



Medicare Benefits Schedule Review Taskforce

Post Consultation Report from the Consumer Panel

2020



Acknowledgement

The Consumer Panel acknowledges the traditional custodians of the lands, seas and waters known as Australia and we express our respect to Elders past, present and emerging. We acknowledge that the land and the law, language and culture are as important today as they have always been to Aboriginal and Torres Strait Islander people and are integral to health and wellbeing.

Statement of appreciation

The Consumer Panel expresses our thanks for the support received from Secretariat members. We acknowledge the commitment and hard work of consumers on Taskforce committees and working groups and thank the consumers and committee chairs who responded to our survey and the organisations and individuals who responded as part of our public consultation process on the report.

Purpose of this Report

The purpose of this Report is to outline the work of the Consumer Panel and consumer involvement throughout the MBS Review, to provide information on lessons learnt, and to make recommendations to the Taskforce on consumer-related health technology considerations, both immediate and systemic.

Though the Taskforce has developed a mechanism for reviewing the MBS items at a clinical or cost relative level, the Consumer Panel are of the opinion that further work is required in order to effectively fulfil the statement of 'improving health outcomes for patients'.

The Consumer Panel support all or any of its recommendations to be considered by a future review mechanism, and that any future review should include a specific committee dedicated to consumer elements.



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1. Executive summary

1.1 Medicare Benefits Schedule Review Taskforce

The Medicare Benefits Schedule (MBS) Review Taskforce (the Taskforce) was established in 2015 to look at how the more than 5,700 MBS items could be aligned with contemporary clinical evidence and practice to improve health outcomes for patients. This included identifying any services that were unnecessary, outdated or potentially unsafe.

The Taskforce established a range of clinical committees and working groups to advise them.

1.2 Consumers role in the MBS Review

In 2016, the Taskforce established the Consumer Panel (the Panel). Establishment of the Panel was informed by the peak national health consumers' organisation, the Consumers Health Forum of Australia (CHF) (1) and Panel members comprised all consumers who had participated at that time in Taskforce committees and a clinician nominated from the Taskforce.

The Panel's terms of reference encompassed providing advice to the Taskforce and its committees, to undertake and commission tasks, to enable evidence-informed consumer engagement in the MBS Review and, as opportunities arose, to modernise all aspects of the MBS. Their scope was to include:

1. Administrative rules and mechanisms
2. Information access and use of plain English
3. Communications and community engagement
4. Induction, training and support of consumer representatives and their committees.

1.3 Key Issues

The terms of reference of the Panel are in keeping with contemporary co-design approaches to health policy and services.

The Panel initially established tools and templates for committees to support inclusion of consumer evidence and perspectives in committee and Taskforce reports; to guide public consultations; and to inform consumer recruitment, induction and support. This guidance was compiled in the Panel's Consumer Engagement Resource (the Resource). In 2017, the Resource was updated to include consumer principles as endorsed by the Taskforce and additional tools, processes and guidelines for committees.

On occasion, the Consumer Panel was asked for advice on Taskforce recommendations or clinical committee draft reports.

Feedback from committee chairs and consumers on committees via a survey distributed late in 2018 indicated differing, and evolving, approaches to consumer engagement in committee work and significant consumer impact and influence in many areas. Anecdotal



feedback was received that the consumer-focused sections of the committee reports (consumer impact and summary statements) were highly valued.

The evidence of genuine partnerships within the MBS Review between consumers, clinicians and policy-makers demonstrated that the presence of consumers on committees can enable considerations of value from a consumer perspective and what can be lost when partnering with consumers is not business-as-usual in health technology reviews. (2)

1.4 Key recommendations

Collectively the 10 consumer members of the Consumer Panel served on approximately 31 committees and working groups including one consumer member who sits on the Taskforce. Consumers who participated in the MBS Review, via the Panel and in committee work, brought a wealth of knowledge and experience in consumer engagement in health research, policy, services and practice. Consideration of their shared perspectives, of survey responses from committee chairs and consumer members; and from the public consultation process informed the Panel's recommendations, detailed in this report. (Also refer Section 7. Recommendations p. 35):

1. Principles:

Apply principle-based decision-making to build a consumer-centered MBS.

The Panel recommends that 12 consumer principles, previously endorsed by the Taskforce, and modified in response to public consultation, are utilised for further development and application in future health technology deliberations and decision-making.

2. Practice:

The Consumer Panel Consumer Engagement resource is used as a reference in future planning for ongoing review of the MBS.

The Consumer Engagement Resource has a number of tools and templates that can be further co-designed and customised to guide partnerships to achieve consumer-centered health policy including health technology assessment and review.

3. Priorities:

Consumer priorities and perspectives are key drivers in an ongoing cycle of MBS review.

The Panel recommends that 15 priorities, identified in the Review, are provided for initial consideration in framing future approaches to ongoing review of the MBS - and other publicly-funded health technologies.

4. Partnership:

A genuine, evidence-informed partnership between consumers, clinicians, researchers and policy-makers drives an ongoing MBS cycle of review.

The Panel recommends that ten initial areas in which to focus partnership activity are provided to inform future approaches to ongoing review of the MBS – and other publicly funded health technologies.



2. About the Medicare Benefits Schedule (MBS) Review and Taskforce

2.1 Medicare and the MBS

2.1.1 What is Medicare?

Medicare is Australia's universal health scheme. It enables all Australian residents (and some overseas visitors) to have access to a wide range of health services and medicines at little or no cost.

Introduced in 1984, Medicare has three components:

- Free public hospital services for public patients.
- Subsidised drugs covered by the Pharmaceutical Benefits Scheme (PBS).
- Subsidised health professional services listed on the MBS.

2.2 What is the MBS?

The MBS is a listing of the health professional services subsidised by the Australian Government. There are more than 5,700 MBS items, which provide benefits to patients for a comprehensive range of services, including consultations, diagnostic tests and surgery.

2.3 What is the MBS Review Taskforce?

The Government established the Taskforce as an advisory body to review all of the 5,700 MBS items to ensure they are aligned with contemporary clinical evidence and practice and improve health outcomes for patients. The Taskforce was also charged with modernising the MBS by identifying any services that may be unnecessary, outdated or potentially unsafe.

The MBS Review was to be clinician-led, and there were no attached targets for savings.

The Taskforce is committed to providing recommendations to the Minister that will allow the MBS to deliver on each of these four key goals:

- **Affordable and universal access** — the evidence demonstrates that the MBS supports very good access to primary care services for most Australians, particularly in urban Australia. However, despite increases in the specialist workforce over the last decade, access to many specialist services remains problematic, with some rural patients being particularly under-served.
- **Best practice health services** — one of the core objectives of the MBS Review is to modernise the MBS, ensuring that individual items and their descriptors are consistent with contemporary best practice and the evidence base when possible. Although the Medical Services Advisory Committee (MSAC) plays a crucial role in thoroughly evaluating new services, the vast majority of existing MBS items pre-date this process and have never been reviewed.



- **Value for the individual patient** — another core objective of the MBS Review is to support the delivery of services that are appropriate to the patient's needs, provide real clinical value and do not expose the patient to unnecessary risk or expense.
- **Value for the health system** — achieving the above elements of the vision will go a long way to achieving improved value for the health system overall. Reducing the volume of services that provide little or no clinical benefit will enable resources to be redirected to new and existing services that have proven benefit and are underused, particularly for patients who cannot readily access those services currently.

2.4 The Taskforce's approach

The Taskforce is reviewing existing MBS items, with a primary focus on ensuring that individual items and usage meet the definition of best practice. Within the Taskforce's brief, there is considerable scope to review and provide advice on all aspects that would contribute to a modern, transparent and responsive system. This includes not only making recommendations about adding new items or services to the MBS, but also about an MBS structure that could better accommodate changing health service models.

The Taskforce has made a conscious decision to be ambitious in its approach, and to seize this unique opportunity to recommend changes to modernise the MBS at all levels, from the clinical detail of individual items, to administrative rules and mechanisms, to structural, whole-of-MBS issues. The Taskforce will also develop a mechanism for an ongoing review of the MBS once the current review has concluded.

As the MBS Review is clinician-led, the Taskforce decided that clinical committees should conduct the detailed review of MBS items. The committees are broad-based in their membership, and members have been appointed in an individual capacity, rather than as representatives of any organisation.

The Taskforce asked the committees to review MBS items using a framework based on Professor Adam Elshaug's appropriate use criteria (3). The framework consists of seven steps:

1. Develop an initial fact base for all items under consideration, drawing on the relevant data and literature.
2. Identify items that are obsolete, are of questionable clinical value, (4)¹ are misused² and/or pose a risk to patient safety. This step includes prioritising items as "priority 1",

¹ The use of an intervention that evidence suggests confers no or very little benefit on patients; or where the risk of harm exceeds the likely benefit; or, more broadly, where the added costs of the intervention do not provide proportional added benefits.

² The use of MBS services for purposes other than those intended. This includes a range of behaviours, from failing to adhere to particular item descriptors or rules through to deliberate fraud.



“priority 2” or “priority 3”, using a prioritisation methodology (described in more detail below).

3. Identify any issues, develop hypotheses for recommendations and create a work plan (including establishing working groups, when required) to arrive at recommendations for each item.
4. Gather further data, clinical guidelines and relevant literature in order to make provisional recommendations and draft accompanying rationales, as per the work plan. This process begins with priority 1 items, continues with priority 2 items and concludes with priority 3 items. This step also involves consultation with relevant stakeholders within the committee, working groups, and relevant colleagues or colleges. For complex cases, full appropriate use criteria were developed for the item’s explanatory notes.
5. Review the provisional recommendations and the accompanying rationales, and gather further evidence as required.
6. Finalise the recommendations in preparation for broader stakeholder consultation.
7. Incorporate feedback gathered during stakeholder consultation and finalise the review report, which provides recommendations for the Taskforce.

All MBS items will be reviewed during the course of the MBS Review. However, given the breadth of the review and its timeframe, each clinical committee has to develop a work plan and assign priorities, keeping in mind the objectives of the review. Committees use a robust prioritisation methodology to focus their attention and resources on the most important items requiring review. This was determined based on a combination of two standard metrics, derived from the appropriate use criteria (3):

- Service volume.
- The likelihood that the item needed to be revised, determined by indicators such as identified safety concerns, geographic or temporal variation, delivery irregularity, the potential misuse of indications or other concerns raised by the clinical committee (such as inappropriate co-claiming).

2.5 Consumer engagement in the Review

The MBS Review was characterised throughout by the different understandings and expectations of clinicians, policy makers and consumers about the nature and/or priority to be given to effective consumer engagement. This is reflected in the engagement approaches, opportunities and challenges described in this account of the work of Panel and consumer engagement in the MBS Review.

Initially, the national health consumer peak body, the Consumers Health Forum of Australia, was approached to inform consumer engagement in the Review. In 2015, the Consumers Health Forum:

- Published a report on the role of health consumer representatives in health decision making (<https://chf.org.au/sites/default/files/role-of-reps-health-decision-making-2015.pdf>).
- Conducted a rapid review of international practice to inform improved consumer engagement in the Review. The review (unpublished, Nunn 2015) appraised five



relevant models and found *a general consensus that obtaining [consumer] perspectives is important*; it also found a *lack of evaluative evidence on the comparative merit of different approaches* (p9).

- Provided a consultation report (3 December 2015) with 12 explicit recommendations to engage consumers.
- Made a submission to the Taskforce (1), recommending a public consultation process and health literacy campaign.

Conversations were held between the Department and the Consumers Health Forum regarding recruitment of consumers to Taskforce committees and provision of training. A partnership approach was considered where the Consumers Health Forum would advertise available positions on clinical committees, and the Department would maintain an open nomination process via its website (in the same manner as clinicians were recruited).

As the Review progressed, consumer engagement occurred at three levels: via the Consumer Panel, individual consumers on committees and via public or targeted consultation:

- One and subsequently two consumers were appointed to most clinical committees and working groups. Consumers were identified in a range of ways: completion of an online expression of interest; completion of a Consumers Health Forum expression of interest; or direct nomination by the committee chairperson.
- Wider public consultation was managed by the Department and occurred mainly via:
 - online responses to draft reports and
 - targeted methods where reports were sent directly to stakeholders and/or meetings were held with stakeholders to discuss draft recommendations.

The formation of the Consumer Panel in 2016 reflected the priority given by the Taskforce to consumer engagement in the Review.



3. The Consumer Panel

3.1 Background

There was a commitment at the highest levels, from the outset, to consumer engagement in the MBS Review. When announcing the Review, the then-Minister said:

[we will] work hand-in-hand with health professionals and patients to deliver a healthier Medicare ... reform [will] draw on a broad range of expertise and experiences ... including: clinicians (GPs and Specialists); consumer and patient representatives; academics; Primary Health Networks; nurses; allied health professionals; health economists; and states and territories. (5)

There was already national agreement and support for health care occurring through a patient / person/ consumer-centred approach, via partnerships between health professionals and consumers at the individual, service and system level (see Glossary of consumer terminology – section 10). The nature of these partnerships was detailed by the Australian Commission for Safety and Quality in Health Care (ACSQHC) and supported by all Australian health ministers and governments:

The patient-centred approach to health care treats each person respectfully as an individual human being and not as a condition to be treated. It involves not just the patient, but families, carers and other supporters. It is concerned about the patient's comfort and surroundings as well as their beliefs and values. A patient-centred approach makes care safer and of higher quality. It provides demonstrable personal, clinical and organisational benefits. It also satisfies an ethical imperative – involving patients in their own care and in the planning and governance of the health system is the right thing to do. (6)

The Review was established as clinician-led, structured around clinical practice, with consumers to be invited to give input and feedback:

...we are calling on many small groups of clinicians, including those operating at the frontline of healthcare, to efficiently and effectively review the available evidence and generate recommendations with input and feedback from consumers and other stakeholders. (7)

During this period, consumers, clinicians, researchers and policy influencers were articulating the health practice and system imperative for consumer-centred care. The Consumers Health Forum of Australia, as the peak national health consumer body, joined with The George Institute for Global Health to release a shared vision: 'Putting the consumer first – Creating a consumer-centred health system for a 21st century Australia. A health policy report, April 2016' (8):

This report made eight recommendations:

1. Develop a National Vision for Australia's Health 2025 through the Council of Australian Governments (COAG), that describes and commits to the principles of consumer-centred healthcare



2. Involve consumers in governance arrangements throughout all levels of healthcare and research
3. Invest in empowering consumers to become more involved in healthcare design and delivery, and self-management of their health
4. Define consumer-centred professional practice as a core healthcare professional competency across all levels of healthcare education, to grow skills in working with patients and as part of multidisciplinary teams
5. Ensure that consumer experience drives the health system by routinely measuring and benchmarking patient experiences and outcomes across the health system, and making this information publically available to allow informed decision-making
6. Enable innovation in healthcare while ensuring new approaches are evidence-based, developed collaboratively and 'fit for purpose'
7. Adjust drivers to create the right policy, infrastructure and incentive platforms to drive change and support consumer-centred care
8. Develop a change management strategy to facilitate the implementation of a consumer-centred health system

3.2 Establishment of the Consumer Panel

Consumer advocacy from a range of quarters led to the convening of a meeting in June 2016 by the Department and the Consumers Health Forum, to which consumers already appointed to Taskforce Committees were invited. A significant outcome of this meeting was the formation of the MBS Review Taskforce Consumer Panel. All current consumer members of Taskforce Committees were invited – and agreed – to form the Panel. The first meeting was held in September 2016.

The Panel was supported by a secretariat within the Department of Health.

The Panel met 14 times (five face to face, nine via teleconference) between September 2016 and January 2020: three times in 2016, seven times in 2017, twice in 2018, once in 2019 and in January 2020. Considerable work was also undertaken out of session.

3.3 Consumer Panel Terms of Reference

The Panel's Terms of Reference remained unchanged throughout the Review, although the actual work referred to the Panel reflected only some aspects of this scope.

The Panel's agreed deliverables and expectations stated that the Panel was to:

1. Support the work of Taskforce committees
2. Address systemic improvements to the MBS

The full terms of reference are in Appendix A. Outputs in relation to each of these areas are summarised in sections 4 and 5 of this report.



3.4 Consumer Panel members

Table 1: Consumer Panel members

Name	Position/organisation	Taskforce committees & working groups
Ms Debra Kay PSM	(Chair) Consumer Representative Member, Medical Services Advisory Committee (MSAC) Member, Health Technology Assessment Consumer Consultative Committee	Thoracic Medicine Clinical Committee, Principles and Rules Committee, Specialists and Consultants Clinical Committee, Foot and Ankle Working Group, After Hours Working Group, GP/Consumer Joint Working Group.
Ms Rebecca James	(Executive Member) MBS Review Taskforce (Ex-Officio)	MBS Review Taskforce Primary Care Phase 2 Clinical Committee, Colorectal Clinical Committee, Ophthalmology Clinical Committee, Optometry Clinical Committee.
Mr John Stubbs	(Executive Member) Chief Executive Officer, CanSpeak Member, Medical Services Advisory Committee Consumer Representative, Member Health Technology Assessment Consumer Consultative Committee	Oncology Clinical Committee, Pain Management Clinical Committee, Neurology and Neurosurgery Clinical Committee, Review of Paediatric Surgery Working Group Report
Ms Geraldine Robertson	Consumer Representative, Consumers Health Forum & Breast Cancer Network Australia	Diagnostic Imaging Clinical Committee, Colorectal Surgery Clinical Committee, Breast Cancer Surgery and Reconstruction Working Group.
Ms Karen Carey	Member, National Health and Medical Research Council & Chair, Community and Consumer Advisory Group Consumer Representative	Cardiac Services Clinical Committee.
Ms Helen Maxwell- Wright	Consumer Representative Director, Maxwell-Wright Associates, Panel of Chairs, Monitoring Committee, Medicines	Eating Disorders Working Group, Optometry Clinical Committee, Endocrinology Clinical Committee, Anaesthesia Clinical Committee.
Ms Eileen Jerga AM	Consumer Representative Member, Medical Services Advisory Committee (MSAC), Member, Health Technology Assessment Consumer Consultative Committee.	Vascular Clinical Committee, Intensive Care and Emergency Medicine Clinical Committee, Neurology and Neurosurgery Clinical Committee, Review of Paediatric Surgery Working Group Report
Ms Alison Marcus	Registered Nurse Consumer Representative, Member of Health Technology Assessment Consumer Consultative Committee	Colorectal Surgery Clinical Committee, Renal Clinical Committee, Urology Clinical Committee.



Name	Position/organisation	Taskforce committees & working groups
Mr Adam Friederich	Immune Deficiencies Foundation Australia Consumer representative	Dermatology, Allergy, and Immunology Clinical Committee, Review of Paediatric Surgery Working Group Report
Professor Michael Besser AM	MBS Review Taskforce (Ex-Officio)	MBS Review Taskforce and all surgical clinical committees.

3.5 Declared interests and potential conflicts

All members of the Taskforce, clinical committees and working groups, including the Panel, were asked to declare any conflicts of interest at the start of their involvement and reminded to update their declarations periodically. All Panel members complied with this requirement.



4. Consumer Panel role #1:

Support the work of Taskforce Committees

The Panel's Terms of Reference outline a role in **supporting the work of Taskforce Committees**, including clinical committees and the Principle and Rules Committee.

Excerpts from the Panel's Terms of Reference are below in *italics*.

[Supporting the work of Taskforce committees] may include:

- a) Development and implementation of a consumer engagement strategy.*
- b) Commissioning evaluation of the strategy.*
- c) Development of measurable and observable checkpoints for consumer engagement across the work of the Taskforce (for example, in induction, the conduct of clinical committees and the preparation of reports).*
- d) Involvement in the development, implementation and evaluation of consumer engagement training.*
- e) Mentoring new consumer representatives and chairs of Taskforce clinical committees.*
- f) Development or adaptation of templates and guidelines to support and promote efficient and comparable reporting of consumer perspectives.*
- g) Reviewing reports and providing advice to the Taskforce about how to make these accessible to consumers and communities.*

The Panel took a strategic approach to its work with outputs that included:

- a) Development and implementation of a consumer engagement strategy and commissioning an evaluation of the strategy.
- b) Development of measurable and observable checkpoints for consumer engagement across the work of the Taskforce (for example, in induction, the conduct of clinical committees and the preparation of reports).
- c) Involvement in the development, implementation and evaluation of consumer engagement training.

The Panel developed comprehensive information to include in consumer engagement training and recommended that, at a minimum, committee chairs should participate in training with consumers to ensure a supportive environment and shared responsibility for consumer input into the work of committees.

Material developed by the Panel for potential inclusion in training was included in the Consumer Engagement Resource. Information, tools and templates in the resource address:

- Consumer recruitment, role and expectations
- Consumer principles to guide Review deliberations and decisions
- Examples of questions to focus consumer perspectives in reports
- Critical checkpoints for consumer engagement in the work of clinical committees



- Recommended approach to targeted public consultation
- Public communication checklist
- A consumer perspective on evidence
- Hints and tips for consumers on committees
- Support available to consumers and others on committees
- Consumer-related terminology

Panel members participated in induction teleconferences with consumers which outlined the role of consumer representatives, discussed the elements of the Consumer Engagement Resource, and to answer any questions new consumer representatives had about their role in the Review. There was positive feedback on this process.

In addition, committee chairs held introductory meetings with consumers and other committee members to outline Review objectives and methodology. This process acknowledged the value of consumer input to the process.

a) Mentoring new consumer representatives and chairs of Taskforce clinical committees.

A support and mentoring model was developed and all Panel members made themselves available to participate in this work. Some consumers reported being supported by more experienced consumers on their committee (where more than one consumer was appointed) and Panel members reported receiving occasional calls from a consumer wanting to discuss their approach to committee work.

b) Development or adaptation of templates and guidelines to support and promote efficient and comparable reporting of consumer perspectives.

c) Reviewing reports and providing advice to the Taskforce about how to make these accessible to consumers and communities.

This is the area in which the work of the Panel can be said to have the most visible influence. Early in their establishment, the Panel developed templates for specific consumer components of committee reports. These templates and examples of their use were published in the Resource along with other tools:

- Consumer engagement summary
- Consumer impact statement
- Consumer report i.e. summary table of recommendations and rationale.

The way in which these were developed varied; feedback was received that these sections of the reports were widely appreciated by the clinicians and consumers.

Regarding the reviewing of reports from a consumer perspective, draft reports for public consultation were on occasion sent to the Panel for comment.

In addition, policy officers often spoke with Panel members about potentially contentious Taskforce recommendations, including proposed changes to after-hours consultations, and communication strategies related colonoscopy service recommendations.



5. Consumer Panel role #2:

Address systemic improvements to the MBS

The second focus of the Panel was to **assist the Taskforce to address systemic improvements to the MBS**.

Excerpts from the Panel's Terms of Reference are below in *italics*.

[Addressing systemic improvements to the MBS] *may include:*

- a) Commissioning development of a plain English guide for the MBS.*
- b) Scoping how to develop plain English descriptors and hyperlinks to clinical guidelines and plain English Clinical Guidelines.*
- c) Development of a glossary of terms.*
- d) Development of evidence-informed consumer engagement principles, policy and procedures.*
- *Commissioning development of a plain English guide for the MBS.*
- *Scoping how to develop plain English descriptors and hyperlinks to clinical guidelines and plain English Clinical Guidelines.*

Though this piece of work was seen as valuable, it was subsequently determined as out of the scope for the MBS Review at this time, however the Panel recommends that it be considered as part of any future review process. This work is preliminary; the Consumer Panel considers that further work on shared understandings of terminology is important to effective consumer engagement to 'improve outcomes for patients'.

- *Development of a glossary of terms.*

The Panel drafted a glossary, with working definitions of terminology commonly used in the Review (see Glossary of consumer terminology – section 10).

- *Development of evidence-informed consumer engagement principles, policy and procedures.*

Early in its work, the Panel developed a set of Consumer Principles to Guide Review deliberations and decisions. These were formally accepted by the Taskforce. These Principles are included in the Panel's recommendations (see section 7).



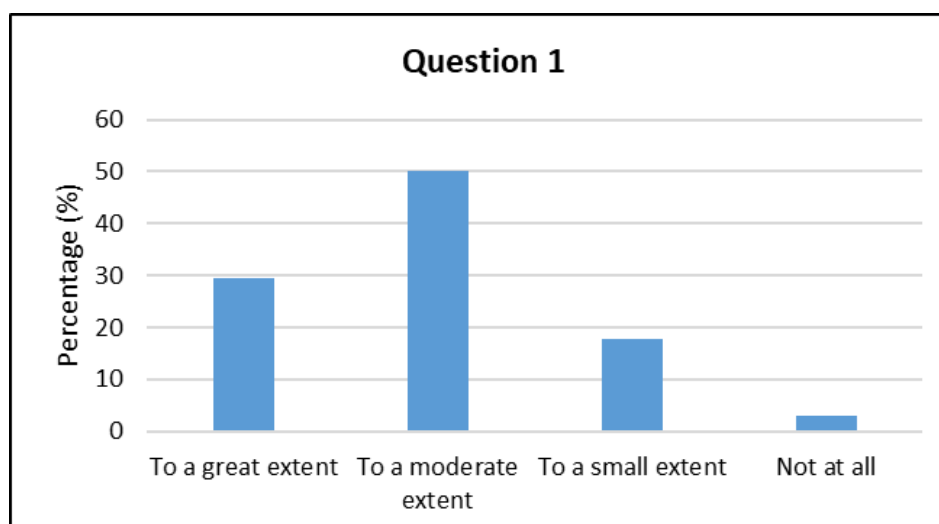
6. Consumer impact and influence in the review

The Panel drafted a survey for Consumers on Committees and another for clinicians and secretariat members. The draft surveys were sent to all committee Chairpersons and all Consumer members of Committees or Working Groups. 37 Chairpersons and 34 Consumers responded, which was approximately a 51% response rate for Consumers and 44% for Chairpersons.

Chairperson survey feedback

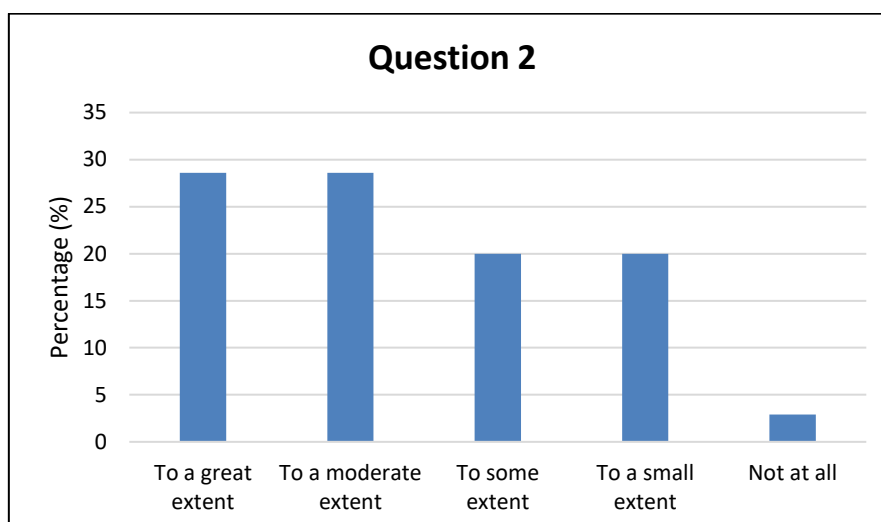
Question 1

To what extent did the clinical committee/working group enable consumer perspectives to influence the **day-to-day work of the clinical committee/working group**?



Question 2

Overall, to what extent did consumer perspectives influence the **findings and recommendations** of the clinical committee/working group?



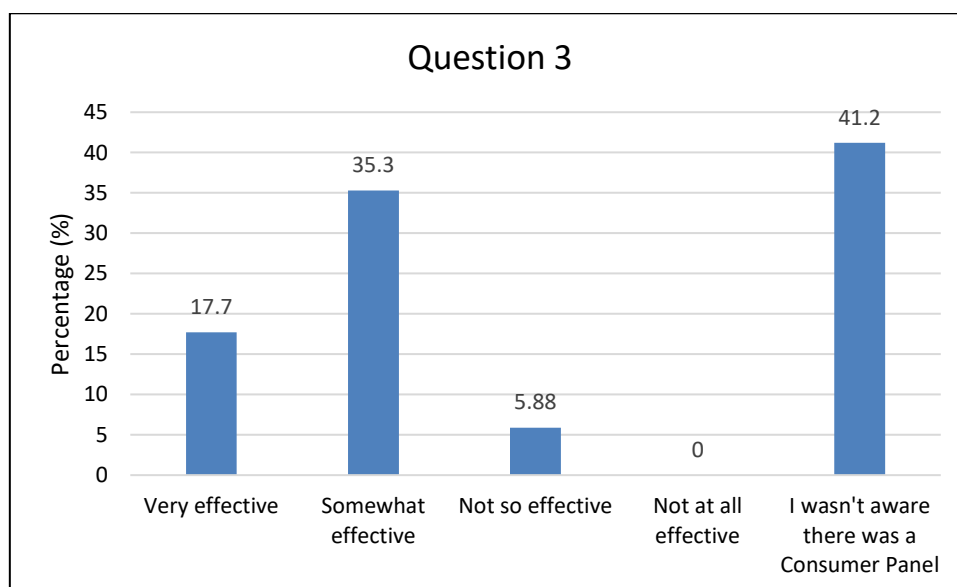
- The majority of respondents reported that the committee process enabled inclusion of consumer perspectives. Comments included:
 - *They were equal members*
 - *As chair, it was my responsibility to ensure all voices were heard*
 - *We tried to examine every item from the perspective of the consumer*
 - *The consumer being present alone reminded us the health system is primarily about service to consumers not primarily about convenience to providers*
 - *Had to specifically invite them to comment, which they did well once invited*
 - *No process to explore consumer priorities as a key method – not consistent with best modern co-design principles.*
- Several saw the technical nature of discussions as a barrier to consumer contributions:
 - *Were very well prepared. However we dealt with highly technical material...so the opportunity to contribute was limited*
 - *Consumer views on complex medical decision-making are often not that useful*
- Some chairs prioritised areas of consumer expertise, including access, lived experience and patient preferences:
 - *...technical issues dominated discussions but we found our Consumer Reps were excellent...especially when we actively sought their input*
 - *The entire work of the Committee begins with the position of what is best for patients and we are helped a great deal by an active Consumer*
 - *...the most helpful insights were in the area of access*
 - *... having been patients previously...a great perspective*
 - *...consumer influence in dealing with disadvantage such as patients in remote regions*



- ...highlighting issues of importance for consumers – informed consent, availability, out of pocket expenses, rules and restrictions that cause patient inconvenience or anxiety, safety issues etc...
- Over half the respondents reported that consumers influenced recommendations to a moderate or great extent:
 - Major decisions influenced greatly by consumers
 - ...a major influence on some of the decisions made
 - ...their specific advice is reflected in the recommendations
 - ...definitely influenced our deliberations and final report
 - Useful and informative interactions on each item/group
- A small number of respondents reported consumers did not contribute, or influence at all:
 - Not at all
 - Feedback from consumer very indirect and via third party
 - Input was useful and appreciated but did not really alter recommendations

Question 3

How effective was the Consumer Panel in supporting consumer representatives on the clinical committees/working groups?



- The majority of chairs (48%) felt the Consumer Panel was somewhat to very effective in supporting the consumer representatives. However, 41% did not know the Consumer Panel existed.
- Some respondents mentioned their induction:



- *In the briefing prior ...there was a clear message to ensure that the consumer reps were encouraged to participate, that their contributions were heard and valued, and that theirs was a priority role...*
- There was a strong view from the chairs that consumers helped keep the committees on track:
 - *Very influential in ensuring we stuck to the terms of reference and that we put the interest of the consumer (patient) at the forefront.*
 - *The MBS has been very 'doctor' focused...Consumer Representatives have been able to realign the focus.*
 - *Frequent return to consumer focus; real life examples of how decisions (and current practice) impacts on consumers; assisted in balancing clinically-centric assessment of consequences.*
 - *Ensuring there is a plain language version on the recommendations is important.*
- Some respondents considered the consumers had little value to offer:
 - *Raised some consumer related matters although in a somewhat idealistic and not terribly practical way.*
 - *One Consumer seemed to have a personal agenda based on individual experience...unrelated to the purpose of the Committee.*
 - *No positive influence noted.*

Chairperson comment on consumer influence:

- *Mental health: accessibility to services for disadvantaged consumers – whether on the basis of cost, isolation, availability of expertise; provision of different levels of care according to patient need; provision of group support and increasing access to group support in rural areas; emphasis on consultations between family, patient and treating professionals.*
- *Framing descriptors: to be consumer-centred and focus on patient priorities and needs.*
- *Data utilisation and referral: better analysis of how the release of practitioner level cost data would assist in informed choice by consumers and how to contextualise data in concert with referring GP.*
- *Enrolment of a patient with their GP: to ensure the enrolment would deliver benefits and not limit choice.*
- *End-of-life care planning: (funding) models.*
- *CPAP education and mask fitting: incorporated in patient attendance time.*
- *Nuclear stress testing: in lieu of more expensive stress echo for patients in rural and remote areas.*
- *Safety and access: prioritised (several Committees).*
- *Radiology: removing penalty for more than one procedure a day will increase consumer convenience at no extra cost to the MBS.*
- *After-hours access: fair and reasonable model from consumer perspective*



- *Psychiatry: strong emphasis on family interventions.*
- *Oncology: rationale for bundling items.*

Chairperson suggestions re future engagement of consumers on committees:

- Retain much of what we had:
 - *I think the process went well. Hopefully the consumer reps all agree.*
 - *One of the best ways to support professionals to move beyond self-interest is to have an articulate consumer who can describe how their needs are not being satisfactorily met.*
- Consider appointing more consumers to committees:
 - *Maybe two, for individual support.*
 - *At least three...to enable formation of subgroups without overwhelming individuals, and also to provide support among the consumers.*
- Ensure consumers have relevant skills and experience:
 - *...experienced, committed reps provide information otherwise not articulated.*
 - *experience in the healthcare system, health literacy.*
 - *some background in the technical aspects.*
 - *experience in the health sector and ...direct patient journey experience.*
 - *confidence to speak out even when others may not want them to do so.*
 - *appreciate state/federal jurisdictional disharmonies.*
 - *Regional and rural consumers need more representation...to be visible.*
 - *Better represent all consumer groups – ages, cancer, disabled, low SES.*
- Brief consumers:
 - *A good briefing and early connection with their peers.*
 - *Possibly a short briefing on terminology.*
 - *Good backgrounding...regarding the clinical field for review.*
- Connect them with their peers:
 - *Consumers ...should be able to caucus with other consumers.*
- Brief chairs and consumers:
 - *A more formal liaison between consumers and chairs.*
 - *Meetings between consumer reps, chair and Consumer Panel chair.*
- Develop a tool for decision-making:
 - *criteria that apply to every recommendation and are measured against them.*
 - *Better early co-design methods... develop best practice consumer led reforms.*
- Ensure the agenda structures inclusion of consumer contributions:

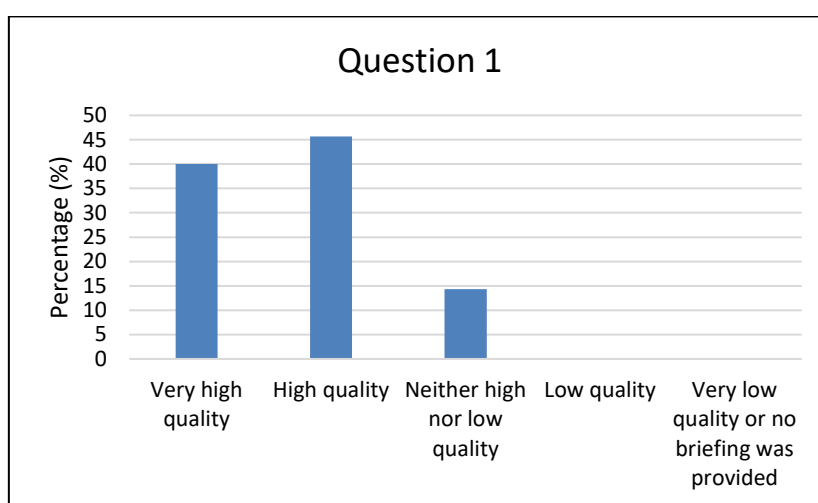


- *Alter the agenda structure to include consumer-led discussion and feedback relative to the business at hand.*
- *Any consumer perspective needs to be stressed earlier in the deliberations.*
- *Ask them to speak about their experience of the Australian healthcare systems as a whole and not just about the MBS.*

Consumer survey feedback

Question 1

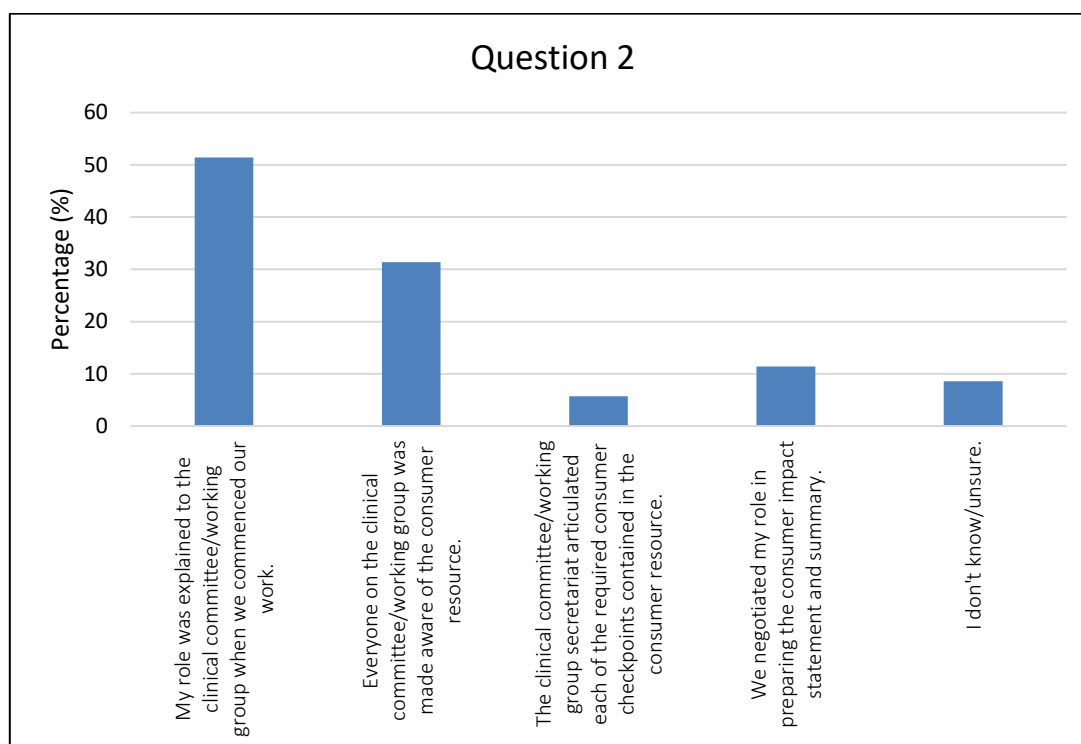
How do you rate the quality of the briefing and information you were provided about your role on your clinical committee(s)/working group(s)?



- The majority of consumers reported receiving a high quality briefing although how this occurred varied:
 - *I was on two groups ... information and what was asked for was inconsistent.*
 - *There was little briefing though written info was generally provided.*
 - *Received only generic information from CHF and nothing from DOH.*
 - *Material got better as time went on.*
 - *Support staff excellent.*

Question 2

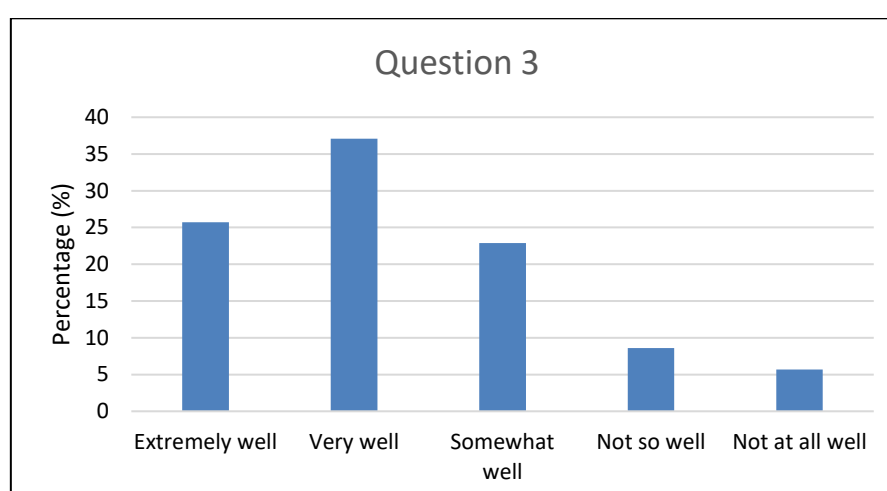
How was the clinical committee/working group informed about your role?



- Approximately half reported their role was explained to the committee and one in three reported that the Consumer Engagement Resource was mentioned:
 - *The Committee was used to consumer participation.*
 - *Appeared not to be explained/understood.*

Question 3

In your opinion, how well did the other members understand your role?

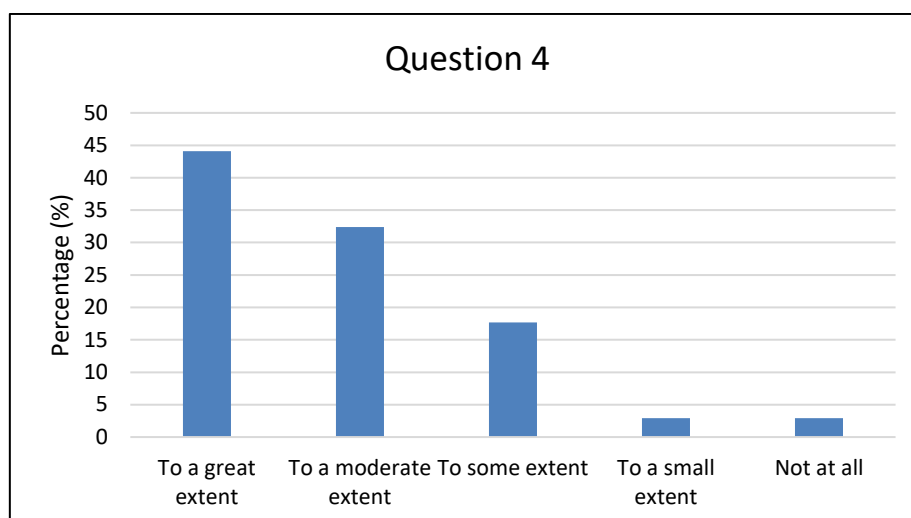


- A majority reported that committee members understood the consumer role:
 - *The initial group was different to subsequent groups as the experience of all concerned improved.*



Question 4

To what extent did the clinical committee / working group value consumer perspectives and factor these into their deliberations and decisions?



- Throughout the surveys some areas of influence were cited:
 - Aboriginal impacts.
 - Key principles underlining a new model of primary care.
 - Inclusion of pathology items for consideration by Endocrinology Committee.
 - Inclusion of disease severity as well as number of conditions as a factor.
 - Inclusion of patients with special needs.
 - Advocacy for rural and remote patients.
 - Quality of life outcomes as significant in surgical items.
 - Remote access to medical care.
 - New services adopted: DEXA scans for women taking certain chemo drugs and new treatment option for colon surgery.
 - Constantly adhering to principles, access, safety and consent.
 - Putting joint injections back on the MBS.
 - Urology: prostate biopsy recommendations and informed consent.
 - Diagnostic medicine: CDS with consumer information.
 - Colorectal group: stomal therapy services.
 - Moderation of different interest/professional groups.
 - Use of plain language in final report.



- Item #319 and adverse descriptors removed.
- Access to best practice multidisciplinary pain management; specialist access to item numbers for pain management care plans ensuring GP included.
- Family impact awareness: eating disorders.
- End of life: new MBS item proposed.
- Perspective: GP levels of expertise.

Consumer suggestions re future engagement of consumers on committees:

- Retain aspects that worked:
 - *Committee members offered help, explained terminology, and did not get irritated by my questioning.*
 - *Secretarial support was excellent.*
 - *The group I worked with were all extremely supportive and I don't believe this could have been improved upon.*
 - *The process was clear, well-directed...I could] participate as an equal...*
- Stronger induction process:
 - *More access to explanation of medical intricacy...*
 - *More explanation ...examples of previous [consumer] contributions*
 - *Glossary of abbreviations.*
 - *Mentorship or buddying for newer folk.*
- Establishment of a relationship with the chair prior to meetings commencing:
 - *A better briefing of the process prior to starting.*
- More comprehensive overview provided to the clinical Committee on role of consumers and value of this contribution:
 - *Go through the consumer pack with every committee member.*
 - *Would have been good for doctors ...to be better informed about our value.*
 - *At the first meeting have the consumer acknowledged by DOH/Chair and their role comprehensively explained to the Committee.*
- Provision of consistent, comparable data:
 - *There were different data sets provided. For example, there generally wasn't data on out of pocket costs, waiting times or consumer preferences.*
 - *Reliance on service volume data doesn't provide an indicator on quality.*
 - *Technical nature of clinical procedures requires reliance on advice of the clinicians present, so decisions were made from a clinical perspective.*



- Timely processes:
 - *Provide consumer guide on appointment.*
 - *Documents...should be provided at least a week prior to meetings.*
 - *Kept more informed of what was happening in subgroups.*
 - *Perhaps, an agenda item at the end – a consumer's opinion. Sometimes it was difficult to get a word in.*
 - *It would have been helpful to have independent (one on one) conversations ...to discuss particular points of contention... but they are all busy clinicians...*
 - *It got better as there was greater collective experience – this should be an on-going process in concert with ACSQHC, MSAC and learned colleges with HTA consumer involvement.*
- Face to face processes:
 - *Teleconferences do have issues ... a lot is gained by face to face meetings.*
- Secretarial support:
 - *I found the Department to be good to work with despite the time pressure...The consultants are capable individuals and firms however we need to ensure that the brief is the same no matter what the medical area...*
- Focus:
 - *To prepare the health system for the future, we need to do more than patch up and update. It has to be a whole of health system reform – states have to be included, as do hospitals, private health insurers, consumer groups and the medical fraternity. MBS alone will not make the difference everyone is looking for and it is a blunt instrument....a bold but necessary goal.*

Consumer perception of impact

- Most consumers felt their committee had had some impact:
 - *Everyone identified valued changes to the MBS items to improve access*
 - *Impactful recommendations...evidence-based, use of registries assists greatly*
 - *Felt progress was made along the way*
 - *Direction achieved – obsolete item removed, new ones introduced, existing ones refined. Fraudulent billing identified...*
 - *Did away with double up procedures*
 - *We already have a positive result and are thrilled*
 - *I think the shifts were minimal in real impact*
 - *Whether these are actually delivered will be up to government*



- The majority of consumers felt that they influenced recommendations to a moderate extent. Consumers noted that they often voiced minority opinions and assisted in keeping the committee focussed on consumer-centred care:
 - *It varied. I felt I was there as a reminder to members that they have a responsibility to patients...most people on Committees were patient-centred.*
 - *Other Committee members valued my experience.*
 - *The representation of GPs and consumers was less dominant.*
 - *[with] partisan behaviour on the part of professionals it was often the consumer voice that was ultimately accepted – a little like Switzerland.*
 - *Renal dialysis in remote communities, CDS, Stomal therapy access, transitional care for paediatric to adult services.*
- Other comments:
 - *Thoroughly appreciated being part of the MBS review process. Was heartened by the clinicians involved and the attitude towards patient care whilst being mindful of the sustainability of the MBS.*
 - *The Panel has been very useful and the Resource is excellent.*
 - *It is so important to have consumers from a diverse background at the table – not just on the menu.*
 - *I think it would be important for well experienced consumers to fulfil these roles into the future.*
 - *We need a much greater focus on support for prevention and self-management which avoids the need to seek medical services.*
 - *I would like the reviewing of the MBS to be a continuous review to keep the scheme up to date.*



7. Recommendations

The Consumer Panel has reflected on the experience of its members on MBS Review committees; feedback from the survey of committee chairs and consumers; public consultation feedback; and current literature and evidence regarding partnering with consumers effectively in health policy, research, services and care. The following recommendations are the outcome of the Panel workshopping these varied sources of information and perspectives on consumer engagement.

RECOMMENDATION 1: PRINCIPLES

Apply principle-based decision-making to build a consumer-centred MBS

One of the first outputs of the Consumer Panel was a set of principles to be applied in deliberations and decision-making to ensure a consumer-centred MBS. These Principles were endorsed by the Taskforce.

The Panel reiterates its recommendation (2016) that the following principles are applied and further developed in MBS Review deliberations and decision-making.

1. The MBS Review, and ongoing MBS management is co-designed.

- Evidence-informed consumer engagement is integrated in the design, implementation, monitoring and evaluation of the MBS to ensure it meets the needs, values and preferences of consumers and the community*, not just clinicians, industry and policy makers.

*As per the definition of consumer-centred care outlined in Patient-centred care: Improving quality and safety through partnerships with patients and consumers. (6)

2. The MBS Review supports the development of an Australian health care system that is safe and high quality; provides equity of access and outcome for patients; delivers improvements in patient outcomes; supports the efficient and effective use of resources; and is sustainable.

3. Design and use of MBS Items support safe, evidence-based, high quality consumer-centred care.

- MBS items with significant potential health impacts are linked to contemporary evidence.
- The MBS allows sufficient flexibility to tailor treatments and care to the specific needs of individual patients, which may not align directly with Guidelines, but where the variation is well considered and appropriate.

4. Design and use of MBS Items support fair and equitable access and outcomes for all.

For example:

- Address geographic location as a barrier by proactively looking at scope of practice of more than one clinical group, and reimbursement for clinical services that reflects the cost of service provision in regional and remote settings



- Ensure changes to the MBS do not drive an unreasonable increase in out-of-pocket expenses, particularly for vulnerable groups such as people with, or at risk of, multiple chronic diseases
- 5. The MBS ensures equality of access to medical services, regardless of whether it is provided in the public or private sector.**
 - 6. MBS Review processes encompass assessment of individual and systemic health quality and economic benefit.**
 - Real out of pocket (OOP) expenses for consumers are calculated when determining (relative) Item costs; a total OOP is calculated where multiple services are associated with the condition being treated; and for long term conditions the OOP is calculated for a longer period and potentially for the entire patient journey.
 - Quality and economic benefit (or cost effectiveness) are two different things to be balanced one against the other, and not assessed as one parameter.
 - 7. The MBS is a dynamic and responsive system that only funds services that improve health outcomes.**
 - This may require new systems of data collection and analysis and new ways of public reporting.
 - 8. Use of MBS data is maximised for public benefit, and with appropriate governance to ensure that public benefit does not cause harm to the individual.**
 - Ongoing monitoring /post-market surveillance/data availability for research purposes is integrated into the use of the MBS to support evaluation and review for quality assurance.
 - 9. Lack of evidence does not always mean that an item is not effective and should be removed. It does confirm the imperative for data collection and post market surveillance that can meaningfully track the appropriate use of MBS items.**
 - 10. The MBS Review does not remove access to a service where it is appropriate for the care of a small, defined patient group.**
 - If necessary, the descriptor can be amended to ensure Item use is targeted to the appropriate patients, and only accessed by the appropriately trained clinicians.
 - 11. Patient Reported (Adverse) Outcomes Measures (PR[A]OMs), Patient Reported Experience Measures (PREMS) and other quality of life measures are considered along with clinical outcomes measures when determining safety, quality, efficiency, efficacy, access and currency of MBS Items.**
 - 12. Implementation of the MBS Review:**
 - Supports business practices that enable consumers to make fully informed decisions including clinical information and cost comparisons across public and private options.
 - Inhibits listing of multiple Items for single consultations/treatments.
 - Addresses conflict of interest and full disclosure regarding any recommended device/service.



- Uses the MBS to fund universal access to safe health care, particularly for the most vulnerable – and not simply convenience of access.
- Is reported upon publicly in ways that ensure clinicians and corporate beneficiaries of Medicare are accountable to consumers as patients and taxpayers.
- Is quality assured and incentivised through professional practice measures such as training.

Additional considerations

The Panel also noted that:

- Further development of consumer principles is likely to include principles related to reporting, disclosure, transparency and regulatory oversight as well as communication and informed (financial) consent. *For example:*
 - Not every health service has a consumer cost reimbursement via the MBS
 - Practitioners that exploit the MBS are reported to the regulatory authority
 - Simplicity where possible in the MBS supports professional conduct – and identification and management of alleged unprofessional conduct.
- All practitioners in the MBS Review can be considered to have a Conflict Of Interest: this is inevitable. Genuine, structured and supported consumer feedback in Review reports is required to ensure the conflicts have been successfully managed as well as to ensure the recommendations work in the best interests of the consumers to whom the reimbursements will be paid.
- Principles and learnings from the MBS Review should be applied more broadly to future reviews in the public space, other government agencies or health technology processes.

RECOMMENDATION 2: PRACTICE

The Consumer Panel Consumer Engagement Resource is used as a reference in future planning for ongoing review of the MBS.

The Consumer Engagement Resource has a number of tools that could be further developed by and for all partners in any ongoing review of the MBS – and other health technologies. They include:

- Consumer recruitment, role and expectations
- Consumer principles to guide Review deliberations and decisions
- Examples of questions to focus consumer perspectives in reports
- Critical checkpoints for consumer engagement in the work of clinical committees
- Recommended approach to targeted public consultation
- Public communication checklist
- A consumer perspective on evidence



- Hints and tips for consumers on committees
- Support available to consumers and others on committees
- Consumer-related terminology
- Consumer engagement summary
- Consumer impact statement
- Consumer report i.e. summary table of recommendations and rationale.

RECOMMENDATION 3: PRIORITIES

Consumer priorities and perspectives are key drivers of an ongoing MBS cycle of review.

Consumer priorities and perspectives articulated in the MBS Review to date include:

1. **Value:** integrate person-centred determinants of value including:
 - a. Equity of access and outcome.
 - b. Contribution to holistic, integrated, coordinated health (and social) care.
 - c. Contribution to the person's health care goals.
 - d. Inclusive, acceptable, non-discriminatory practice.
 - e. Evidence to support the above.
2. **Appropriate Access:** 'Appropriate is defined as *'contributes to an improved health outcome'*.
3. **Principles and rules:** undertake a comprehensive, person-centred care review of MBS principles and rules.
4. **Informed consent and informed financial consent:** ensure these are explicitly described, required and audited for compliance.
5. **Patient reported outcomes measures (PROMs):** actively seek and promote development and use of these in applications, assessments and reviews.
6. **Health economics:** include consumer costs, including out of pocket costs, in health economic assessments; assess health and economic benefit and cost at a system and individual level, and also longitudinally as well as episodically.
7. **Integrated, coordinated care:** ensure items are not considered in isolation of the person's holistic care and their overall use of the MBS – and the Pharmaceutical Benefits Schedule (PBS).
8. **Futures focus:**
 - a. Maintain a futures focus with 'action items for the future' a standard component of every review report.
 - b. Considers elements of out-of-scope (but relevant) items, unintended consequences, workforce issues, effective data collection.



9. **Data:** address the consumer-related data gap through a data strategy that includes care pathways; patient reported outcome measures (PROMs); variations in access to care; people's motivations to take action for their health; social determinants and supply and demand.
10. **Workforce:** integrate considerations of, and proactive planning for, workforce issues related to MBS reform.
11. **Equipment:** incorporate considerations of equipment and other capital investment in the review process.
12. **Agility:** able to adapt and adjust successfully in the face of on-going and rapid technological change in healthcare ensuring inclusive consumer engagement. (9)
13. **Audit on recommendations:** including data, access, quality and unintended consequences.
14. **Transparency:** both organisational and consumer-centred transparency in treatment options, out-of-pocket costs, potential risks and realistic outcomes. (10)
15. **Structural Links between Health Systems:** creation of public policy that reflects stronger and better relationships between the various health-care delivery systems.

RECOMMENDATION 4: PARTNERSHIP

A genuine, evidence-informed partnership between consumers, clinicians, researchers and policy-makers drives an ongoing MBS cycle of review.

Considerations to achieve this include:

1. **Consumer Secretariat:** establish and resource a Consumer Secretariat whose role is specifically to support consumer engagement in MBS reform.
2. **Consumer engagement:** work with the Health Technology Assessment Consumer Consultative Committee to develop a systemic model of consumer engagement that includes communication with and feedback from targeted patient, consumer and community groups and the general public.
3. **Capacity building:** work with the Health Technology Assessment Consumer Consultative Committee to develop sustainable systems for public communications (including plain language public summary documents) and education sessions and tools for patient, consumer and community groups who have an interest in the MBS.
4. **Health literacy:** co-design tools for consumers and clinicians to support consumer health literacy in relation to consultations, tests and procedures. Include co-design shared decision-making/decision-support tools and processes and quality, accessible information, linking with Healthdirect as relevant.
5. **Practitioner audits:** co-design compliance priorities, processes and reporting and 'peer' supervision' instruments.
6. **Safety and quality:** coordinate schedules of work with the Australian Commission on Safety and Quality in Health Care, including development of clinical standards, partnering with consumers and patient reported outcomes (PROMs).



7. **Clinical registries:** develop a coordinated approach to the establishment, quality assurance and use of clinical registries including the use of patient reported outcomes.
8. **Quality assurance processes** - integrate these and include:
 - a. Co-designed standards, guidelines and professional and service accreditation.
 - b. Review cycles including reports of predicted and actuals.
9. **New and developing knowledge:** build on the findings of the Taskforce.
10. **Research:** establish a research agenda and partnerships with a focus on how person-centred care, including genuine informed consent, can drive individual and systemic value in health care.



8. Lessons Learnt

During the process of the MBS Review the Panel has identified a number of lessons learnt which should be incorporated into an ongoing review mechanism or any future HTA processes. These are listed below:

- Consumer-related data should be provided as part of the standard data packs to committees to address elements on the consumer principles.
- Consumers who are to work on culturally sensitive committees should receive cultural competency training as a minimal to support them in their role. Other key training should be encouraged where the consumers feel they lack the expertise for the specific function (especially if a consumer with subject matter expertise cannot be appointed).
- Ensure there is “first-hand” consumer representation from the rural and remote and indigenous sectors.
- Consumers would benefit from a formal, specifically designed, training process prior to their appointments to Committees.
- A need to engage consumers (and clinicians) from all age demographics in future reviews to capture the whole “consumer experience”.
- Engagement with stakeholders at the onset of any Review to ensure a holistic approach to the consumer experience is considered.



9. Summary

Overall the Panel is of the opinion that there was genuine consumer involvement in the Review which was considered positive, effective, and influenced outcomes both on an individual clinical committee level, and for the Taskforce overall.

Consumer involvement was noted to have changed the tone of clinical committee discussions for the positive, changed the culture of how the task of reviewing clinical items was approached and improved the overall credibility of the MBS Review by ensuring that it was dual-led and was not simply performed by clinicians, for clinicians.

Some of the key outputs of the Panel, which ultimately contributed to the success of the Review, were the induction of consumers to clinical committees, the Consumer Resource and the consumer elements of the clinical reports including the summary tables, which explained the recommendations in plain English.

9.1 Future directions/opportunity/obligation

This report outlines four detailed recommendations in relation to principles, practice, priorities and partnerships to progress consumer-centred review of the MBS and other health technologies. These recommendations are informed by contemporary literature, policy and practice in health policy, research, services and care and as such must be integrated into business-as-usual if consumer engagement is to move from rhetoric to reality.

The Panel provided a valuable foundation for consumer engagement not only in relation to the MBS and the development of Australia's health system. It is also a model for other areas of public policy, where the key question is "How and what benefit does this deliver to consumers and the community."

9.2 Lessons Learnt

This report also contains a number of lessons learnt during the process of the MBS Review which relate to process. The Panel intends for these lessons learnt to be considered for an ongoing review mechanism, or any futures reviews held by the Department of Health in relation to Health Technologies.



10. Glossary of consumer-related terminology

The MBS Review uses a number of clinical terms that have a specific meaning in the MBS context: the Secretariat can explain these terms to Committee members. The following terms and definitions relate specifically to patients, consumers and the community, as applied in the Review.

TERM	DEFINITION OF TERM
Community	A group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches (11)
Consumer	<p>Patients and potential patients, carers, and people who use health care services.</p> <p>Collectively, 'consumers' and 'community members' may be referred to as 'the public'.</p> <p>The Australian Commission on Safety and Quality in Health Care definition: members of the public who use, or are potential users of health care services - patients, consumers, families, carers and other support people. (2) (11)</p>
Patient	A person receiving medical services because of a problem or a check-up. (12)
Carers	Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. (13)
Consumer representative	Someone who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person may be nominated by, and may be accountable to, an organisation of consumers. This consumer representative however may have a narrower view as they are speaking on behalf of their organisation and not necessarily that of the wider community. A consumer representative may be appropriately trained or may undergo training and be supported to advocate for consumer-centred health care. (11)
Consumer- or person- or patient-centred care	Patient or consumer-centred care is health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. (6)
Health literacy	<p>Individual health literacy is the knowledge, motivation, skills and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care, and make appropriate decisions.</p> <p>The health literacy environment is the infrastructure, policies, processes, materials, people and relationships that have an impact on the way in</p>



TERM	DEFINITION OF TERM																																			
	which people access, understand, appraise and apply health-related information and service. (14)																																			
Public participation	<p>Any process that involves the public in problem-solving or decision-making and that uses public input to make better decisions. (15)</p> <p>IAP2 PUBLIC PARTICIPATION SPECTRUM</p> <p>INCREASING LEVEL OF PUBLIC IMPACT</p> <table><tr><th>INFORM</th><th>CONSULT</th><th>INVOLVE</th><th>COLLABORATE</th><th>EMPOWER</th></tr><tr><td>Public Participation Goal:</td><td>Public Participation Goal:</td><td>Public Participation Goal:</td><td>Public Participation Goal:</td><td>Public Participation Goal:</td></tr><tr><td>To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.</td><td>To obtain public feedback on analysis, alternatives and/or decisions.</td><td>To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.</td><td>To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.</td><td>To place final decision-making in the hands of the public.</td></tr><tr><td>Promise to the Public:</td><td>Promise to the Public:</td><td>Promise to the Public:</td><td>Promise to the Public:</td><td>Promise to the Public:</td></tr><tr><td>We will keep you informed.</td><td>We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.</td><td>We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.</td><td>We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.</td><td>We will implement what you decide.</td></tr><tr><td>Example Tools:</td><td>Example Tools:</td><td>Example Tools:</td><td>Example Tools:</td><td>Example Tools:</td></tr><tr><td><ul style="list-style-type: none">• fact sheets• web sites• open houses.</td><td><ul style="list-style-type: none">• public comment• focus groups• surveys• public meetings.</td><td><ul style="list-style-type: none">• workshops• deliberate polling.</td><td><ul style="list-style-type: none">• citizen advisory committees• consensus-building• participatory decision-making.</td><td><ul style="list-style-type: none">• citizen juries• ballots• delegated decisions.</td></tr></table> <p>© Copyright IAP2. All rights reserved.</p>	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER	Public Participation Goal:	Public Participation Goal:	Public Participation Goal:	Public Participation Goal:	Public Participation Goal:	To provide the public with balanced and objective information to assist them in understanding the problems, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.	Promise to the Public:	Promise to the Public:	Promise to the Public:	Promise to the Public:	Promise to the Public:	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for direct advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.	Example Tools:	Example Tools:	Example Tools:	Example Tools:	Example Tools:	<ul style="list-style-type: none">• fact sheets• web sites• open houses.	<ul style="list-style-type: none">• public comment• focus groups• surveys• public meetings.	<ul style="list-style-type: none">• workshops• deliberate polling.	<ul style="list-style-type: none">• citizen advisory committees• consensus-building• participatory decision-making.	<ul style="list-style-type: none">• citizen juries• ballots• delegated decisions.
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Healthcare rights	<p>Principles of client-centred care and health rights are enshrined in the <i>Australian Charter of Healthcare Rights</i> The Charter outlines seven rights that apply to all people in all places where health care is provided in Australia. (16)</p> <p>Access</p> <ul style="list-style-type: none">• Healthcare services and treatment that meets my needs. <p>Safety</p> <ul style="list-style-type: none">• Receive safe and high quality health care that meets national standards• Be cared for in an environment that is safe and makes me feel safe <p>Respect</p> <ul style="list-style-type: none">• Be treated as an individual, and with dignity and respect• Have my culture, identity, beliefs and choices recognised and respected <p>Partnership</p> <ul style="list-style-type: none">• Ask questions and be involved in open and honest communication• Make decisions with my healthcare provider, to the extent that I choose and am able to• Include the people that I want in planning and decision-making																																			



TERM	DEFINITION OF TERM
	<p>Information Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent</p> <ul style="list-style-type: none"> • Receive information about services, waiting times and costs • Be given assistance, when I need it, to help me to understand and use health information • Access my health information • Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe <p>Privacy</p> <ul style="list-style-type: none"> • Have my personal privacy respected • Have information about me and my health kept secure and confidential <p>Give Feedback</p> <ul style="list-style-type: none"> • Provide feedback or make a complaint without it affecting the way that I am treated • Have my concerns addressed in a transparent and timely way • Share my experience and participate to improve the quality of care and health services
<p>Clinical Practice Guidelines (CPGs)</p>	<p>Clinical Practice Guidelines are statements that include recommendations intended to optimise patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options. They are different from other sources of health information because they present recommendations about what should or should not be provided or done, something that other sources of information do not generally do. Since many of these recommendations will directly affect the care received by patients and the public, it seems natural that efforts should be made to produce guideline-derived materials that are meant to be used by patients and the public to support their health care decisions.</p> <p>The adequate application of a guideline does not only imply strict adherence to guideline recommendations but also reasonable non-adherence due to a patient's individual preferences or circumstances. It is crucial that guidelines convey this idea to both physicians and patients and provide information to facilitate decision making the importance of presenting recommendations that relate to self-management was one of the strongest messages (from patients and the public) relatively few patient versions in the English language currently meet this need. (17)</p> <p>Note: Guidelines in some areas are difficult to access because of software incompatibility. It is important to ask for the Guidelines appropriate for your Committee.</p>
<p>Transparency in healthcare</p>	<p>The free, uninhibited flow of information that is open to the scrutiny of others. (18)</p>



TERM	DEFINITION OF TERM
Value in healthcare	<p>Where would we start if care and support were person-centred?</p> <ul style="list-style-type: none">• We would start by understanding what matters to the patient.• Every encounter would be one which embraces the patient as person rather than object.• We would explore their health beliefs, motivations, knowledge, skills, learning styles and familial and social context as well as according to their disease and demography.• Interventions would be targeted and tailored based on these insights to support people to achieve their goals. <p>[We would] measure:</p> <ul style="list-style-type: none">• How far people's preferences are supported.• How confident and able people are to manage their long-term conditions better.• The extent to which the NHS has been successful, working in partnership with others such as social care, housing and the voluntary sector, supporting people to achieve their outcomes. (19)



11. Appendices

- A. Consumer Panel Terms of Reference
- B. Consumer Engagement Resource
- C. Consumer Engagement in the MBS Review - Frequently Asked Questions
- D. Guidance for Committee Chairpersons to Support Effective Engagement of Consumer Members



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Appendix A Terms of Reference of the Consumer Panel for the MBS Review Taskforce

This document sets out the terms of reference, composition and membership of the Consumer Panel and procedures for managing meetings.

Attached is the Role of Consumer Representatives on Clinical Committees from the Guidance for Clinical Committees (Attachment A).

1. TERMS OF REFERENCE

The Consumer Panel provides advice, and undertakes and commissions tasks, to enable evidence-informed consumer engagement in the Review and, as opportunities arise, to modernise all aspects of the MBS.

Their scope includes:

1. Administrative rules and mechanisms
2. Information access and use of plain English
3. Communications and community engagement
4. Induction, training and support of consumer representatives and their committees.

1.1 Deliverables and Expectations

The Panel will develop a work plan to:

1. Support the work of Taskforce committees

This may include:

- a) Development and implementation of a consumer engagement strategy.
- b) Commissioning evaluation of the strategy.
- c) Development of measureable and observable checkpoints for consumer engagement across the work of the Taskforce (for example, in induction, the conduct of clinical committees and the preparation of reports).
- d) Involvement in the development, implementation and evaluation of consumer engagement training.
- e) Mentoring new consumer representatives and chairs of Taskforce clinical committees.
- f) Development or adaptation of templates and guidelines to support and promote efficient and comparable reporting of consumer perspectives.
- g) Reviewing reports and providing advice to the Taskforce about how to make these accessible to consumers and communities.

2. Address systemic improvements to the MBS

This may include:



- a) Commissioning development of a plain English guide for the MBS.
- b) Scoping how to develop plain English descriptors and hyperlinks to clinical guidelines and plain English Clinical Guidelines.
- c) Development of a glossary of terms.
- d) Development of evidence-informed consumer engagement principles, policy and procedures.

1.2 Timeframes

Timeframes will be outlined in the Panel's work plan, as approved by the Taskforce.

2. COMPOSITION AND MEMBERSHIP OF THE CONSUMER PANEL

The Consumer Panel will comprise an Executive and general members.

The Executive will provide cross-representation over elements of various Committees to promote consistency across consumer involvement and foster strategic focus. It will also proactively communicate any outcomes that could inform the broader agenda to modernise the MBS.

The Executive will comprise:

- a) The Chair;
- b) Taskforce Consumer Representative;
- c) The Medical Services Advisory Committee (MSAC) representative; and
- d) MSAC Evaluation Subcommittee (ESC) consumer representatives.

The general members of the Consumer Panel will be drawn from consumer representatives on active clinical committees via an expression of interest (EOI) process.

Consumer Panel Members comprise:

- a) members with qualifications and/or experience in sitting on consumer committees,
- b) members who have experience participating in the development of national policy, planning and service decisions which affect the health of consumers; and
- c) members who are willing to support and promote consumers who are to be involved in health policy, planning and service decisions.



Attachment A

Role of the Consumer Representative on Clinical Committees (excerpt from the Guidance for Clinical Committees).

“Consumers may offer different and complimentary perspectives to those of professionals”³.

The role of the consumer on the committees is valued for providing relevant and different perspectives to the clinical experts. Being involved in the setting of agendas for clinical committee meetings will ensure key messages have time to be heard — consumer representatives should speak to the Chair to arrange time within the agenda to raise consumer issues. During the meeting, before an item is closed, consider whether there is anything additional that needs to be considered from a patient or carer perspective that may bolster the committee arguments or provide an alternative point of view for consideration.

Preparing for the meeting: articulate, as far as possible, the key messages from consumer submissions to the MBS Review as they relate to the clinical committee. Consumer representatives may also need to seek further input by going out into the public and researching attitudes and beliefs in order to be able to represent the perspective of some members of the public. In particular this could involve:

- Talking to relevant organisations to gather perspectives
- Articulating any differences between specific groups of people (for example, patients, people affected by different conditions, or people with different genetic variations of known significance, may have different priorities)
- Collecting and synthesising relevant stories or case studies (similar to the ‘real people real data’ project that Consumers Health Forum did for MSAC)⁴.

³ Nilsen, ES, Myrhaug HT, Johansen M, Oliver S & Oxman AD (2006) “Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material (review)” *Cochrane Database of Systematic Reviews*, Issue 3.

⁴ <https://www.chf.org.au/real-people-real-data-project.php>



Appendix B **Consumer Engagement Resource**

The Consumer Engagement Resource is intended to be used as a resource for clinical committees and secretariat personnel during an MBS Review. It is a living document that must be contextualised to the terms of reference of a clinical committee or working group.



Appendix C Consumer Engagement in the MBS Review

Frequently Asked Questions

How do clinical committees and working groups function in the Review?

Clinical committees typically conduct a series of meetings, both face-to-face and via teleconference. Consumer representatives are sometimes required to respond to committee / working group business out-of-session via email.

How are clinical committees structured?

Each clinical committee reviews the current MBS items available to the relevant clinical field, in light of contemporary clinical evidence and practice. The clinicians on the committee are appointed in their individual capacity, not as a representative of their profession, and are drawn from the relevant medical field, related disciplines and health system experts.

Most clinical committees have two consumer representatives to provide consumer perspectives on the MBS items being discussed. Some clinical committees have had one consumer representative.

What are working groups?

Occasionally a clinical committee determines that a sub-group is required to consider specific issue or item(s). This working group may undertake research and/or gather evidence before reporting back to the clinical committee on their findings and recommendations.

Is there an induction process?

All clinical committee members are supplied with an induction pack and invited by the secretariat to undertake an induction process. The chair of the clinical committee will usually make an introductory call to consumer representatives.

A free online introduction to consumer representation is available at:

<http://elearning.ourhealth.org.au/guidelines/>

The Consumer Engagement Resource, prepared by the Consumer Panel, provides the necessary tools to effectively participate in the clinical committee discussions.

How long am I expected to commit to the committee?

The time required for a clinical committee to complete its work varies.

First, a clinical committee reviews the relevant MBS items and develops recommendations in a draft report for the consideration of the Taskforce.

If endorsed by the Taskforce for consultation, the draft report is then released for consultation. Following the closure of consultation period, the clinical committee reviews the feedback received and considers if any changes to the recommendations are required.

A post consultation report is then provided to the Taskforce for consideration, concluding the work of the clinical committee.



What is expected of me as a consumer representative on a clinical committee?

Primarily, the role of the consumer representative is to provide an **independent** consumer perspective to the items being discussed and reviewed. Consumer representatives are not expected to have clinical expertise. Some points to keep in mind when considering the discussions and evidence being put forward by the clinicians could include:-

- Safety, will any changes impact safety?
- Quality, will any changes impact quality of services?
- Access, will any changes impact accessibility for consumers?
- Effectiveness, will any changes impact on delivery and effectiveness?
- Cost effectiveness, will changes deliver value for money?

How do I prepare for the meetings?

All clinical committee members are required to read the agenda, meeting, and research papers. These will assist in understanding and contributing to the clinical committee's discussions.

Clinical committee members can expect to receive papers in the week prior to the meeting.

How many clinical committee meetings will be held and am I expected to attend each one?

A face-to-face induction meeting of the clinical committee will be held to familiarise members with the process of the review.

Over the course of the clinical committee's work there will usually be at least two face-to-face meetings (allow a full day for each).

Up to five teleconferences are held over the life of the clinical committee, and once consultation has closed a further meeting (it may be face-to-face, but normally a teleconference) is typically held to discuss stakeholder feedback and any necessary changes to the final report arising from consultation, before it goes back to the Taskforce for consideration.

Face to face meetings are held in a capital city (Sydney, Melbourne, Brisbane or Canberra).

Whilst all clinical committee members are encouraged to attend all the meetings to enable maximum consumer input, the Department understands that this may not at times be feasible. Minutes are disseminated from the secretariat after each meeting to inform members of the discussion and decisions made.

***Who arranges and pays for my accommodation and travel costs and any other expenses, when I attend a face-to-face meeting?***

Once a face-to-face meeting has been confirmed, the secretariat contacts clinical committee members to obtain their travel preferences. Air and/or train fares and accommodation, where required, are booked by the secretariat and itineraries emailed to members.

Any additional costs such as taxi are reimbursed to members after the meeting. An expenses claim form is to be completed by members at the meeting and provided to the secretariat along with receipts for any costs incurred.

Will I be paid for my time in meetings and out-of-session work?

Sitting fees are paid for the time spent attending the clinical committee face-to-face and teleconference meetings. This payment encompasses covers preparation and follow-up work for each meeting.

How do I request information and key data to assist me in my preparation?

Requests for data can be directed to the secretariat.

What is the methodology used for resolving different interpretations of the evidence presented?

Clinical committees are comprised of experts who bring up to date practical and scientific expertise to the review process. The committee will consider best available, high quality scientific evidence, and where this is unavailable may request an evidence review to inform consideration of specific items.

Consumer-related evidence on quality and access should be made available to the committee prior to the first or second meeting.

It may be difficult to predict the precise consumer or clinician response to a proposed item change.

This highlights the importance of clear and concise explanatory notes, supported by a consultation process with consumers and clinicians, prior to the finalisation of recommendations by the committee.

How are MBS items grouped as in-scope and out-of-scope?

MBS items for a new medical procedure may require consideration by the Medical Services Advisory Committee. At the first meeting of the clinical committee the chair will outline those items and issues that are in-scope.

Can I request a mentor if I feel I need additional support?

Yes. The Consumer Panel can assist with referring an experienced MBS review consumer who will be able to offer additional support clinical committee members.



Appendix D Guidance for Committee Chairpersons to Support Effective Engagement of Consumer Members

This checklist is focussed on supporting chairpersons to effectively engage consumer members on clinical committees, and to engage all committee members in ensuring consumer evidence and perspectives are valued and influential in committee work.

1. Make personal contact with consumer members when they are appointed to the committee; outline your approach to chairing the group to ensure consumer evidence and perspectives are genuinely integrated; and remain open to questions from consumer members re committee process, outputs and outcomes.
2. Arrange and participate with the secretariat in effective induction of consumer members. Induction should include written documentation and an online (if not in-person) session that allows for questions to be answered and issues /opportunities to be addressed/taken on notice.
3. Ensure all committee members have access to information about the consumer members' induction so that they understand the role of consumer members, and their own role in enabling consumer evidence and perspectives to be integrated into the committee's work, in accordance with the terms of reference. Offer additional information to any committee member who requests it, and arrange an education session for the Committee as required.
4. Check on the availability of peers (other/experienced consumer members) and collaborators (other non-consumer committee members) who can provide support/mentoring, as requested by consumer members, and within the confidentiality restraints of the Committee's work.
5. Ensure your committee's operational guidelines explicitly outline the role of members, individually and collectively, and how all voices will be heard and valued; how decisions are made; and how grievance is managed to ensure compliance with the group's terms of reference – including the integration of consumer evidence and perspectives.
6. Ensure agendas, minutes, reports, briefings and internal communications explicitly address consumer input and outcomes; are circulated in a timely manner; and can be understood by all committee members. This may require the use of consumer summaries and glossaries.
7. Ensure external communications about the committee's work is readily understood and accessed by consumer organisations and the general public.
8. Ensure research and consultation processes enable the consumer members – and all committee members – to consider the perspectives and priorities of community groups who have been – and continue to be - historically disadvantaged within health systems and services.
9. Ensure you enable decisions to be made that include consumer evidence and perspectives; do not use your position to bias or reinterpret the consumer members' input and advice.
10. At the beginning of the meeting (when you outline the purpose and anticipated outcomes of the meeting), and at the close of the meeting (when you summarise outcomes and next steps), check with consumer members, and all Committee members, that consumer priorities and perspectives have been explicitly considered and documented.