# Recognising Consumers' Contributions to Health Research

*A collaboration between Research Australia and the Australian National University to develop a framework to support the remuneration of consumers for their involvement in research*



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Championing Australian health & medical research & innovation

Australian National University

# Foreword

Consumers bring lived wisdom to health research, and they remind us of who research is for. Their insights sharpen relevance, their experiences ground innovation, and their perspectives guide better care. When consumers are at the table, research is not only more inclusive but also more impactful.

While expectations of consumer engagement have grown, how we recognise and reward those contributions has not kept pace. Across Australia, approaches vary widely. Some consumers are remunerated for their time, some are reimbursed for out-of-pocket costs, and others are offered little more than thanks. Researchers and organisations often face administrative hurdles, unclear policies, and fragmented guidance. The result is inconsistency, and at times, inequity.

This report presents Australia's first co-designed recognition framework, developed by Research Australia in partnership with the National Centre for Epidemiology and Population Health, Australian National University. Informed by international best practice and shaped by healthcare consumers and organisational representatives, the framework translates values into practice. It aligns with the principles set out in the forthcoming revised NHMRC *Statement on Consumer and Community Involvement in Health and Medical Research* and provides practical mechanisms to operationalise its core values: respect, partnership, mutual benefit, equity and inclusion.

The findings are both timely and transformative. They point to the need for national consistency, dedicated funding, and recognition that goes beyond financial recognition to include authorship, conference presentations, and skills development. Above all, they make clear that valuing consumer expertise is not optional. It is essential to research integrity and to the future of our health research community.

We invite you to read this report and consider how you can embed its recommendations to create a research culture that is fairer, stronger, and more responsive to the needs of all Australians.

# Executive Summary

## Background

Consumer engagement is increasingly expected in Australian health research, driven by both public expectations and funding requirements. However, there is no consistent national approach to remunerating consumers for their contributions. While some jurisdictions and organisations have introduced policies, these vary significantly and often create administrative challenges. In contrast, countries such as the United Kingdom (UK) and Canada have adopted national guidelines to support fair and consistent practice.

## Project Overview

To address this gap, Research Australia partnered with the National Centre for Epidemiology and Population Health at the Australian National University with the aim to co-design a national remuneration framework for recognising consumer contributions in health research.

A Consumer Remuneration Working Group (CRWG), comprising ten Research Australia member organisations, including universities, medical research institutes, local health district, and not-for-profit and consumer-led bodies, guided the project throughout.

The study followed a three-phase mixed-methods design:

- A rapid evidence review examining the peer-reviewed and grey literature, and existing remuneration policies across Australia.
- A national survey of Research Australia members providing baseline data on current practices and stakeholder support for national guidance.
- Deliberative workshops with consumers and research organisations informing the co-design of a draft framework, which was further refined in consultation with the CRWG.

We thank and acknowledge the contributions of the following members of Research Australia who have agreed for their logos to appear as part of this paper:



Australian National University

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The KIDS RESEARCH INSTITUTE AUSTRALIA

Sydney Health Partners

NARI NATIONAL AGEING RESEARCH INSTITUTE

## Key Insights

The survey results found high levels of recognition of consumer contributions (92%) but inconsistent financial remuneration practices (56%). Approaches to recognition varied, with organisations citing administrative complexity and unclear funding guidance as key barriers. A large majority (93%) supported the development of national guidelines to improve consistency, fairness, and efficiency.

Building on these results, six deliberative workshops were conducted (including consumers with lived experience of chronic conditions).

These sessions shaped the core elements of the framework, including:

- Payment rates: Consensus on AUD $50 per hour for participation in research and AUD $40-50 per hour for collaboration roles.
- Payment methods: Gift cards favoured for convenience and tax implications, with flexibility for consumer choice essential.
- Reimbursement: Universal agreement that all out-of-pocket expenses should be covered, with upfront clarity about coverage.
- Non-financial recognition: Strong value placed on co-authorship, conference presentations, skills development, and additional approaches including referrals and mentorship

Workshop participants emphasised the importance of consumer choice, upfront clarity, and administrative simplicity.

## Recognition Framework

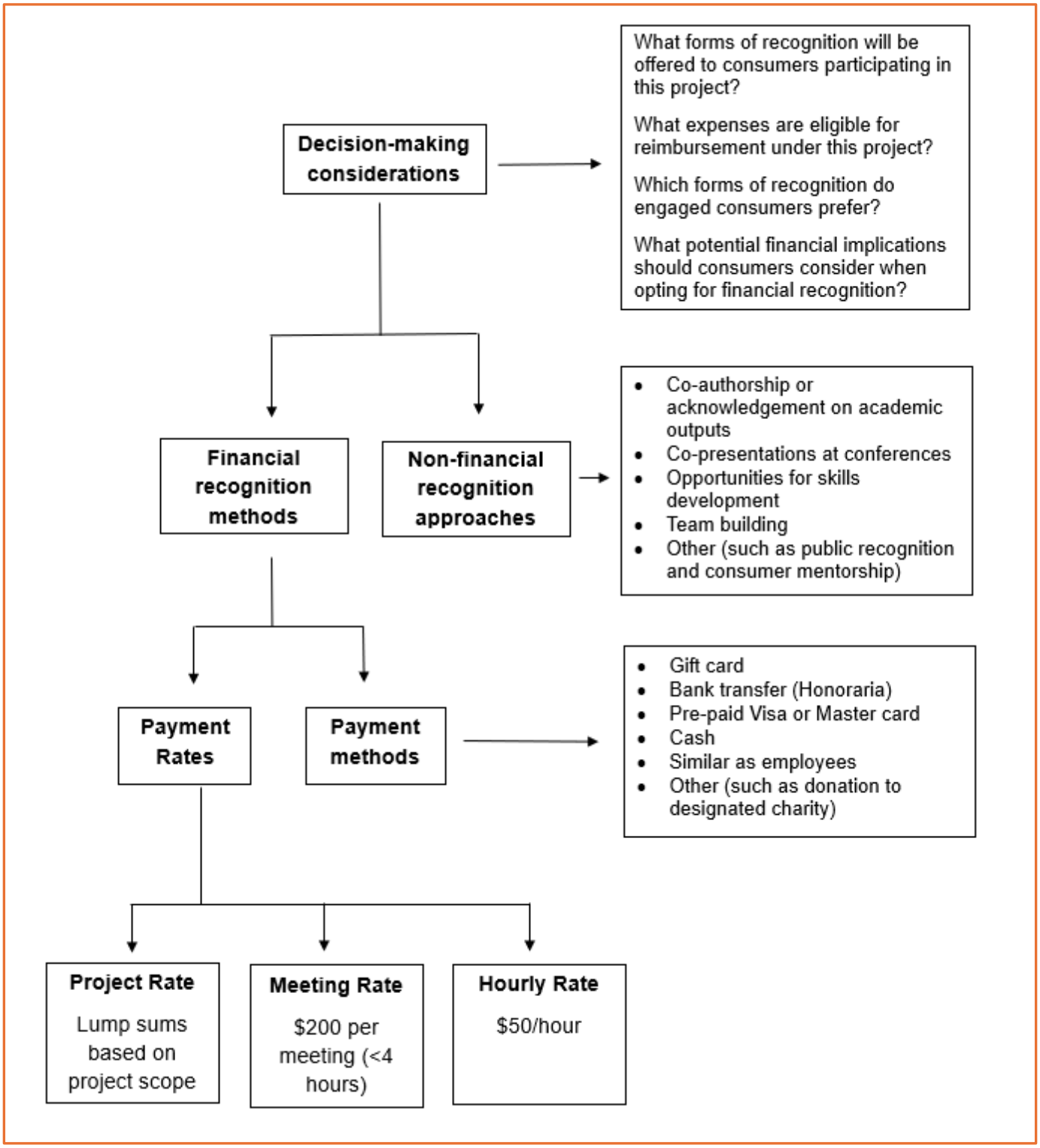



**Figure 1:** Framework for recognising consumer contributions in health research.

## Recommendations

The project produced seven overarching recommendations to support national implementation:

- Recognise consumer expertise as a valued contribution to research.
- Establish national guidelines outlining financial and non-financial recognition practices.
- Promote national consistency through shared standards and regular review.
- Encourage funding bodies to allocate dedicated remuneration budgets.
- Support organisational capacity with toolkits, policies, and training.
- Streamline payment processes to reduce administrative burden.
- Advance equity by removing barriers for underrepresented groups.

## Impact

As far as we are aware, this co-designed recognition framework is the first of its kind in Australia. It offers practical tools, guiding questions, and flexible options that can be adopted by research organisations. The framework supports inclusive, transparent, and sustainable engagement, and aligns with both national priorities and international best practice.

## Conclusion

This project delivers a timely and practical solution to a long-standing challenge in health research. By centring the voices of consumers and research organisations, the framework provides a strong foundation for consistent and ethical remuneration practices across Australia. Its adoption will help ensure that consumer contributions are fairly recognised, valued, and supported into the future.

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We also gratefully acknowledge the survey and workshop participants, whose insights and experiences informed the co-design of a framework that reflects what matters to them. Their contributions are central to advancing meaningful and inclusive research that supports better health and wellbeing for all.

# Introduction

Consumers, defined as individuals with lived experience of specific health conditions, offer valuable experiential insights and can contribute to the design, conduct, and dissemination of research projects[1,2]. In Australia, consumer engagement is increasingly recognised as essential to producing high-quality, relevant, and impactful health research[3]. Major funding bodies such as the Medical Research Future Fund (MRFF) and the National Health and Medical Research Council (NHMRC) are leading efforts to embed consumer involvement across the research cycle[2,4]. Despite this growing recognition, researchers face significant challenges in engaging a diverse range of consumers and appropriately recognising their contributions[5,6]. These challenges include uncertainty around suitable forms of recognition, inconsistent or inadequate remuneration, time and resource constraints, and limited organisational guidance or infrastructure to support meaningful engagement[5,7-9]. Institutional rigidity and a lack of clear policy support further compound these difficulties[8].

A pivotal aspect of these challenges relates to the issue of remuneration – financial compensation offered to consumers in recognition of their contribution of time, skills and expertise to research projects[8,10]. Remuneration can take various forms, including direct compensation and reimbursement for out-of-pocket expenses such as travel, parking, meals, and childcare[5,11-13]. Offering remuneration may allow consumer partners from different socioeconomic population groups to be engaged in research and thus encourage the inclusion of diverse perspectives[11].

To support researchers in engaging consumers in health research, various institutions have developed frameworks and guidelines aimed at addressing the intricate issue of remuneration[5]. Examples of these institutions include the National Institute for Health Research (NIHR) from the United Kingdom (UK)[14], the Patient-Centred Outcomes Research Institute (PCORI) from the US[15], Strategy for Patient-oriented Research (SPOR) from the Canadian Institutes for Health Research (CIHR)[16], the Belgian Health Care Knowledge Centre[17], and Australian Genomics[18]. Notably, there are currently no national guidelines in Australia[17].

Health consumer organisations within the Australian states and territories, including New South Wales (NSW)[19], Queensland[20], the Australian Capital Territory (ACT), Western Australia (WA)[22] and South Australia (SA)[23], have developed their own remuneration policies for consumer engagement; however, there is considerable variation in remuneration rates across jurisdictions. Limited research has examined how Australian health research organisations recognise consumers' contributions, both financially and non-financially. Additionally, the perspectives of health and research organisations on remuneration, such as eligibility criteria, payment methods, and implementation challenges, remain unclear. A key gap in the existing literature is whether national consensus on a recognition framework is necessary to support consumer engagement in research practices, at the same time addressing the diverse needs of consumers and organisations.

## Aim

The study aimed to collaborate with Australian health research organisations and consumers to develop clear, practical guidelines to support remuneration for consumers' contributions to health research in Australia.

The specific objectives of this study were to:

1. Review international best practices and guidelines for consumer remuneration in health research.
2. Examine current remuneration practices in Australian health research and explore organisations' experiences and perspectives.
3. Analyse existing consumer remuneration policies in health research across Australian states and territories to identify variations.
4. Co-design a remuneration framework through consultation with key stakeholders, including health research organisations and consumers with lived experience of chronic health conditions.

A remuneration framework that health research organisations can adopt would establish a foundation for national guidelines on recognising consumer engagement in health research. Ultimately, this effort aims to support more inclusive and patient-centred research practices that reflect the needs of the communities most affected by health research outcomes.

# Methodology

This study followed a three-phase approach: (1) Evidence review, (2) Stakeholder survey, and (3) Development of a recognition framework. Figure 1 outlines the framework development process (Appendix B), highlighting how and where consumer engagement was incorporated.

A sequential exploratory approach was adopted to ensure continuous involvement from the CRWG at every stage. This approach allowed for iterative refinement of research questions, survey design and distribution, and recognition models discussed in the deliberative workshops, based on CRWG feedback.

### Phase 1: Evidence Review

A rapid review of both academic and grey literature, as well as existing policies in use across Australia, was conducted to identify key frameworks and components for recognising consumer contributions to health research. The findings from this review informed the development of the stakeholder survey in phase 2.

### Phase 2: Stakeholder Survey

The stakeholder survey aimed to examine how health organisations, both for-profit and not-for-profit, recognise and remunerate consumers for their contributions to health research. A cross-sectional survey was developed and distributed to assess current remuneration practices and recognition approaches across different research organisations.

### Phase 3: Development of a Remuneration Framework

Building on the findings from the evidence review and stakeholder survey, potential models for recognising consumer contributions were developed. These models were first presented to the CRWG for initial feedback and refinement. They were then discussed in deliberative workshops with key stakeholders to assess their feasibility and acceptability in real-world research settings.

# Key Recommendations

## A Framework for Recognising Consumers' Contribution to Health Research

This mixed-method study, integrating survey data on current remuneration practices with findings from deliberative workshops, revealed both challenges and practical solutions for establishing a consistent approach to consumer recognition in health research. The following recommendations informed the development a comprehensive framework that ensures fair, transparent, and consistent remuneration practices across Australia.

### 1. Recognise consumers' expertise and value

**Finding:** Survey and workshop participants emphasised the importance of formally recognising the expertise that consumers bring to research.

> "Many consumers are deterred from working with researchers due to bad experiences where they feel they were taken advantage of. If there were guidelines on minimal remuneration for engagement, it would improve researchers' understanding that consumers need to be compensated fairly and empower consumers to ask for what they deserve."
>
> — Survey respondent

**Recommendation:** Research organisations should implement comprehensive recognition frameworks that:

- Provide appropriate financial remuneration reflecting consumers' unique expertise
- Include meaningful non-financial recognition (e.g., co-authorship, acknowledgments, certificates)
- Offer professional development opportunities for consumers
- Involve consumers meaningfully in research dissemination activities (e.g., conference presentations)

## 2. Establish national remuneration guidelines

**Finding:** Survey and workshop participants emphasised the critical importance of creating national guidelines to promote consistent recognition and remuneration of consumers engaged in research.

> "Having a consistent remuneration guideline across Australia in terms of the amount you provide and how you're paying that... needs to translate through the organisation to make the process straightforward."
>
> — Workshop participant

**Recommendation:** Develop and implement comprehensive national remuneration guidelines endorsed by key stakeholders including research funding bodies, universities, health services, and consumer organisations. These guidelines should:

- Specify standard hourly rates for different types of consumer engagement
- Outline appropriate payment methods and timing
- Include approaches for non-financial recognition
- Provide templates for budgeting consumer engagement in research proposals

## 3. Ensure consistent implementation across organisations

**Finding:** Survey and workshop participants advocated for uniformity in remuneration practices across different research organisations to prevent confusion and inequity.

> "National consistency in payments would allow organisations to follow best practice and consumers to know what to expect when working with different/multiple organisations."
>
> — Survey respondent

**Recommendation:** Implement a coordinated national approach that:

- Establishes clear standards that apply consistently across all research institutions
- Facilitates regular review and update of remuneration frameworks
- Addresses both financial remuneration and non-financial recognition approaches

### 4. Secure dedicated funding allocations

**Finding:** Survey and workshop participants identified inadequate funding as a primary barrier to appropriate consumer remuneration.

> "We already face a significant shortfall in research funding, and if we are also to remunerate consumers, what will be left for the actual research? The administering organisations and funding bodies need to account for this if it is to happen."
>
> — Survey respondent

**Recommendation:** Research organisations and major funding bodies including the NHMRC and MRFF should:

- Explicitly include budget allocations for consumer remuneration in research grants
- Support establishment of central institutional funds specifically for consumer recognition
- Provide funding for early-stage consumer consultation before grant submissions
- Recognise that Consumer Reference Groups often support multiple research initiatives simultaneously

### 5. Build organisational capacity

**Finding:** Survey and workshop participants believed that implementing national guidelines would strengthen research organisations' ability to effectively engage and remunerate consumers.

> "Having standardised rates is easier to create policy around and raise awareness."
>
> — Survey respondent

**Recommendation:** Universities and research institutions should:

- Develop standardised policies based on national remuneration guidelines
- Create templates for ethics applications that include consumer remuneration
- Provide budget planning tools for different types of consumer engagement

- Offer training resources to help research teams incorporate consumer recognition from project inception

### 6. Streamline administrative processes

**Finding:** Survey and workshop participants described significant administrative barriers to consumer remuneration, with complex financial systems at universities and health districts creating unnecessary obstacles.

> "Administration often requires several hoops and lots of double-checking to ensure payment is made."
>
> — Survey respondent

**Recommendation:** Research organisations should establish simplified, consumer-friendly payment processes that:

- Reduce the administrative burden for both consumers and researchers
- Integrate payment systems across university and health service boundaries
- Provide dedicated administrative support for managing consumer payments
- Ensure accessibility for consumers with diverse needs and capabilities

### 7. Promote equity and diversity

**Finding:** Survey and workshop participants highlighted how inconsistent remuneration practices create inequities and limit diversity in consumer representation.

> "When consumers are not paid correctly, we will only attract consumers who can afford the time and expense of taking part and reduce the diversity of voices heard."
>
> — Survey respondent

**Recommendation:** Research organisations should implement equitable remuneration frameworks that:

- Acknowledge all consumers' contributions fairly and consistently
- Establish clear criteria for different levels of remuneration based on contribution and time commitment

- Actively monitor the diversity of consumer representatives
- Ensure remuneration practices support inclusion of consumers from varied backgrounds, including traditionally under-represented groups

# Findings

## Phase One: Evidence Review

A rapid review of the literature, including grey literature and relevant policies currently in use across Australia, was conducted to identify existing frameworks and key components for recognising consumers' contributions to health research. The review intended to address the central project question: "How can we better recognise consumers' contributions to health research?" The search targeted existing recognition frameworks relevant to consumer engagement and focused on three sources: (1) peer-reviewed literature, (2) grey literature on consumer contribution recognition, and (3) remuneration policy documents from Australia's eight states and territories.

Search terms for the peer-reviewed literature included consumer engagement, consumer and community involvement, patient engagement, public and patient involvement, patient partnership, health research, remuneration, compensation, reimbursement, framework, models, tool, and guide. Both Australian and international frameworks/models were considered. All identified sources were reviewed to extract approaches for recognising consumers' contributions that align with the consumer engagement context.

A scoping review, published in December 2023, summarised available guidance and policy documents on consumer compensation, aligning well with the purpose of this study.[17] This scoping review, based on peer-reviewed literature, was adopted as an international reference. It synthesised non-financial and financial compensation methods from 65 identified documents, providing a comprehensive overview of financial compensation recommendations (e.g., monetary values) across three categories: consultation, collaboration, and other forms of engagement in research activities (Appendix C Financial compensation recommendations from literature).

Additional documents related to the recognition of consumer engagement were also retrieved, particularly from the NIHR in the UK, the Patient-Cantered Outcomes Research Institute (PCORI) in the United States (US), and the Canadian Institutes of

Health Research (CIHR). Furthermore, policy documents concerning the recognition of consumer engagement in Australia were reviewed, including the remuneration methods currently recommended by state-based consumer organisations across all eight states and territories (Appendix D Remuneration methods recommended by state-based consumer organisation in Australia).

To maintain consistency, remuneration policies from other organisations, such as government departments, were excluded. In order to gain a comprehensive understanding of consumer engagement practices in Australia and avoid confusion regarding the varying names of consumer organisations across the country, we reached out to the Consumers Health Forum for confirmation about the consumer organisations in Australia.

During the process of evidence review, it became clear that considering remuneration alone was inadequate, as other methods of recognising consumers' contributions were highly valued by both research organisations and consumers and often utilised in practice. The framework was therefore referred to as a 'recognition framework' rather than a 'remuneration framework'.

## Phase Two: Stakeholder Survey

This phase aimed to examine how health organisations—both for-profit and not-for-profit—currently recognise and remunerate consumers for their contributions to health research. The objective was to explore the experiences and attitudes of health organisation members toward consumer remuneration practices. A cross-sectional design was employed, utilising a co-designed survey to assess existing remuneration approaches for consumer contributions to health research.

### Survey Development

The survey was developed in collaboration with the CRWG following a multistep process, beginning with a review of existing remuneration practices in both Australian and international contexts (phase 1). This was followed by consultation with CRWG. Pilot testing was conducted with three researchers with lived experience, all of whom had extensive expertise in consumer engagement in health research to ensure that the survey was accessible, comprehensive, and accurately captured the broad range of experiences identified by members of the working group and the research team. The survey also contained space for participants to describe different experiences not referred to in the survey questions.

### Survey Administration

The finalised anonymous survey (see Appendix E) consisted of 67 multiple-choice and open-text questions, aiming to provide a thorough understanding of remuneration and other recognition practices. It was administered online using Qualtrics (an online survey tool) in English, with no paper-based option. The survey was distributed by Research Australia to approximately 160 member organisations of Research Australia across eight states and territories via email invitation. Three rounds of email invitations were sent in December 2023 and January 2024, and the survey closed on 29 February 2024.

## Survey Results

### *Survey Response*

503 recipients of the email invitation opened the email, and 124 respondents were recorded by Qualtrics as accessing the survey, of which 110 completed the survey and whose responses are included in the analyses (22% response). Participant characteristics are presented in Table 2-1.

Table 2-1 Descriptive statistics of participating organisations (N=110)

| Variable | n | % |
|---|---|---|
| Type[a] | | |
| University | 52 | 47.3 |
| Medical Research Institute | 32 | 29.1 |
| Research organisation | 11 | 10.0 |
| Health care provider | 2 | 1.8 |
| Non-government organisation | 9 | 8.2 |
| None of the above | 3 | 2.7 |
| Type of Not-for-profit or For-profit[a] | | |
| Not-for-profit | 98 | 89.1 |
| For-profit | 11 | 10.0 |
| Size of organisations[a] | | |
| >50 employees | 89 | 80.9 |
| 21 – 50 employees | 6 | 5.5 |
| 11 – 20 employees | 5 | 4.5 |
| < 10 employees | 9 | 8.2 |

[a]N=109, missing for one participant.

Most participants (86%) were from the academic field with 47% from universities, 29% from medical research institutes and 10% from research organisations. Similarly, most participants were from not-for-profit organisations (89%) and larger organisations (81%) with more than 50 employees.

### *Recognition of consumer engagement*

A large proportion of participants (92%) recognised consumers' contributions to health research; 56% of participants provided financial remuneration and 36% of participants provided non-financial methods of recognition (Table 2-2). In relation to financial remuneration, 39% of participants used gift cards, 30% of participants paid directly to consumers' bank accounts, 18% of participants used prepaid visa or master cards, and 6% of participants paid cash. In relation to non-financial recognition, 28% of participants recognised consumers' contribution academically, including co-authorship or acknowledgement on publications, 22% of participants provided training or skills

development opportunities for consumers, and 22% of participants organised team building activities to support consumers' contribution.

Table 2-2 Types and methods of consumer recognition

| Variable | n | % |
|---|---|---|
| Whether support consumer contribution | | |
| Yes | 101 | 91.8 |
| No | 3 | 2.7 |
| Unsure | 6 | 5.5 |
| How to recognise contribution | | |
| Financial remuneration | 86 | 56.6 |
| Non-financial recognition | 55 | 36.2 |
| None | 11 | 7.2 |
| Financial remuneration methods* | | |
| Payment via a gift card | 71 | 39.9 |
| Payment via prepaid Visa or Mastercard | 32 | 18.0 |
| Direct payment - into a bank account | 54 | 30.3 |
| Direct payment – cash | 11 | 6.2 |
| Other | 10 | 5.6 |
| Non-financial recognition methods* | | |
| Provision of training or opportunities for skills development | 37 | 22.7 |
| Academic recognition, such as co-authorship or acknowledgment on publications | 46 | 28.2 |
| Co-presentations at conferences | 33 | 20.2 |
| Team building activities, such as social gatherings | 36 | 22.1 |
| Other | 11 | 6.7 |

*multi-choice questions.

### *Targets for financial recognition*

Financial remuneration was most commonly (24% of organisations) provided for consumers involved in advisory groups or steering committees, and in research teams (Table 2-3). 21% of participating organisations remunerated consumers for participation in non-treatment related research, such as interviews and focus groups, while it was less common to remunerate consumers for participation in treatment related studies (e.g., clinical trials) (13%) or when they were engaged as consumer involvement coordinators (8%) or for consumer advocacy organisations (7%).

**Table 2-3 Who is recognised for their contributions to research?**

| Variable | n | % |
|---|---|---|
| Who is the target for remuneration* | | |
| Consumers involved in advisory groups or steering committees | 73 | 24.4 |
| Consumers involved in research teams, i.e., lived experienced researchers | 72 | 24.4 |
| Consumers participating in treatment related studies e.g., clinical trials | 41 | 13.7 |
| Consumers participating in non-treatment related research e.g., interviews, focus groups. | 64 | 21.4 |
| Involvement coordinators who facilitate access to consumers (e.g., members of disease advocacy organisations) | 25 | 8.4 |
| Consumer-led non-government advocacy organisations (advocating on behalf of consumers) | 20 | 6.7 |
| Other | 4 | 1.3 |
| Total | 299 | 100% |

*multi-choice questions.

### Rates/amounts for financial remuneration

The most common methods of remuneration used by participating organisations were paying (1) an hourly rate or (2) an amount per meeting/activity (Table 2-4). This trend was similar across the five different roles consumers may adopt (advisor, team member, participant, coordinator, and representative). It was particularly evident for consumers who were members of advisory groups or steering committees and those who were members of research teams, with 45% of participants using an hourly rate. In contrast, fewer participants reported using an hourly rate to recognise consumers' contributions for participating in research (14%) where 47% utilised a per meeting/activity rate as their remuneration approach.

**Table 2-4 Methods of financial remuneration for consumer engagement**

| Remuneration type | Advisor* | | Team member# | | Participant** | | Coordinator## | | Representative*** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % | n | % |
| Payment of an hourly rate | 31 | 44.9 | 41 | 48.2 | 6 | 14.3 | 8 | 32 | 4 | 20 |
| Payment per meeting/activity | 32 | 46.4 | 25 | 29.4 | 20 | 47.6 | 3 | 12 | 2 | 10 |
| Ongoing retainer | 0 | 0 | 5 | 5.9 | 1 | 2.4 | 4 | 16 | 2 | 10 |
| No payment | 1 | 1.4 | 4 | 4.7 | 4 | 9.5 | 2 | 8 | 2 | 10 |
| Other | 5 | 7.2 | 8 | 9.4 | 4 | 9.5 | 3 | 12 | 8 | 40 |
| Unsure | 0 | 0 | 2 | 2.4 | 7 | 16.7 | 5 | 20 | 2 | 10 |
| In Total | 69 | 100% | 85 | 100% | 42 | 100% | 25 | 100% | 20 | 100% |

* Advisor: Being a member of advisory groups or steering committees.

# Team member: Being a member of a research team i.e., lived experienced researchers.
** Participant: Being a participant of research, including treatment related studies e.g., clinical trials and non-treatment related research e.g., interviews, focus groups.
## Coordinator: Being a coordinator for consumer engagement who facilitate access to consumers (e.g., members of disease advocacy organisations).
*** Representative: Being a representative for consumer-led non-government organisations advocating on behalf of consumers.

### *The process of recognising consumer engagement*

Participants were queried on several aspects of the recognition process for consumer engagement, including the presence of a formal onboarding process, provision of information on potential impacts of paid remuneration, allowance for consumers to decline financial remuneration, and documentary requirements regarding remuneration. This survey segment aimed to explore the remuneration process for consumer engagement in current practice.

Equal numbers of participants (43.2%) had or did not have a formal process for onboarding consumers (Table 2-5-1). 44% of participants indicated they provided information on potential impacts of paid remuneration, while 29% and 26% of participants did not provide or were unsure about such information respectively. Nearly 60% of participants provided the option for consumers to choose not to accept financial remuneration or to donate to a nominated charity.

**Table 2-5-1 Processes and options related to onboarding consumers**

| | Formal process* | | Impact information# | | Not accept remuneration## | | Documentary requirements*** | |
|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % |
| Yes | 35 | 43.2 | 15 | 44.1 | 20 | 58.8 | 28 | 82.4 |
| No | 35 | 43.2 | 10 | 29.4 | 6 | 17.6 | 4 | 11.8 |
| Unsure | 11 | 13.6 | 9 | 26.5 | 8 | 23.5 | 2 | 5.9 |
| In total | 81 | 100% | 34 | 100% | 34 | 100% | 34 | 100% |

*A formal process for onboarding consumers

# Information of potential impacts of paid remuneration?

## Option for consumers to choose not to accept financial remuneration or to donate to a nominated charity

*** Having documentary requirements related to remuneration

In terms of potential burdens associated with onboarding consumers, such as documentary requirements, over 80% of participants reported having to complete paperwork related to remuneration. 80% of participating organisations reported using one or two forms for onboarding consumers in the first instance and for each occasion of engagement (Table 2-5-2). Over half of participants reported spending 1-5 hours to onboard a consumer, while more than 70% reported spending 1-4 hours organising remuneration for five consumers following a focus group or interviews.

Table 2-5-2 Time spent onboarding and remunerating consumers

| | First instance* | | each occasion# | | | Onboard a consumer** | | Remuneration for five consumers## | |
|---|---|---|---|---|---|---|---|---|---|
| Forms | n | % | n | % | Hours | n | % | n | % |
| 1-2 | 21 | 75 | 22 | 81.5 | <1 | 5 | 14.7 | 15 | 45.5 |
| 3-4 | 2 | 7.1 | 0 | 0 | 1-2 | 12 | 35.3 | 10 | 30.3 |
| >5 | 1 | 3.6 | 0 | 0 | 3-5 | 8 | 23.5 | 2 | 6.1 |
| Unsure | 4 | 14.3 | 5 | 18.5 | 6-8 | 2 | 5.9 | 0 | 0 |
| | | | | | >8 | 3 | 8.8 | 0 | 0 |
| | | | | | Unsure | 4 | 11.8 | 6 | 18.2 |
| In total | 28 | 100% | 27 | 100% | | 34 | 100% | 33 | 100% |

*How many forms in the first instance when onboarding consumers?

# How many forms for each occasion of engagement?

** How many hours to onboard a health care consumer?

## How many hours to organise remuneration for five consumers following a focus group or interviews?

### *Additional costs of consumer engagement*

Aside from remuneration recognising their direct involvement in research, survey participants described remuneration or reimbursement for additional costs incurred by consumers as part of their involvement.

Table 2-6 Remuneration or reimbursement of additional costs of engagement.

| Variable | | n | % |
|---|---|---|---|
| Additional costs of engagement* | | | |
| Transport (taxi, bus) | | 49 | 32.0 |
| Parking fees | | 46 | 30.1 |
| Time for pre-reading | | 39 | 25.5 |
| Something else not listed above | | 12 | 7.8 |
| No, we do not remunerate for additional costs such as the above. | | 7 | 4.6 |
| Unsure | | 0 | 0 |
| | Total | 153 | 100% |
| How to remunerate/reimburse for taxi fares? | | n | % |
| Provide taxi voucher up-front | | 24 | 40.7 |
| Reimburse taxi fare | | 24 | 40.7 |
| Unsure | | 2 | 3.4 |
| Other | | 9 | 15.3 |
| | Total | 59 | 100% |
| How to remunerate/reimburse for parking? | | n | % |
| Provide parking permit | | 23 | 31.5 |
| Pay for parking upfront | | 11 | 15.1 |
| Reimburse for parking fees paid | | 32 | 43.8 |
| Unsure | | 1 | 1.4 |
| Other | | 6 | 8.2 |
| | Total | 73 | 100% |
| How to remunerate/reimburse for pre-reading? | | n | % |
| Incorporate into hourly rate for involvement | | 36 | 85.7 |
| Set rate | | 4 | 9.5 |
| No payment | | 1 | 2.4 |
| Other | | 1 | 2.4 |
| | Total | 42 | 100% |

*multi-choice questions.

93% of participants indicated that they remunerated or reimbursed consumers for the additional costs of being involved, the majority of which were for transport (taxi or bus), parking fees and time for pre-reading (a total of 87% of responses). More than 80% of organisations either provided taxi vouchers up-front or reimbursed costs afterwards. For parking fees, 15% of organisations paid upfront, and over 40% reimbursed parking fees afterwards, while 30% of organisations provided a parking permit. For the pre-reading, over 85% of participating organisations incorporated this into the hourly rate for involvement.

### *Opinions about remuneration guidelines*

**1. What would make the remuneration process easier?**

Using an open-response item, participants were asked what factors would make the remuneration process easier for them in practice. 67/110 of participants provided free-text responses. The most frequently mentioned factors were the development of national guidelines (n=24, 36%), the establishment of easy and supportive processes (n=21, 31%), and the provision of funding support from relevant authorities (n=15, 22%).

**a) Developing national guidelines**

The importance of creating national guidelines to promote consistent recognition and remuneration of consumers engaged in research was identified by more than one third of survey participants. These guidelines should include recommended rates and methods for financial remuneration, as well as approaches for non-financial recognition, providing clarity for both consumers and researchers. Overall, responses specifically highlighted the need for detailed guidance on payment structures: *"national guidance/education materials on hourly rates, and options for remuneration."* Participants in the deliberative workshops identified the need for uniformity in recognition approaches across different research organisations, with one participant noting the importance of *"having a consistent remuneration guideline across Australia in terms of the amount you provide and how you're paying that. This then needs to translate through to the organisation to make the process straightforward."* Participants specifically called for *"standardised basic rates that are agreed upon by all research organisations"* and a *"standard process across Australia, so everyone knows how to pay, and organisations won't be at risk."*

**b) Creating an easy and supportive process**

Nearly one-third of respondents described the need for simplified and streamlined administrative processes to facilitate consumer recognition and remuneration. Current systems present significant barriers, with one respondent highlighting that *"administration often requires several hoops and lots of double-checking to ensure payment is made."* Financial systems at universities and health districts were specifically identified as problematic: *"We operate our accounts through a university and health district. The financial systems of both organisations are very complex and do not manage consumer payments easily, e.g., they require invoices to be issued for payment."* Another respondent described needing a range of systems to support the process: *"smoother onboarding in the university system, easier payment process (the current spreadsheet system should be integrated into our online system)."* The administrative burden extended to researchers as well: *"It's easy but time-consuming for researchers running multiple projects. It would help to have an administrative assistant for all of this, so researchers can focus on the content and academic documentation."* Survey respondents suggested potential solutions, including: *"coordinated support by a central area at the university—which sets and applies policy and procedures, and manages payments (like travel or claim expenses, which are much easier once you're set up)."*

**c) Securing funding support from authorities**

One-fifth of respondents identified the essential role of funding support from key authorities in enabling effective consumer recognition and remuneration. Financial pressures on research budgets make the need for dedicated funding for consumer engagement essential. Survey respondents were direct about funding needs: *"Funding from funding bodies like NHMRC and MRFF is essential"* and *"Funding availability is crucial! We do not have funds earmarked for this purpose."* The study showed that without specific funding allocation from these major bodies, institutions struggle to properly recognise and remunerate consumers. One respondent articulated the financial dilemma clearly: *"We already face a significant shortfall in research funding, and if we are also to remunerate consumers, what will be left for the actual research? The administering organisations and funding bodies need to account for this if it is to happen."* Innovative funding approaches were suggested, with one participant proposing *"having*

*a central fund within the organisation for consumer remuneration, rather than making it project-specific, would be beneficial. Often, consumer reference groups support multiple teams and projects, making it challenging to determine which team or project code should bear the remuneration costs."*

2. **Whether it would be helpful to have national guidelines or recommendations for consumer remuneration**?

Over 93% of survey participants expressed support for the development of national guidelines or recommendations for consumer remuneration, with only five participants (6.5%) expressing disagreement. When asked to elaborate on their reasons for supporting national guidelines, 69 participants provided at least one rationale through free-text responses. The most frequently mentioned reasons included facilitating consistency across organisations, supporting research organisations, ensuring equitable recognition practices, and valuing and acknowledging consumer expertise.

a) Facilitating consistency across organisations

Survey respondents advocated for national guidelines to ensure uniform practices across different research organisations.

- *"Consumers contribute to research across many organisations, and the lack of consistency in remuneration payments creates confusion amongst consumers and researchers. A standard process will remove one of the main barriers to consumers being paid in a fair and timely way."*
- *"To ensure consistency across organisations, so consumers aren't expected to provide support, feedback, etc., for free from some services but are remunerated appropriately from others."*

The benefits of consistency were clearly articulated:

- *"Having a policy or guideline from a reputable source will also make it easier to set up processes within organisations and to set expectations from both researchers and consumers around budgeting."*
- *"Standardised amounts across projects set expectations for consumers and would be useful for justifying grant budgets."*

- *"National consistency in payments would allow organisations to follow best practice and consumers to know what to expect when working with different/multiple organisations."*
- *"There should be consistency across all organisations regarding consumer engagement. Remuneration guidelines would ensure that consumers understand the 'rules' of remuneration, which would not vary from place to place."*

b) Supporting research organisations

Nineteen respondents believed that implementing national guidelines would strengthen research organisations' capacity to effectively engage consumers and it would also assist with streamlining administrative processes.

- *"Having a clear national guide would be helpful and allow organisations to focus on specific issues that affect them."*
- *"I personally think this would be useful and then the organisation would need to align with this. This would make it simpler to administer."*
- *"having standardised rates is easier to create policy around and raise awareness."*

Additionally, standardised guidelines would support the preparation of ethics applications and grant proposals: *"Guidelines can be useful to justify reimbursement in ethics applications, grant applications, and to other funders."* Survey participants identified the particular benefit for early-stage research: *"There is also the issue of finding funding to support consumer consultation in the early conceptualisation stages of a research project. Setting a national standard would support academic institutions to budget for such activities in the pre-grant preparation stages with greater certainty."* Another noted the value for complex studies: *"Can budget for multisite, national studies with consumers involved across states."*

c) Ensuring equitable recognition practice

Sixteen respondents highlighted the importance of equitable recognition practices that acknowledge all consumers fairly, regardless of their background or the organisation

they work with. The current variations in recognition approaches create inequities and limit diversity in consumer representation.

- *"When consumers are not paid correctly, we will only attract consumers who can afford the time and expense of taking part and reduce the diversity of voices heard."*
- *"Different rates everywhere. Confusing for consumers. Institutions are also unsure if they're doing the right thing, so standardised guidelines would remove this concern."*

Jurisdictional complexity was identified as another factor contributing to inequitable recognition: *"The Commonwealth payment document is so complex you need a lawyer to interpret it! It's confusing and inconsistent. A set of National Rates and Guidelines would be helpful."*

d) Valuing and acknowledging consumer expertise

Fifteen respondents emphasised the importance of formally recognising the value and expertise that consumers bring to research. They suggested that national guidelines would provide a framework for appropriate acknowledgment of consumers' contributions and promote respect for their unique perspectives.

- *"Recognition of the valuable role consumers play in research"*
- *"For equity and to acknowledge consumer involvement appropriately."*

One participant explicitly connected recognition to empowerment: *"National guidance would not only support researchers in developing their budgets for grants, but also give some clarity and confidence to consumers when they engage in research."*

Respondents identified that proper recognition through clear guidelines would address power imbalances and prevent exploitation: *"Many consumers are deterred from working with researchers due to bad experiences where they feel they were taken advantage of (and likely were!). If there were guidelines on minimal remuneration for engagement, it would improve researchers' understanding that consumers need to be compensated fairly, and empower consumers to ask for what they deserve."*

Some survey respondents indicated that consumers' contributions are often undervalued, creating barriers to diverse and meaningful engagement. Establishing formal recognition practices would signal the importance of consumer expertise and help transform research culture to one that genuinely values lived experience alongside academic knowledge.

## Phase Three: Development of Recognition Framework

This phase consisted of three stages: 1) the development of potential recognition models based on the survey results, 2) conduct of deliberative workshops with member organisations of Research Australia and consumers with chronic conditions, and 3) consultation with the CRWG to finalise the recognition framework.

### Development of Potential Models

Four potential models were developed addressing key aspects of consumer remuneration: rates of financial remuneration, financial remuneration methods, non-financial recognition methods, and a decision-making support tool for remuneration.

Based on the survey results (Appendix F), the majority of engagement activities (85.2%) focused on collaboration, consultation, and participation. Similarly, recommended monetary values for financial compensation in international contexts (Appendix C) also centred on these three levels of engagement. While from the remuneration methods recommended by state-based organisations in Australia, only the Health Consumers' Organisation in Victoria provided specific rates for consumer-led engagement (Appendix D). Consequently, the initial remuneration model, which focused exclusively on financial remuneration, outlined rates and ranges for collaboration, consultation, and participation (Appendix G).

The second model addressed financial payment methods, including reimbursement coverage, and was developed based on survey results and the latest review (Appendix H).[17] The third model focused on non-financial recognition methods - Appendix I outlines 12 non-financial recognition methods identified in the review, as well as those reported by survey participants, highlighting both similarities and differences. The fourth model was a decision support tool for remuneration (Appendix J). This tool, developed by The Change Foundation[24], an independent health policy think tank in Ontario, Canada, aims to facilitate better patient experience and engagement. It was presented in the workshops to elicit stakeholders' perceptions of its potential application within the Australian context.

The above mentioned four potential remuneration models were presented to the CRWG for feedback, and during this online meeting, participants confirmed these

four models and provided suggestions on the recruitment strategy for deliberative workshop participants.

## Conduct of Deliberative Workshops

Six deliberative workshops were conducted: three with individual consumers with chronic conditions and three with not-for-profit consumer representative member organisations of Research Australia. A total of 21 participants were recruited via mailing lists of Research Australia members and through the professional networks of CRWG members. The participants included 9 consumers with chronic conditions and 13 representatives from Research Australia member organisations. The audio recordings from the workshops were transcribed, and framework analysis of data was conducted following Laurie J. Goldsmith's five-step approach[25]. The results are presented according to four potential models developed in the stage 2: 1) Financial payment rates, 2) financial recognition methods and reimbursement coverage, 3) non-financial recognition approaches, and the 4) remuneration decision-making support tool.

### *Financial payment rates*

This component explores financial payment rates across three levels of engagement: consultation, collaboration, and active participation (Appendix G). Three subcomponents emerged: the methods for determining rates, the fiscal amount of rates, and payment implications.

Regarding methods, participants offered varying perspectives on flat rates, meeting rates, and hourly rates. Flat rates were favoured by most participants for their flexibility and practicality, as they allow researchers to choose remuneration methods, such as gift cards, and adjust amounts to fit specific research contexts. Additionally, flat rates were seen as reducing administrative burdens for those managing payments while still acknowledging consumers' contributions. One participant specifically noted that flat rates benefit both researchers—by minimising financial strain on projects—and consumers—by offering a meaningful form of recognition.

In terms of the fiscal amount for rates, three participants provided a specific number based on the model we provided during workshops (Appendix G), while among participants who commented on this issue, most of them agreed that AUD $50 per

hour is a suitable amount for recognising consumers' active participation in research, drawing on their experiences with activities like focus groups or interviews. This figure was based on Australia's minimum wage (AUD $24.80 per hour), with the suggestion to double this rate to more adequately reflect consumers' contributions. For roles involving collaboration (e.g., as a member of a research team), participants recommended AUD $40–50 per hour. Opinions were more varied regarding payment for consultation roles (e.g., advisory board member). One participant advocated for a higher rate (>AUD $50 per hour) for consumers in consultation roles, while another suggested that those in advisory roles should receive lower remuneration rates, given the ongoing nature of their involvement. One participant proposed that consumers in advisory roles be paid similarly to research assistants working on the project.

Payment implications were highlighted by participants from both research organisations and consumers with chronic conditions during the deliberative workshops. One key issue was the tax impact of financial payments. Participants from research organisations expressed a preference for honoraria because it is not considered taxable income. Similarly, consumers noted that financial payments received through engagement activities must be factored into their tax considerations. Another concern raised was the potential impact on pensions. For instance, one consumer participant shared that she might consider withdrawing from certain committees to avoid earning amounts that could affect her eligibility for pension benefits when she qualifies to claim them.

### *Financial recognition methods and reimbursement coverage*

Different perspectives on payment methods for consumer engagement were described, including the provision of gift cards, bank account transfers (honoraria), pre-paid Visa or MasterCard, cash, and employee-style payments. Gift cards were favoured by both consumers and organisation representatives for two main reasons: convenience (ease of use and lower administrative burden) and tax implications (no need to be declared, which avoids complications with social benefits or taxes). Bank account transfers (honoraria), preferred for larger sums or ongoing payments, were seen as the most appropriate option when contextually suitable, as noted by a representative from a not-for-profit organisation. Participants expressed varied opinions about pre-paid Visa or MasterCard. These were preferred over gift cards

due to their broader acceptance but were seen as less convenient for individuals living in rural or regional areas. As a result, participants suggested offering flexible payment methods and providing consumers with a range of options. Regarding cash payments, opinions were mixed. One participant preferred to avoid cash, while another consumer participant and a not-for-profit organisation representative welcomed it. Additionally, one organisation representative proposed treating consumers engaged in research as employees (e.g., research assistants) and compensating them with salaries.

Regarding reimbursement, all participants, including consumers and organisational representatives, agreed that any out-of-pocket expenses should be covered by the research project. One organisational representative stressed the importance of covering IT and phone charges, as consumers are expected to engage in research activities via phone or internet. Another consumer participant suggested that fees for support workers or carers should also be reimbursed if needed for participation.

A key subcomponent that emerged was the need for upfront clarity about reimbursement coverage, which involved two aspects: "pay upfront" and "notify upfront." "Pay upfront" refers to reimbursing consumers for anticipated out-of-pocket expenses, such as taxi or parking fees, before they incur the costs, thus preventing them from having to pay upfront and seek reimbursement later. "Notify upfront" applies to both consumers and researchers. Consumers should inform researchers in advance if they expect reimbursement for unforeseen costs related to their participation, such as support workers or carers. Researchers, in turn, must be transparent about funding availability, acknowledge funding limits, and offer alternatives for engagement.

### *Non-financial recognition approaches*

The discussion on non-financial recognition approaches, drawing on both international contexts and survey results, primarily centred on four aspects: 1) co-authorship and acknowledgement on publications, 2) co-presentations at conferences, 3) opportunities for skills development, and 4) team building. Furthermore, workshop participants proposed three additional suggestions: 5) referrals to relevant projects, 6) consumer mentorship, and 7) public recognition.

Most participants valued having their names included in publications, either as co-authors or through acknowledgements, as it provided a tangible recognition of their contributions. Co-presentation at conferences was similarly appreciated, as it strengthened the partnership between consumers and researchers. While participants acknowledged the value of skills development opportunities, such as training, many had not previously considered their significance. One consumer participant emphasised the importance of team building, highlighting the sense of belonging it fosters, as consumers involved as research collaborators see themselves as integral members of the research team.

Beyond these primary recognition methods, three further suggestions were offered. One consumer participant advocated for being referred to other relevant projects through academic networks, noting that this could help consumers with chronic conditions access additional job opportunities despite their reduced working capacity. Consumer mentorship was suggested by an organisational representative, who argued that having an experienced mentor could help new consumers engage more effectively in research projects. Public recognition, such as listing engaged consumers on project websites, was also highlighted as an effective method, with younger consumers using it as a tool for job applications.

### *Remuneration decision-making support tool*

Participants from research organisations and consumers with chronic conditions expressed contrasting views about the proposed decision-support tool for remuneration. Representatives from organisations generally viewed the tool positively, recognising its potential to encourage researchers to thoughtfully plan engagement strategies and optimise the integration of consumer contributions within a research framework. As one organisational representative noted, the tool could guide researchers in considering "how you might plan your engagement activity." In contrast, many consumers expressed scepticism towards the tool, describing it as subjective and inefficient. For these participants, the need for such a tool was deemed unnecessary, given their conviction that consumers should be remunerated for their contributions as a matter of principle. As one consumer explained, *"It might be more an organisational point of thing. From our point of view, we should be reimbursed or remunerated for our involvement."* Further suggestions emerged from organisational representatives, including incorporating additional criteria, such as

*"the relevance of the consumers or the skills that the individual or organisation brings to the research,"* to ensure that researchers engage the most suitable consumers for each project. After considerable deliberation in each workshop, it was agreed that the decision-making support tool was not relevant for use in the Australian context, where recognition and remuneration of consumer involvement in research is an accepted practice and not something to be determined on a case-by-case basis.

Therefore, the decision-making support tool developed by The Change Foundation was excluded from the final framework. Instead, we developed four key questions to guide remuneration decision-making:

> *(1) What forms of recognition will be offered to consumers participating in this project?*
>
> *(2) What expenses are eligible for reimbursement under this project?*
>
> *(3) Which forms of recognition do engaged consumers prefer?*
>
> *(4) What potential financial implications should consumers consider when opting for financial recognition?*

These questions provide a more flexible framework that acknowledges the fundamental importance of remuneration while allowing for contextual considerations.

## Consultation with the CRWG

The final stage of developing the framework involved summarising the findings from deliberative workshops, integrating them with the survey results and using the integrated findings to inform the development of two recognition frameworks: one for funded research organisations and another for those without funding. We then met with the CRWG to finalise the recognition frameworks.

The CRWG endorsed the core elements of the framework as essential for recognising consumers' contributions and suggested refinements. Key suggestions included integrating the two models into one single framework, ensuring non-financial recognition for all consumers even when financial remuneration is possible, and emphasising that non-financial recognition cannot replace financial remuneration. Consequently, the final remuneration framework prioritises flexibility by offering three payment options (project rate, meeting rate, and hourly rate) rather than prescribing a single approach. This flexibility extends to payment methods, allowing organisations to choose from options such as gift cards, bank transfers, or pre-paid cards based on consumers' preferences and circumstances. The framework also emphasises inclusivity and addresses equity issues by promoting consistent remuneration practices across Australia, regardless of project type or geographic location. This approach aims to encourage participation from consumers with diverse socio-economic backgrounds, as they can anticipate fair remuneration for their valuable contributions, thus reducing financial barriers to engagement that disproportionately affect underrepresented groups.

Incorporating this feedback, the finalised framework (Figure 2) provides practical guidance to support financial and non-financial recognition of consumers' contribution to health research based on funding availability and consumer preferences. The process begins with decision-making considerations, where researchers evaluate available recognition options, including availability of funding for remuneration and reimbursement, implications of receiving payments for individual consumers, and discussions with consumers to identify their preferred methods of payment. The framework establishes that non-financial recognition involves tailoring approaches to consumers' needs, while financial recognition requires discussions about payment methods and rates, ensuring all contributions are appropriately acknowledged regardless of circumstances.

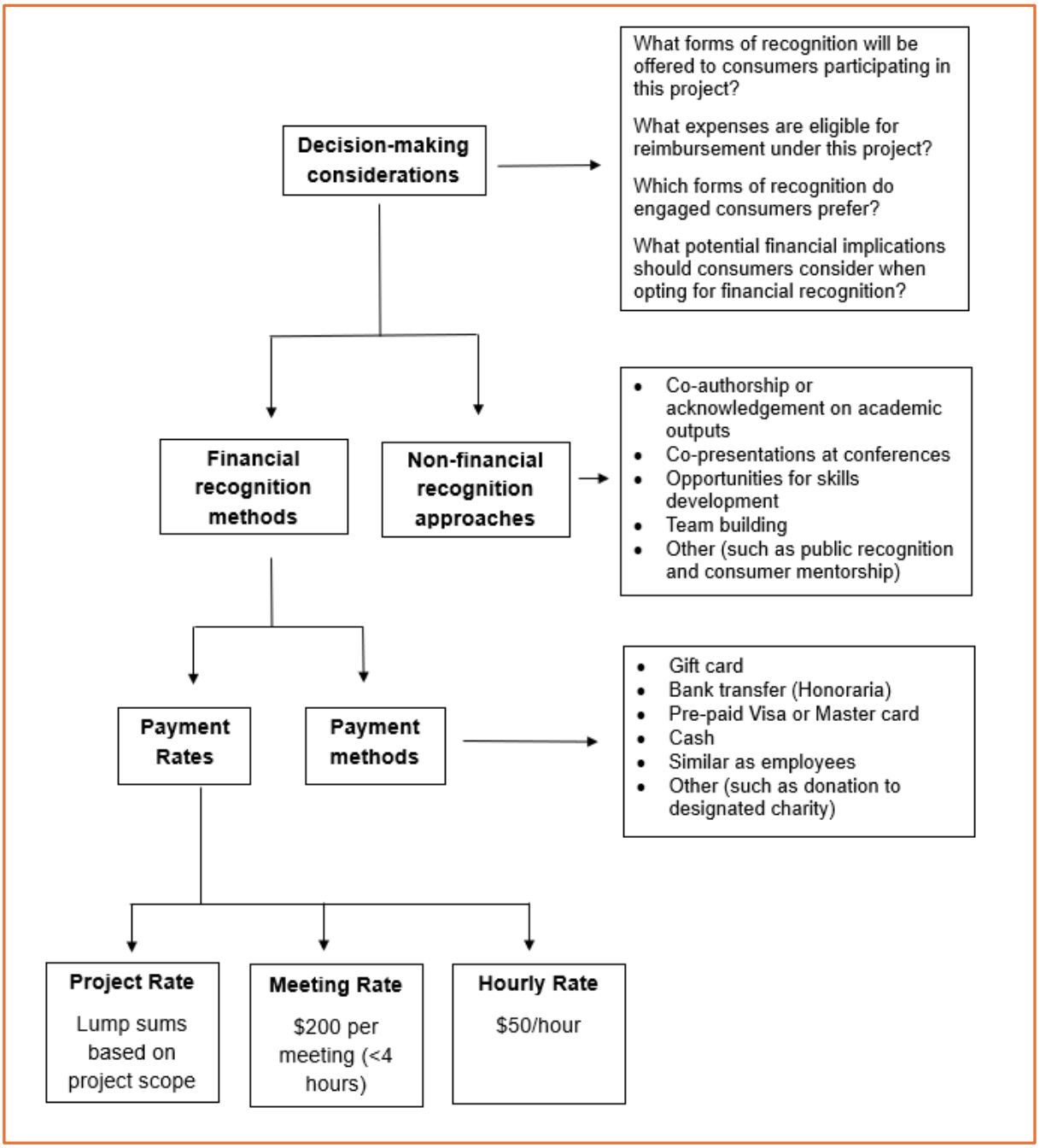



Figure 2 Recognition framework for acknowledging consumers' contribution to health research

# Conclusion

This study marks a major step forward in recognising the contributions of consumers to Australian health research. For the first time, a national, evidence-based framework has been developed to guide how consumer engagement is acknowledged and compensated.

Drawing on a review of the literature, stakeholder surveys, and deliberative workshops, the project found strong support for consumer engagement, but also inconsistencies in how contributions are recognised. While the majority of surveyed organisational representatives value consumer input, just over half offer financial remuneration, with wide variation in practice.

The developed framework provides practical and flexible tools to support fair and consistent recognition. It includes options for payment (such as gift cards or hourly rates), recommended rate structures, non-financial recognition (such as co-authorship or conference participation), and administrative guidance. Consumers with chronic conditions and representatives from researcher organisations co-designed the framework, ensuring it reflects diverse needs and preferences.

The framework is ready for implementation and offers a clear path for improving practice while supporting longer-term cultural change. Further research is recommended to explore how the framework is used in practice, its impact on consumer experiences, and how its influences on research quality.

By adopting this framework, the Australian health research community can take meaningful steps towards more ethical, inclusive, and impactful research. With continued collaboration, Australia can lead the way in recognising the vital contributions of consumers to better health outcomes

## Appendix A: CRWG Terms of Reference

# Consumer Remuneration Working Group

### Terms of Reference

## Why we have convened this Working Group

The NHMRC describes the three aspects of consumer remuneration as removing barriers to involvement based on financial constraints through reimbursement; utilising payment to show respect and value for consumer engagement, and ensuring payment does not lead to unreasonable risks for those involved in research. The aim of this working group is to find ways to best remunerate health care consumers in a variety of circumstances through collecting views from multiple organisations and backgrounds. The findings of this working group will be used to develop a Research Australia guide to consumer remuneration, which will give due consideration to the differing circumstances (financial or otherwise) of different members of the research community.

## The role of this Working Group

This Working Group will advise the health and medical research sector on developing consumer remuneration approaches.

The Working Group will:

- Identify best practice methods of financially remunerating consumers involved in research;
- Discuss different socioeconomic groups and financial circumstances within subject populations to identify potential variations in payment methods;
- Consider specific factors for individual consumers that pose challenges and considerations to the remuneration process. E.g. social welfare and pension eligibility requirements

## Membership

Research Australia's Consumer Remuneration Working Group is open to Research Australia members and will comprise individuals from the following organisations to ensure consideration of a wide variety of perspectives.

- National Centre for Epidemiology and Population Health, ANU
- Bellberry Limited
- Sydney Health Partners
- Mito Foundation
- Cerebral Palsy Alliance
- Murdoch Children's Research Institute
- The Kids Institute of Australia
- National Ageing Research Institute
- Curtin Involve
- Sydney Local Health District

## Meeting Schedule

This Working Group will meet four times over a period of twelve months with the first meeting to take place on Thursday 27 July 2023 via Zoom.

## Authority

The Consumer Remuneration Working Group has no formal authority to act for or on behalf of Research Australia and is not a formal Committee of Research Australia under Research Australia's Constitution.

## Appendix B:

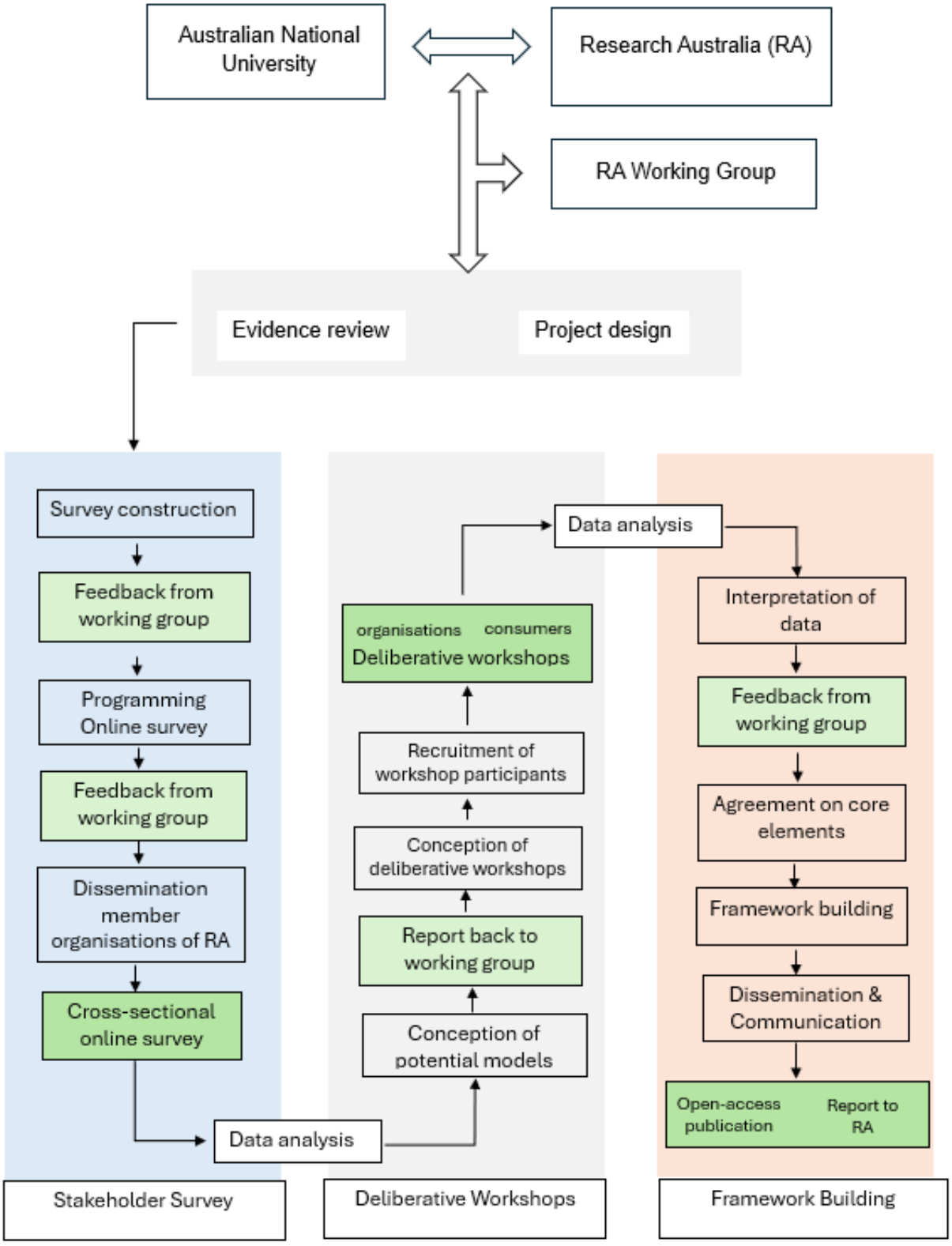



**Figure 1** Project framework with indication of consumer engagement

## Appendix C: Financial remuneration recommendations from the peer-reviewed literature

**Synthesis of financial compensation recommendations (i.e., monetary value) across guidance and policy documents*.**

| | Collaboration | Consultation | Other patient engagement in research activities |
|---|---|---|---|
| Description | Activities include willing and able to participate in meetings by phone or in person, providing feedback on research outputs or manuscripts. | Activities include being a member of a governing or steering committee and leading work such as teaching or knowledge dissemination. | Specified in rates. |
| Recommended monetary value of financial compensation | $19/hour (USD) with a range of $12-50 (USD) or $ 380-609/ year (USD) depending on the number of activities. | $38/hour (USD) with a range of $25-50/hour or $761-1141/year (USD). | $57 (<50 pages) ~ $346 (401+) (USD) for reviewing documents<br>$76 USD preparing and delivering a formal presentation<br>$ 114 ~ 173 USD active participation in an external event or attending training<br>$86 ~ 91 USD as a patient partner interviewer<br>$152 USD per conference attended |
| Recommended monetary value transferred to AUD# | $29 AUD/hour<br>Range: $18 ~ 75 AUD/hour<br><br>$571 ~ 915 AUD/year | $57 AUD/hour<br>Range: $38~ 75 AUD/hour<br><br>$1144 ~ 1715 AUD/year | $86 ~ 520 AUD for document reviewer<br>$114 AUD preparing and delivering a formal presentation<br>$171 ~ 260 AUD active participation in an external event or attending training<br>$129 ~ 137 AUD as a patient partner interviewer<br>$228 AUD per conference attended |

* Adapted from Fox, Grace, et al. "What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines." *Health Expectations* 27.1 (2024): e13970.

# The transferred currency rate was 1USD = 1.503 AUD (June 1, 2024).

## Appendix D: Remuneration rates recommended by state-based consumer organisations in Australia

**Remuneration rates recommended by state-based consumer organisations in Australia***

| | Organization | Release date | Remuneration methods | |
|---|---|---|---|---|
| NSW | Health Consumers NSW | Oct 2022 | Hourly rate based on level of engagement | Empower/lead the research, Collaborate/Partner –Strategic Leadership role: $60 per hour; Collaborate/Partner/Advise: $50 per hour; Consult: $40 per hour; Inform: no payment. |
| QLD | Health Consumers Queensland | July 2024 review | Flat rate based on level of engagement | Consumer representatives engaged for ongoing, regular, high-level committees: $234 per meeting 4 hours and under, $469 per meeting over 4 hours. (These two rates incorporate pre-reading and travel time); Consumers engaged in operational level committees and meetings or less formal ways: $50 per hour. |
| ACT | Health Care Consumers Association | July 2024 review | Flat rate | Follows ACT guidelines Health: A meeting of two hours and fifteen minutes duration $75.00 for the initial two hours + $18.75 for the fifteen minutes (provided in 30-minute increments) = $93.75 is how much reimbursement the representative will receive. |
| WA | WA Health Consumers' council | Jan 2024 | Hourly rate | Representatives are eligible for remuneration in the form of a sitting fee per hour for the following activities: committee membership (executive, boards, steering, advisory, reference groups); working parties; forums, focus groups and workshops; selection, evaluation, and recruitment panels. The remuneration is $37.50 per hour or part thereof (2 hour minimum). |
| VIC | Health Consumers Centre | March 2023 | Both flat rate and hourly rate based on level of engagement | Not found. VCCC alliance: Sitting fee for consumer-led/partnership level of engagement: Committee Chair: $238 (≥ 4h); $119 (< 4h); Committee Member: $206 (≥4 h); $103 (< 4h). Sitting fee for Involving: $50/h; Sitting fee for Consulting: $40/h. |
| TAS | Health Consumers Tasmanian | Sep 2022 | Flat rate | Not found. TAS Health Senate: Consumer, Carer, Peak Health Organisations and Community Representatives: $100 per meeting up to 3 hours; $175 per meeting 3-5 hours; $250 per meeting >5 hours. |
| SA | Health Consumer CoLab | June 2021 | Hourly rate | Consumer Sitting Fees and Reimbursement: A sitting fee should be paid at an hourly or set time duration rate that is in proportion to their level of skills, knowledge and contribution as an equal and expert partner in decision-making with the other experts in their field. Recommended rate: $45/h. |
| NT | No Health Consumers organisation | | | |

*Retrieve date: August 2, 2024

## Appendix E: Survey of Australian research organisations

**Survey in Qualtrics**

**Block 1 cover**

You have been invited to participate in this survey as your organisation is a member of Research Australia.
This brief survey is about your experiences and approaches to recognising consumers for their contributions to research, including financial remuneration, within your work at this organisation.
The ethical aspects of this research have been approved by the ANU Human Research Ethics Committee (Protocol 2023/1263)).
Please read the Participant Information Sheet. You may like to download and save a copy for your records.
Completion of this survey indicates that you have read and understood the participant information sheet provided, and consent to participate in this study.

| Topic | Questions |
|---|---|
| **Block 2 basics**<br><br>1. About your organisation | 1. What type of organisation do you work for (please select one):<br>a) University<br>b) Medical Research Institute<br>c) Pharmaceutical company<br>d) Medical technology company<br>e) Research organisation<br>f) Health care provider<br>g) Non-government organisation<br>j) None of the above (go to Q2)<br><br>2. Please describe the type of your organisation: _____<br><br>3. Is your organisation (please select one):<br>a) For-profit<br>b) Not for profit<br><br>4. How many employees are in your organisation?<br>a) < 10 employees<br>b) 11 – 20 employees<br>c) 21 – 50 employees<br>d) >50 employees |
| **Block 3 recognition**<br><br>2. Recognition of consumer # | 5. Does your organisation support health care consumers to contribute to research?<br>a) Yes (go to Q6)<br>b) No (skip to the end of survey)<br>c) Unsure (go to Q6) |

engagement *, involvement**, participation***

6. How does your organisation recognise these contributions from health care consumers? (select all that apply)

a) Financial remuneration (go to Q7, and then Q40)
b) Non-financial remuneration (go to Q9)
c) None (skip to Q50)

7. How does your organisation recognise these contributions? (Select all that apply)

a) Direct payment - into a bank account (go to Q40)
b) Direct payment – cash (go to Q40)
c) Payment via a gift card (e.g., Coles, Woolworths)
d) Payment via prepaid Visa or Mastercard
e) Other (go to Q8)

8. Please describe the other type of financial remuneration in your organisation not listed:

_____

9. How does your organisation recognise these contributions non-financially? (select all that apply)

a) Provision of training or opportunities for skills development
b) Academic recognition, such as co-authorship or acknowledgment on publications
c) Co-presentations at conferences
d) Team building activities, such as social gatherings
e) Other (go to Q10)

10. Please describe the other type of non-financial remuneration in your organisation not listed:_____

11. Who does your organisation remunerate? (Select all that apply)

a) Consumers involved in advisory groups or steering committees (go to Q15)
b) Consumers involved in research teams i.e., Lived experienced researchers (go to Q20)
c) Consumers participating in treatment related studies e.g., clinical trials. (go to Q25)
d) Consumers participating in non-treatment related research e.g., interviews, focus groups. (go to Q25)
e) Involvement coordinators who facilitate access to consumers (e.g., members of disease advocacy organisations) (go to Q30)
f) Consumer-led non-government organisations advocating on behalf of consumers (go to Q 35)
g) Other (go to Q12)

12. Please describe who else your organisation provides remuneration to apart from those listed:_____
(If the text response is not empty, then will go to Q13)

13. How does your organisation remunerate this group (e.g. hourly rate, per meeting, ongoing retainer, unsure)? _____
(If the text response is not empty, then will go to Q14)

14. How much does your organisation pay for this type of remuneration?

---

15. How does your organisation remunerate/reimburse consumers for being a member of advisory groups or steering committee?

a) Amount per hourly rate for involvement (go to Q17)
b) Amount per meeting/activity (go to Q18)
c) Ongoing retainer (go to Q19)
d) No payment
e) Other (go to Q16)

16. Please describe the other type of remuneration for being a member of advisory groups or steering committee in your organisation not listed:

---

17. How much do you pay consumers per hourly rate for involvement?

---

18. How much do you pay consumers per meeting/activity for involvement?

---

19. How much do you pay consumers as an ongoing retainer for involvement?

---

20. How does your organisation remunerate/reimburse consumers for being a member of a research team?

a) An hourly rate for involvement (go to Q22)
b) Amount per meeting/activity (go to Q23)
c) Ongoing retainer (go to Q24)
d) No payment
e) Other (go to Q21)
f) Unsure

21. Please describe the other type of remuneration for being a member of research team in your organisation not listed:

---

22. How much do you pay consumers for being a member of a research team per hour?

---

23. How much do you pay consumers for being a member of a research team per meeting/activity?

---

24. How much do you pay consumers as an ongoing retainer?

---

25. How does your organisation remunerate/reimburse consumers for being a participant of research, such as clinical trials, interview/focus group?

a) An hourly rate for involvement (go to Q 27)
b) Amount per meeting/activity (go to Q 28)
c) Ongoing retainer (go to Q29)
d) No payment
e) Other (go to Q26)
f) Unsure

26. Please describe other type of remuneration for being a participant of a research in your organisation not listed:

_____

27. How much do you pay consumers for being a participant of research per hour?

_____

28. How much do you pay consumers for being a participant of research per meeting/activity?

---

29. How much do you pay consumers for being a participant of research as ongoing retainer?

_____

30. How does your organisation remunerate/reimburse consumers for being a coordinator who facilitates access to consumers (e.g., members of disease advocacy organisations)?

a) An hourly rate for involvement (go to Q32)
b) Amount per meeting/activity (go to Q33)
c) Ongoing retainer (go to Q34)
d) Other (go to Q31)
e) Unsure

31. Please describe the other type of remuneration for being a coordinator in your organisation not listed:

_____

32. How much do you pay consumers for being a coordinator per meeting/activity?

_____

33. How much do you pay consumers for being a coordinator per meeting/activity?

_____

34. How much do you pay consumers for being a coordinator as an ongoing retainer?

_____

35. How does your organisation remunerate/reimburse consumers for being a representative for consumer-led non-government organisations on behalf of consumers?

a) An hourly rate for involvement (go to Q37)
b) Amount per meeting/activity (go to Q38)
c) Ongoing retainer (go to Q39)
d) No payment
e) Other (go to Q36)
f) Unsure

36. Please describe the other type of remuneration not listed that you pay consumers for being a representative for consumer-led non-government organisations:

_____

37. How much do you pay consumers for being a representative for consumer-led non-government organisations per hour?

_____

38. How much do you pay consumers for being a representative for consumer-led non-government organisations per meeting/activity?

_____

39. How much do you pay consumers for being a representative for consumer-led non-government organisations as an ongoing retainer?

_____

3. Remuneration for additional costs of engagement

40. Does your organisation remunerate or reimburse consumers for the following additional costs they may incur in order to be involved in research? (Select all that apply)

a) Transport (taxi, bus) (go to Q42, then go to Q49)
b) Parking fees (go to Q44, then go to Q49)
c) Time for pre-reading (go to Q46, then go to Q49)

d) Something else not listed above (go to Q41)
e) No, we do not remunerate for additional costs such as the above.
f) Unsure

41. Please describe the additional costs not listed that your organisation remunerates consumers for:

_____

4. Mode of payment for additional costs of engagement

42. How does your organisation remunerate or reimburse consumers for taxi fares?

a) Provide taxi voucher up-front
b) Reimburse taxi fare
c) Unsure
d) Other (go to Q43)

43. Please describe other ways not listed in previous options that your organisation remunerates or reimburse consumers for text fares:

---

44. How does your organisation remunerate or reimburse consumers for parking?

a) Provide parking permit
b) Pay for parking upfront
c) Reimburse for parking fees paid
d) Unsure
e) Other (go to Q45)

45. Please describe other ways not listed in previous options that your organisation remunerates or reimburse consumers for parking:

_____

46. How does your organisation remunerate or reimburse consumers for pre-reading?

a) Incorporate into hourly rate for involvement
b) Set rate (go to Q47)
c) No payment
d) Other (go to Q48)
e) Unsure

47. Please describe the set rate when your organisation remunerates or reimburse consumers for pre-reading:

_____

48. Please describe other ways not listed when your organisation remunerates or reimburse consumers for pre-reading:

_____

49. Please describe if there is something else not listed when your organisation remunerates or reimburse consumers for taxi fares, parking and pre-reading?

_____

Block 4 process 5. Process of remuneration and potential burden

50. Does your organisation have a formal process for onboarding consumers into research projects? For example, induction, training, or other support. Please describe:

a) Yes (go to Q51, then go to Q52)
b) No (go to Q63)
c) Unsure (go to Q63)

51. What is the formal process for onboarding consumers into research projects in your organisation? For example, induction, training, or other support.

_____

52. If the remuneration rates of your organisation are publicly available, please insert the link here:

_____

53. Does your organisation provide information to consumers of potential impacts of paid remuneration for involvement in research on their personal situation (such as impact on social security payments)?

a) Yes b) No c) Unsure

54. Does your organisation allow consumers to choose not to accept financial remuneration or to donate these funds to a charity of their choice?

a) Yes b) No c) Unsure

55. Does your organisation have documentary requirements related to remuneration, such as the requirement for consumers to complete specific forms?

a) Yes (go to Q56)
b) No (go to Q63)
c) Unsure (go to Q63)

56. How many forms in the first instance:

a) 1-2; b) 3-4; c) >5; d) Unsure

57. How many forms for each occasion of engagement:

a) 1-2; b) 3-4; c) >5; d) Unsure

58. Who is responsible for managing the process of onboarding and remuneration of consumers? _____

59. How many hours does it take your organisation to onboard a health care consumer? (Excluding training for consumers)
a) <1; b) 1-2; c) 3-5; d) 6-8; e) >8; f) Unsure

60. How many hours does it take to organise remuneration for five consumers who are already registered in your system, following for example a focus group or series of interviews?
a) <1; b) 1-2; c) 3-5; d) 6-8; e) >8; f) Unsure

6. Consumer engagement remuneration guidelines/ advice

61. Do you follow any specific guidelines or advice for remuneration?
a) Yes (go to Q62)
b) No
c) Unsure

62. Please describe the specific guidelines or advice for remuneration your organisation follows:
_____

Block 5 future

7. Future suggestions

63. What would make it easier to remunerate consumers who engage in research in your organisation?
_____

64. Does your organisation think it would be helpful to have national guidelines or recommendations for remuneration of consumers engaging in research?

a) Yes (go to Q65)
b) No (go to Q66)

65. Please explain your reason for choosing Yes
_____

66. Please explain your reason for choosing No
_____

67. To help us reach a broad range of people, please suggest any workplaces, organisations, research or consumer groups or networks you think we should contact to be a part of our research about consumer engagement:

_____

Thank you for taking the time to complete this survey. We truly value the information you have provided. Your responses will contribute to our analyses of consumer remuneration in health research and may provide new clues for recognition of consumer engagement.

## Appendix F: Types of engagement referred to in the survey

### Types of engagement referred to in the survey

| Level of engagement | Survey results | | |
|---|---|---|---|
| | N | % | Description |
| Consumer-leading | 20 | 6.7 | Consumer-led advocate |
| Collaboration | 72 | 24.4 | Team members |
| Active participation (Cooperation) | 109 | 36.4 | Participants, Other (document review, presentation delivery) |
| Consultation | 73 | 24.4 | Advisory group or steering committee, Involvement coordinators |
| Informing* | | | |

*The "Informing" level refers to consumers who receive communications (e.g. newsletters) or attend public events (e.g. symposia) but do not contribute directly to research activities. As this form of engagement does not involve active input or collaboration, it is not typically eligible for remuneration or formal recognition.

## Appendix G: Recognition model 1 focusing on financial remuneration rates

### Recognition model 1 focusing on financial remuneration rates

| | | Consultation | Collaboration | Active Participation (Cooperation) |
|---|---|---|---|---|
| Rates from the published review (Fox, 2024) | Rate<br>Range | $29 AUD/hour<br>Range: $18 ~ 75 AUD/hour<br><br>$571 ~ 915 AUD/year | $57 AUD/hour<br>Range: $38~ 75 AUD/hour<br><br>$1144 ~ 1715 AUD/year | $86 ~ 520 AUD for document reviewer<br>$114 AUD preparing and delivering a formal presentation<br>$171~ 260 AUD active participation in an external event or attending training<br>$129 ~ 137 AUD as a patient partner interviewer<br>$228 AUD per conference attended |
| Rates from survey results | Min-Max | $35~ 100 AUD/hour<br>$50 ~ 400 AUD/meeting | $20 ~ 100 AUD/hour<br>$80 ~ 750 AUD/meeting | $23 ~ 50 AUD/hour<br>$5 ~ 100 AUD/meeting |
| | Interquartile range (25-75%) | $35 ~ 50 AUD/hour<br>$100 ~ 200 AUD/meeting | $30 ~ 50 AUD/hour<br>$200 ~ 300 AUD/meeting | $23 ~ 50 AUD/hour<br>$20 ~ 50 AUD/meeting |

Fox, Grace, et al. "What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines." *Health Expectations* 27.1 (2024): e13970.

## Appendix H: Recognition model 2 focusing on financial remuneration payment methods and reimbursement coverage

**Recognition model 2 focusing on financial remuneration payment methods and reimbursement coverage**

| | Payment methods | | | Reimbursement coverage | | |
|---|---|---|---|---|---|---|
| | | n* | % | | n | % |
| Methods from the published review (Fox, 2024) | Honoraria | 43 | 69 | Conference attendance | 25 | 43 |
| | Gift card | 11 | 18 | Babysitting/caregiver services | 21 | 36 |
| | Salary | 9 | 15 | Accommodations | 9 | 16 |
| | Stipend | 4 | 6 | | | |
| | | N# | % | | N | % |
| Methods from survey results | Cash | 11 | 6.2 | Transport (taxi, bus) | 49 | 33.6 |
| | Bank account transfer | 54 | 30.3 | Parking fees | 46 | 31.5 |
| | Gift card | 71 | 39.9 | Time for pre-reading | 39 | 26.7 |
| | Pre-paid Visa or Master card | 32 | 18 | Something not listed above | 12 | 8.2 |
| | Similar as employees | 10 | 5.6 | | | |

n* referred to the number of guidance and policy documents identified in the review.

N# referred to the number of participants responded to the survey.

Fox, Grace, et al. "What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines." *Health Expectations* 27.1 (2024): e13970.

# Appendix I: Recognition model 3 focusing on non-financial recognition methods

## Recognition model 3 focusing on non-financial recognition methods

| Methods from the latest review (Fox, 2024) | | | Methods from survey results | | |
|---|---|---|---|---|---|
| | n* | % | | N# | % |
| Services or training opportunities | 26 | 40 | Provision of training or opportunities for skills development | 37 | 22.7 |
| Acknowledgement on research outputs | 10 | 15 | Academic recognition, such as co-authorship or acknowledgment on publications | 46 | 28.2 |
| Conference presentation opportunity | 25 | 38 | Co-presentations at conferences | 33 | 20.2 |
| Invitation to a special event | 3 | 4 | Team building activities, such as social gatherings | 36 | 22.1 |
| Co-authorship | 6 | 9 | Other not listed above## | 11 | 6.7 |
| Provision of meals | 11 | 17 | | | |
| Verbal thanks | 9 | 14 | | | |
| In-kind donation | 9 | 14 | | | |
| Gift | 10 | 15 | | | |
| Gift cards[a] | 9 | 14 | | | |
| Honorary appointment | 3 | 4 | | | |
| Co-investigator/co-applicant on grant | 1 | 1 | | | |

n* referred to the number of guidance and policy documents identified in the review.

N# referred to the number of participants responded to the survey.

## Free-text responses for this choice ‘other not listed about’ included: contributions for community, mentorship or consultation, peer-support, results sharing, student credits and gifts.

[a] Gift card offered as a token of appreciation, which is different from the gift cards (for grocery stores, restaurants, retail stores, prepaid visa gift cards etc.) that are considered financial compensation when the value is informed by a formal conversion or consumer partners decide that they want to receive payment in the form of gifts or gift cards.

Fox, Grace, et al. "What guidance exists to support patient partner compensation practices? A scoping review of available policies and guidelines." *Health Expectations* 27.1 (2024): e13970.

## Appendix J: Recognition model 4 focusing on the decision tool* to support remuneration decision-making

### Recognition model 4 focusing on the decision tool* to support remuneration decision-making

| CONTRIBUTING FACTORS | Scale | Score |
|---|---|---|
| **TIME** | | |
| This looks at how much time participants will be asked to contribute (in duration and intensity both). NOTE: If you receive the "Automatic YES," that means payment is required and you need not complete the tool. | | |
| UNDER 8 hours / month | | |
| 8 – 16 hours / month for less than 3 months | 1 POINT | |
| 8 – 16 hours / month for more than 3 months | 2 POINTS | |
| 17 – 40 hours /month for less more than 3 months | 4 POINTS | |
| 17 – 40 hours /month for more than 3 months | 5 POINTS | |
| OVER 40 hours / month | YES | |
| **EQUITY** | | |
| The question here is whether participants will work alongside people (e.g., healthcare workers, academics, policy makers) whose employers are paying them to be there. For scoring purposes, this does not include staff of The Change Foundation, who are assumed to be present at all or most engagement events. | | |
| No paid individuals at the table | 0 | |
| Paid individuals at the table | 5 POINTS | |
| **VULNERABLE-POPULATION STATUS** | | |
| This scores the degree to which participants will be sought from "vulnerable groups," e.g., those who have chronic physical conditions, mental health problems or addictions; are recent immigrants or belong to racial or ethnic minorities; are Aboriginal; have low socio-economic status; or are homeless. | | |
| Not looking to engage vulnerable populations. | 0 | |
| Expect to engage some people from vulnerable populations | 3 POINTS | |
| Will mainly or exclusively engaging people from vulnerable populations | 5 POINTS | |
| **CHALLENGES** | | |
| This scores the likelihood of challenges for participants (e.g., risk of embarrassment, psychological discomfort) OR for the Foundation (e.g., hard cultural- or geographic-representation criteria to meet, history of similar failed projects, or timeline that may dissuade participants). The emphasis here is pragmatic: using payment to help attract and retain people when it may otherwise be hard to do so. However: NOTE that, regardless of payment, project design should aim to minimise any discomfort for participants. | | |
| 0 – 1 challenge foreseen / and/or challenges should be easily dealt with | 0 | |
| A few challenges identified (2 – 3 challenges) | 3 POINTS | |
| Several challenges present (4+ challenges) | 5 POINTS | |
| **ACCOUNTABILITY** | | |
| This is pragmatic again: the less "personal" the medium, the more likely that payment is advisable to strengthen participants' commitment/accountability. This also considers the challenge of maintaining commitment/accountability in projects that exceed certain timeframes. | | |
| Less than 12 Month commitment – any engagement methods | 0 | |
| 12 – 24 Month commitment - some or all in-person engagements | 1 POINTS | |

| | |
|---|---|
| 12 – 24 Month commitment – virtual/remote engagements only (online, phone, etc.) | 2 POINTS |
| More than 24-month commitment - some or all in-person engagements | 4 POINTS |
| More than 24-month commitment – virtual/remote engagements only | 5 POINTS |

| **MITIGATING FACTORS** | **Scale** | **Score** |
|---|---|---|
| **POSITIVE IMPACT** | | |
| The more positive impact, the less likelihood of need for financial compensation. This can mean impact on the participant's life (e.g., community-building, travel or learning opportunities) and/or on the healthcare system (bringing prestige or satisfaction for participants). | | |
| Low or negligible positive impact expected (personal or system) | 0 | |
| Medium positive impact (personal or system) | - 3 POINTS | |
| High positive impact (personal or system) | - 5 POINTS | |
| **ACCESS** | | |
| If the engagement gives participants access to specific treatments, healthcare providers' opinions, etc., this can also mitigate against payment. | | |
| No – no access to treatments or opinions anticipated | 0 | |
| Yes – access to treatments or opinions is anticipated | - 5 POINTS | |
| **OTHER FORMS OF RECOGNITION** | | |
| This can mean any combination of low-recognition options (thank-you cards, meals, etc.), medium recognition options (plaques, "souvenir" clothing, etc.) or high-recognition options (trips, scholarships, etc.). | | |
| No – no other forms of recognition are planned | 0 | |
| Yes – other forms of recognition are planned | - 5 POINTS | |

***** Copied from Change Foundation. "Should Money Come Into It? A Tool for Deciding Whether to Pay Patient-Engagement Participants." (2015).

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