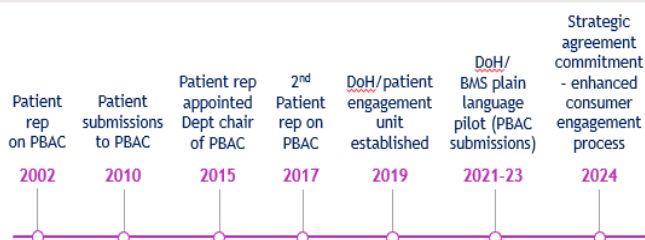


Shaping Healthcare Together Roundtable – Summary

Background

It is widely acknowledged that there has been significant progress in patient/consumer engagement in healthcare systems and specifically HTA processes in Australia. It is also clear that more is needed to embed the patient voice in HTA.

Patient engagement evolution in well-established HTA system



Enhanced Consumer Engagement Process

- Commitment in 2022-27 Strategic Agreement to deliver co-design enhanced consumer engagement process
- Co-design Working Group established
- Public Consultations
- Final Report provided to Mark Butler, Minister for Health & Aged Care (June 2024)
- Report released by govt (Sept 2024)

HTA Policy & Methods Review

- Commitment in 2022-27 Strategic Agreement to deliver review of the HTA policy and methods
- Reference Committee established
- Public consultations including in response to options paper
- Final report provided to Mark Butler, Minister for Health & Aged Care (April 2024)
- Report released by govt (Sept 2024)

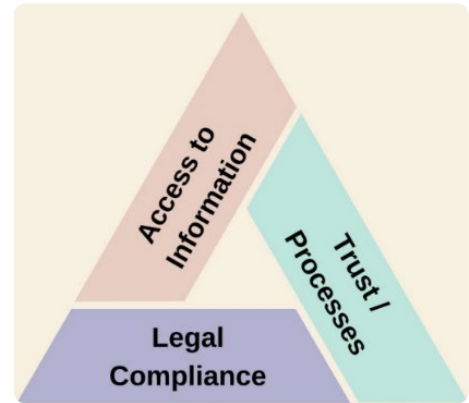
References

- Facilitating early and continuous engagement of patient communities in HTA processes: Discussion Paper and Summary
- Optional:
 - ▶ [Enhance HTA: An Enhanced Consumer Engagement Process in Australian Health Technology Assessment - A report of recommendations](#)
 - ▶ [Accelerating access to the Best Medicines for Australians Now and into the Future: A review of Australia's health technology assessment policies and methods for the Australian Government - Recommendations Summary. Sep 2024](#)

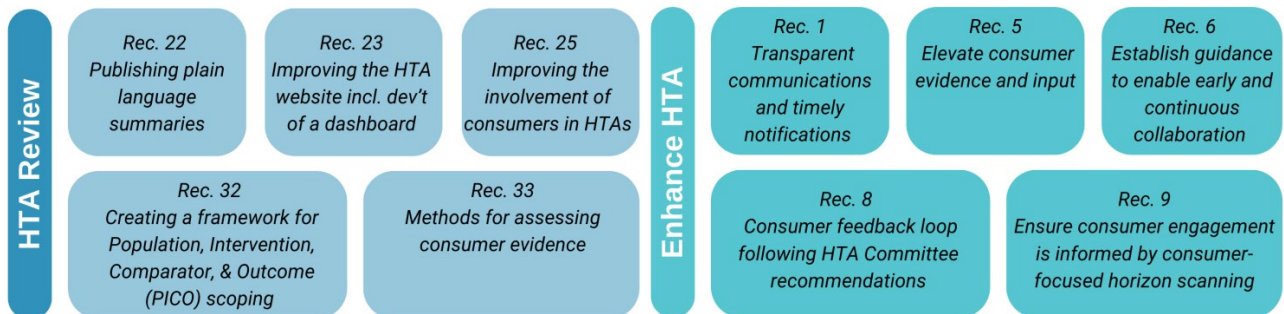
Overview

The **Shaping Healthcare Together** roundtable was convened at the Hyatt Hotel in Canberra with representatives from 27 patient organisations together with representatives from the Pharmaceutical Benefits Advisory Committee (PBAC), Department of Health and Aged Care Consumer Evidence and Engagement Unit (DoHA CEEU) and Medicines Australia. The roundtable was facilitated by **Rosie Yeo**.

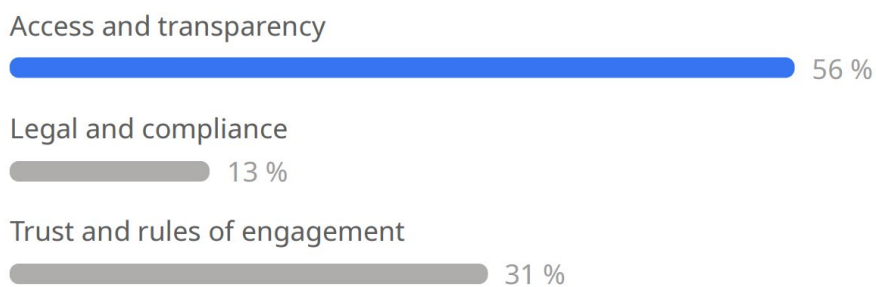
Janelle Bowden, Managing Director of Access CR provided an overview of the paper she had prepared, ‘Facilitating early and continuous engagement of patient communities in HTA processes’, setting the stage for the workshops on three key themes proposed to impact on early and continuous engagement (refer diagram right). Roundtable discussions explored these themes with a view to prioritising where action might be required for each theme, and what actions might enhance capacity for early and continuous engagement and better quality consumer evidence and inputs into HTA.



The three themes aligned with key recommendations from the HTA Review and Enhance HTA reports, related to patient engagement and involvement in HTA. By focusing on early and continuous engagement of patient communities, we hope that learnings from the roundtable will contribute to the public discourse on this important topic and provide ideas to support the implementation of the recommendations from the HTA Review and Enhance HTA reports.



Before each theme was workshopped, participants were asked which theme offered the greatest opportunity for positive change, based on the overview of the ‘Facilitating early and continuous engagement of patient communities in HTA processes’ paper. Results are below, though it is noteworthy that as the roundtable discussions evolved throughout the day, there was broad acknowledgement of the interrelatedness and interdependence of the themes.



Workshop 1: Access to Information

This section focused on:

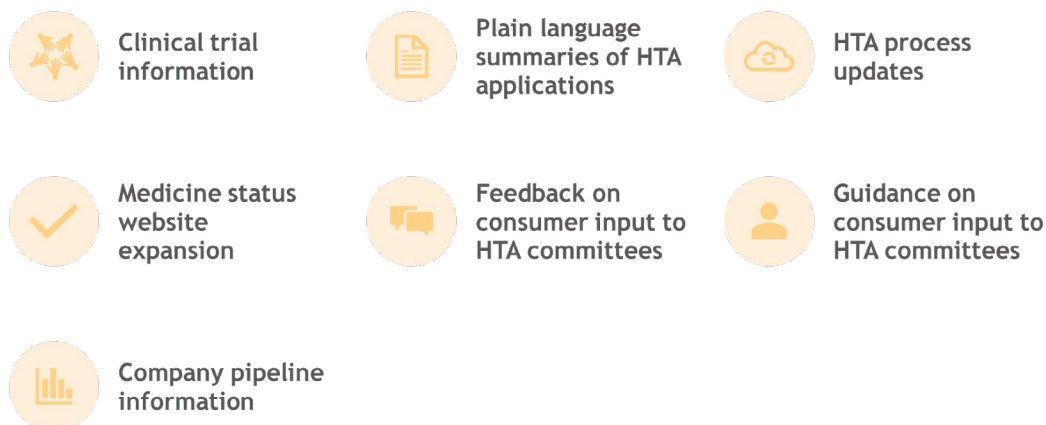
- The information patient communities would like access to;
- Industry barriers to sharing information;
- The role of government/HTA bodies in supporting access to information

Participants discussed current enablers and challenges around access to information and input into HTA processes. They identified current enablers including the important resources at the Consumer Evidence and Engagement Unit and Patient Voice Initiative as well as the role of industry in actively engaging the patient community.

Another enabler discussed was the broad recognition of the patient communities' role in HTA, substantiated by strong patient input into various policy consultations, including the National Medicines Policy, the HTA review and the Enhanced Consumer Engagement Process.

Challenges discussed included barriers like not knowing who to contact at a pharmaceutical company where there is a therapy of interest and resource and capacity issues. Discussions also included the challenges of inconsistency across companies in terms of what information is provided, to whom and when that information is provided and challenges resulting from a lack of feedback regarding HTA input to PBAC for specific submissions.

In groups participants were asked about the types of information they valued access to. They were then asked to consider the options for improving communication and input into HTA processes from those listed below and rank them in order of priority. Missing options could be added.



Most prioritised **Plain language summaries of HTA applications** (and use of plain language in general) highest. It was noted that this could be, in part, implemented in the short term given the Summary of Information for Patients (SIP) pilot. Attendees discussed the need for further consideration of the SIP pilot, the timing of the summary being provided and the resource required to implement it. There was also discussion of the importance of plain language advice and patient engagement earlier in HTA, particularly with respect to multistakeholder agreement of the PICO (Population, Intervention, Comparator and Outcome), and the role of patient communities to inform the population and comparator.

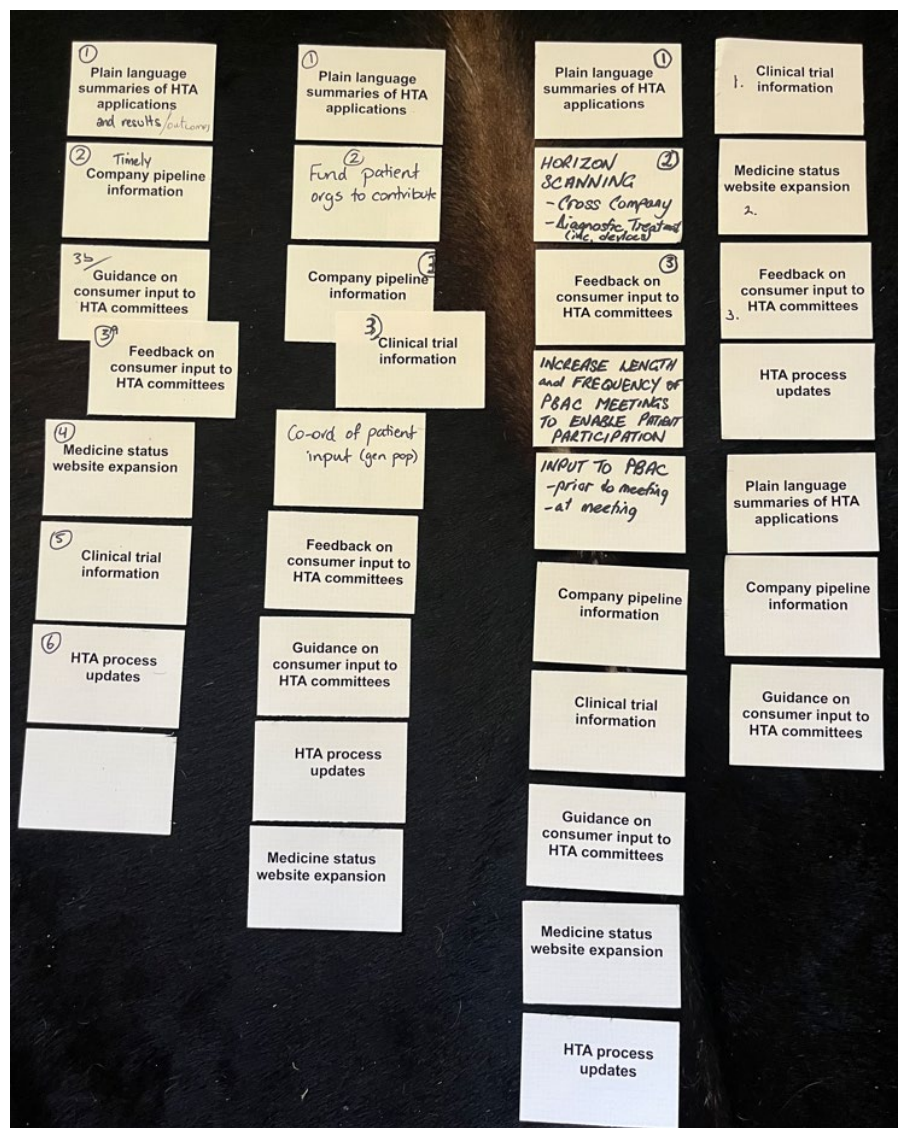
Feedback on consumer input to HTA committees was also considered to be a priority area that needed to be improved with many noting frustrations at not knowing if input had been valued in the decision making process or if it could have been improved. Participants discussed the value of a feedback loop for those providing input but also the value of improved feedback within existing instruments such as the Public Summary Documents (PSDs).

Pipeline information was considered to be a priority for improvement, and there was considerable discussion about the value of centralised horizon scanning as an alternative to company specific information provision regarding future therapies. There was further discussion about the significant benefit of pipeline information for patient organisations including assisting with clinical trial identification for patients or education around new treatments.

There was interesting discussion regarding the need for an increase in PBAC meetings (length and frequency) to facilitate greater patient participation and to accommodate recent capacity issues.

Further, the idea of strategic, co-ordinated communications across a medicine lifecycle from the Department of Health and Aged Care was tabled and received strong support from participants.

Rankings of the information priorities for improvement for each of the four workshop groups are provided (right).



Workshop 2: Legal & Compliance Conditions

This workshop focused on the regulatory framework and specific legislation pertinent to the facilitation of early and continuous consumer engagement.

The framework

TGA

Therapeutic Goods Act 1989	Therapeutic Goods Legislation 1990	X
Therapeutic Goods Administration Advertising Code		

- Cannot advertise prescription medicines to the public
- HCPs exempt from Advertising Code (42AA(1))

Condition of registration: Promotional material (other than Product Info) relating to the registered good must comply with the requirements of the Code of Conduct of Medicines Australia.

Ed 20. 11d): Companies may share information with patient organisations and their representatives. This may include information about prescription medicines if there is a genuine need for the information, the content is relevant to their specific expertise and interest in the therapeutic area, and is **non-promotional**.”



TGA guidance on what is promotional/non-promotional

Medicine Australia

Medicines Australia Code of Conduct Edition 19 (Edition 20)	Guidance: Communicating ethically with patients and their representatives
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When asked if the regulatory environment needed to change in order to facilitate earlier and more continuous engagement, 76% of participants said yes, 11% said no and 15% were unsure. Participants were also asked if the Medicines Australia Code of Conduct raised barriers to communication and engagement. 64% thought the Code did raise barriers to communication and engagement, 7% thought it did not and 29% were unsure.

The presentation from Janelle Bowden on the regulatory framework and associated legislation was illuminating for many and highlighted the complex, and often unclear, nature of compliance. There was consensus that currently interactions with and between all stakeholders tend to be relationship based, lacking formality and clarity. Further, that there are significant differences in the way companies interpret the Code and its application.

While Medicines Australia has recently added guidance to support engagement with patient organisations, it is clear from the insights shared throughout the workshop that many companies are still taking a conservative approach. In turn, patient organisations are unable to access information they need to deliver upon their mission of supporting, educating and/or advocating for patients.

The need for increased **education** for all stakeholders on the application of the Code was identified as being critical to address inconsistencies and provide greater clarity. It was noted that interpretation of the Code is context specific and so further consideration of what is possible in terms of education is needed.

An example provided included a patient organisation that had sought ‘fact check’ advice from a pharmaceutical company for a patient resource. The company advised they could not provide advice due to the Code. Other participants advised they had received ‘fact check’ support from other companies, highlighting the inconsistencies in application of the Code by companies.

Participants were generally not supportive of the idea of having healthcare professional (HCP) representatives for each organisation who could be responsible for receiving certain information that may be restricted for non HCPs. In contrast, participants were supportive of greater flexibility in the Code/legislation to allow open conversations between industry and patient organisations. Discussions included an option that would involve patient organisations being recognised in a similar way to HCPs within the legislation.

Participants also did not support the idea of ‘accreditation’ of patient advocates or patient organisations. While this idea has been considered for the purpose of inclusion or amendment to current TGA legislation to facilitate earlier engagement of patient communities, participants indicated the potential for inequity was too great.

Participants were, however, very supportive of the idea of a formal **patient organisation register** to facilitate communication of HTA information to relevant patient communities and greater awareness of patient community stakeholders. Attendees noted there are a number of organisations (e.g. the Consumer Evidence and Engagement Unit, Patient Voice Initiative, Australian Patient Advocacy Alliance) that maintain lists of patient organisations, and that future efforts should leverage what exists rather than duplicate efforts. Further discussion regarding where a patient organisation register would exist, what information would need to be captured and who could be listed on or access the register would be a valuable next step.



Workshop 3: Trust & Rules of Engagement

This section focused on the trust between stakeholders that is necessary for effective, working relationships and genuine, meaningful partnerships as well as systemic barriers to early and continuous engagement of patient communities.

It was recognised that when stakeholders have different or competing agendas it can mean trust takes more time and effort to build. In a world of changing staff, priorities and resources, maintaining consistency, important for trust, is difficult and requires commitment.

Participants were asked to describe real world barriers to engagement. Contributions to the word cloud can be seen below:



Participants shared international examples where trusted relationships between stakeholders had resulted in positive outcomes or initiatives. These included the use of plain language summaries for HTA submissions in Scotland and the UK, horizon scanning, particularly the public interest meetings in the US and UK where community experience and input is sought, and CADTH's (Canadian Agency for Drug and Technologies in Health) lived experience committee, described as an 'embedded patient voice' within Canada's HTA system.

Multistakeholder fora such as the Shaping Healthcare Together roundtable were identified as an important way to build trust, as was identifying shared goals. Increased guidance on communications with patient communications was thought to be an enabler.

Increasing unification of the patient voice over time was also discussed and it was noted that this has resulted in an increase in trust of patient organisations as a responsible sector to work with.

Priorities & Responsibilities

Participants discussed the priorities for action for government, industry and patient organisations.

Actions for government:

There was broad consensus that the recommendations from the HTA review and Enhance HTA reports should be implemented as a priority. It was agreed that government is responsible for the implementation of the reports and as an extension of this, for ensuring that the patient voice is embedded in HTA processes, spanning the lifecycle of a medicine.



One strategy to support the patient voice being embedded in HTA, and identified as a priority for action, was a plain language framework that would empower and inform patients.

There was some discussion regarding the need for innovative access pathways including those for rare cancers and with regard for genomics. It was noted that there is a need for all stakeholders to collaborate and ideate solutions together.

Actions for Industry:

Priorities identified for industry were for further clarification and education regarding the Medicines Australia Code of Conduct, including how it intersects with the TGA legislation.



It was tabled that industry needs to more consistently acknowledge the important role of patient organisations and aim for an approach that recognises them as equal partners. This is reflective of one of the key tenets of the Conversations for Change report produced by the Consumer Evidence and Engagement Unit of the Department of Health and Aged Care.

There was consensus around the idea that industry, including the industry body, Medicines Australia, should embrace consultation with patient communities and aim to co-design more initiatives relevant for all healthcare stakeholders.

Horizon scanning was discussed as being important for all stakeholders and while linked to company specific pipeline information, there was broad consensus that a multi company platform is needed.

Actions for Patient Organisations:

While there was conjecture about who should design and host a patient register, it was agreed that patient organisations should prioritise this initiative as a way to improve awareness of patient organisations and their important role, and maximise current positive regard for the sector, building upon existing momentum.



Patient organisations also discussed the need to continue to work collaboratively on advocacy efforts and highlighted shared goals regarding the need for innovative access pathways, streamlined processes for biomarker specific medicines, and improved approval times for medicines to be listed on the PBS. It was also noted that there is a significant resource burden on patient organisations in order to contribute to HTA and that mechanisms (particularly funding) to better support this should be explored.

Conclusion

The theme for the two-day Summit was Partnering for Patients. The Summit provided a valuable combination of information and insight exchange together with the opportunity to connect representatives from the pharmaceutical industry, Department of Health & Aged Care, PBAC, patient organisations, patients and parliamentarians. The focus on embedding the patient voice in healthcare and healthcare systems, supporting early and continuous engagement of patient communities in HTA and elevating the patient perspective in HTA and policy decision making more broadly, ultimately aims to ensure better informed HTA decision making and earlier access to medicines.

The event was particularly timely given the rich policy environment and the willingness of parliamentarians to listen to the patient voice. The event theme, attendees and setting created a platform for the opportune announcement of the IAG for the HTA review; a critical step towards healthcare reform that will better serve Australian patients.

For Australians to benefit from the imminent surge of scientific developments, and ensure patients can access treatments when they need them, we need a HTA system that can be agile and responsive. It is also vital that the system listens to those most affected to understand what matters most to them and deliberately and comprehensively accounts for the value of the lived experience.

There is a perfect storm brewing in Australia (and globally) around the willingness and need for the patient community to be engaged early and continuously through the therapeutic product lifecycle, from research to HTA processes and beyond and to ensure Australian patients can access medicines when they need them.

While different stakeholders have competing agendas and healthcare systems are fragmented, the work has been done to create the foundation for positive reform.

In this rapidly evolving, dynamic environment, now is the time for reform. There's a need for strategic focus in defining a roadmap with tactics and responsibilities for all healthcare stakeholders to build upon existing momentum. We all have a role to play in ensuring we progress towards a health system that delivers upon the promise of universal patient access.





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