Commission on Excellence and Innovation in Health.

Generic PROM Selection
Final Report

LET'S PUT IMAGINATION TO WORK

FEBRUARY 2024

Government of South Australia

Acknowledgements

The South Australian Patient Reported Measures Program would like to acknowledge and recognise the guidance and hard work of the Generic PROM Subcommittee in producing this report.

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Terms

Term	Description
ACSQHC	Australian Commission on Safety and Quality in Health Care
AM-PAC	Activity Measure Post-Acute Care
AQoL	Assessment of Quality of Life
BPI	Brief Pain Inventory
BSI	Brief Symptom Inventory
EQ-5D-5L	European Quality of Life 5 Dimensions 5 Level
FACIT	Functional Assessment of Chronic Illness Therapy Measurement System
GCOS	Genetic Counselling Outcomes Scale
HADS	Hospital Anxiety and Depression Scale
HUI	Health Utilities Index
LHN	Local Health Network
MPQ	McGill Pain Questionnaire
NHP	Nottingham Health Profile
PROM	Patient Reported Outcome Measure
PROMIS	Patient Reported Outcome Measurement Information System
QWB-SA	Quality of Well-Being scale Self-Administered
RAND-36	RAND-36 health-related quality of life survey instrument
SCL-90	Symptom Checklist-90
SDS	Sheehan Disability Scale
SF-12; SF-36	Short Form-12
SF-36	Short Form-36
VR-12	Veteran's RAND-12
WHODAS 2.0	World Health Organisation Disability Assessment Schedule 2.0
WHOQOL	World Health Organisation Quality of Life
WHYMPI	West Haven-Yale Multidimensional Pain Inventory
WPAI	Work Productivity and Activity Impairment Questionnaire

Executive Summary

The PRM Program Board endorsed the formation of a Generic PROM Subcommittee in 2022 to provide a recommendation to the Board of a generic PROM for adoption and use in South Australia's public health system (SA Health). The Subcommittee was convened in March 2023.

The Generic PROM Subcommittee agreed to selection methodology following a brief literature review. Selection processes included, but were not limited to, shortlisting of generic PROM tools and consumer and clinician involvement.

The following generic PROM tools were shortlisted:

- EQ-5D-5L
- PROMIS-29.

Consumers were engaged through liaison with the Local Health Network (LHN) Consumer Engagement/Experience Leads. Consumers were asked to complete the EQ-5D-5L, PROMIS-29 and a post-PROM evaluation survey within ZEDOC (the digital solution procured for implementation of the PRM Program in SA) with invitations sent either via email or SMS.

52 consumers across all LHNs participated. 73% preferred the PROMIS-29 to the EQ-5D-5L. Overall, the strong consumer preference across all demographics was for the PROMIS-29. PROMIS-29 was preferred by consumers as it was more comprehensive, detailed and specific. This was despite the PROMIS-29 being a longer tool than the EQ-5D-5L.

The primary objective of clinician engagement was to inform clinicians of the preferred generic PROM as selected by consumers and provide information on how the generic PROM could be incorporated into clinical practice.

Clinician engagement was endorsed by the Generic PROM Subcommittee and encompassed two methods: written communications and virtual consultation sessions.

Feedback received from clinical staff indicated they are supportive of the recommendation for the PROMIS-29 to be the generic PROM for South Australia.

Following a shortlisting process, consumer preferencing and clinician feedback, the PROMIS-29 has emerged as the most appropriate generic PROM for use by South Australian clinical services.

Recommendations

Based on the assessment and consultation that has occurred, the Generic PROM Subcommittee recommends:

1. Endorsement of the PROMIS-29 as the preferred generic PROM tool for consumers aged 18+ years within South Australian clinical services
2. Implementation of the PROMIS-29 within appropriate clinical services utilising ZEDOC
3. Further refinement of preferred condition/demographic-specific PROMs for South Australia occurs.

Introduction

Globally, health systems are increasing their use of PROMs as part of routine patient care. PROMs are measures completed by consumers to measure their health and wellbeing.[1,2]

PROMs can be used throughout the health system at three levels:

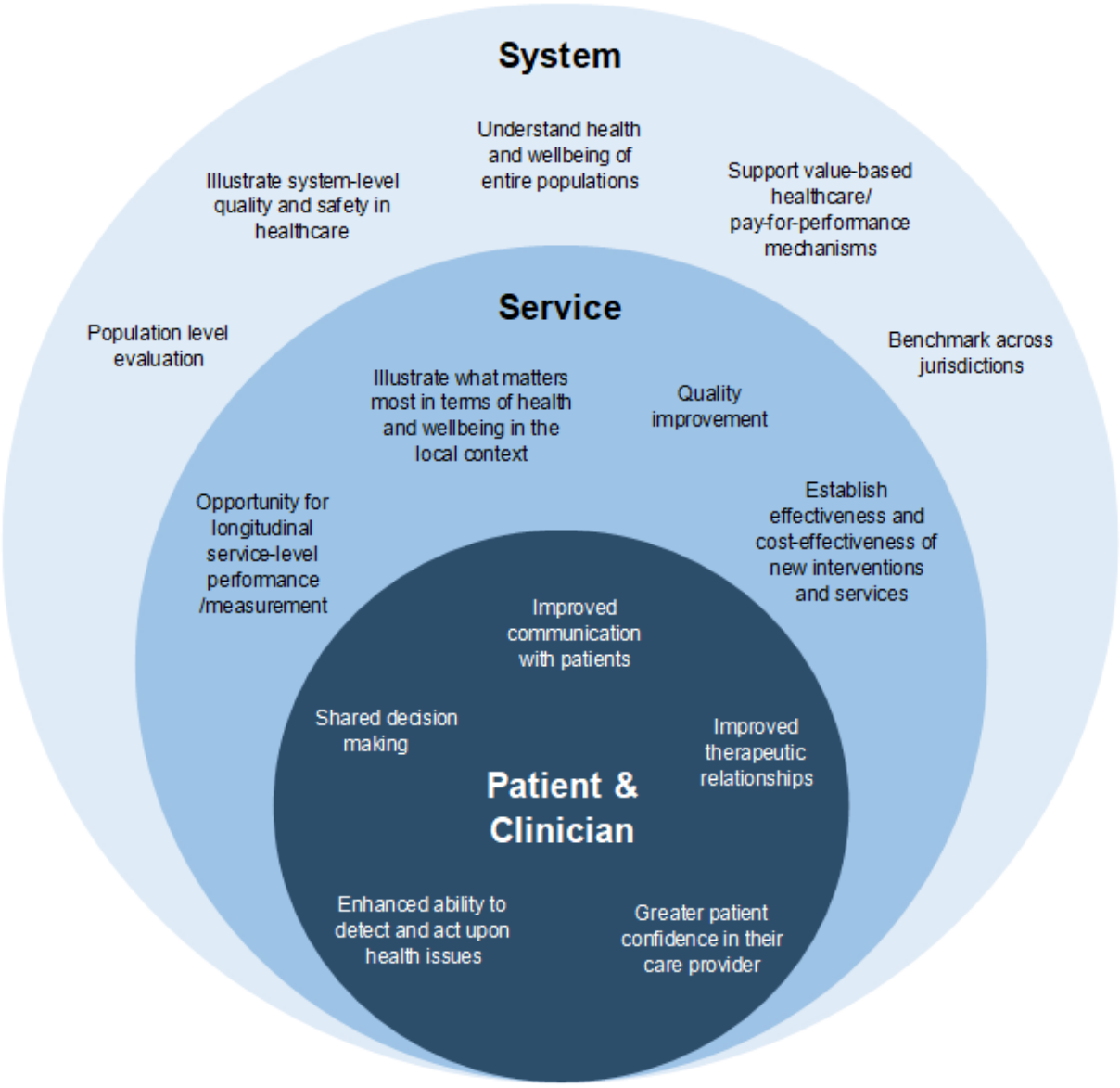

Figure 1: PROM use at 3 levels throughout the health system. Adapted from Al Sayah, 2021[3]

[1] Bull, Teede, Watson, Callander. 2022
[2] Churruca, Pomare, Ellis et. al. 2020
[3] Al Sayah, Jin, Johnson. 2021

The Statewide Patient Reported Measures (PRMs) Program was established in 2021. The vision of the program is:

'A health system that recognises patient reported outcomes and experiences as vital; where feedback is available in real time for clinical and consumer decision-making and information is used at health service and system levels to drive excellence and innovation.'

The principles of the PRM Program are:

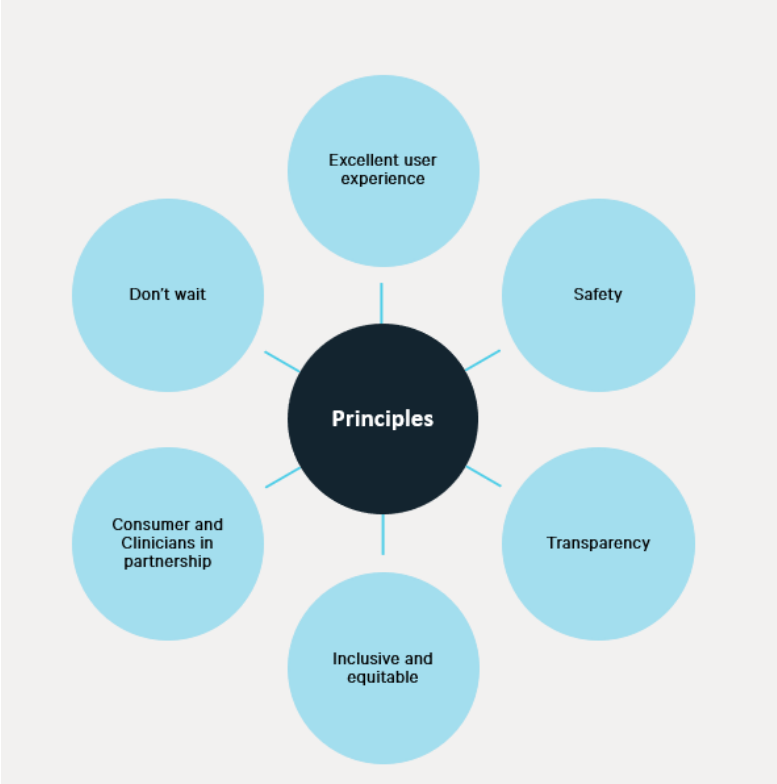

Figure 2: Statewide PRM Program Principles

The selection of a generic PROM for use by South Australian clinical services aligns with the principles of the PRM Program - Consumers and Clinicians in Partnership.

Utilising a generic PROM in South Australia will allow the following to occur:

- Comparison of consumer clinical outcomes (within a clinical service)
- Comparison of performance (between clinical services)
- Evaluation of system-level performance
- Potential comparison of system performance with other states and countries.[2,3]

Types of PROM

PROMs can be generic or condition-specific. Generic PROMs are applicable to a broad range of consumers, conditions or treatments.[1,2,4] A generic PROM allows comparisons to be made across conditions, population groups, over time, and when compared to reference data.[2,3,5] This is a key advantage of implementing generic PROMs within health systems.[3] The selection and use of a generic PROM is based on the idea that consumers have similar desires – good health, excellent services and care that meets their needs.[4]

International Context

The below figure shows generic PROMs in use in overseas jurisdictions, compared with Australia.

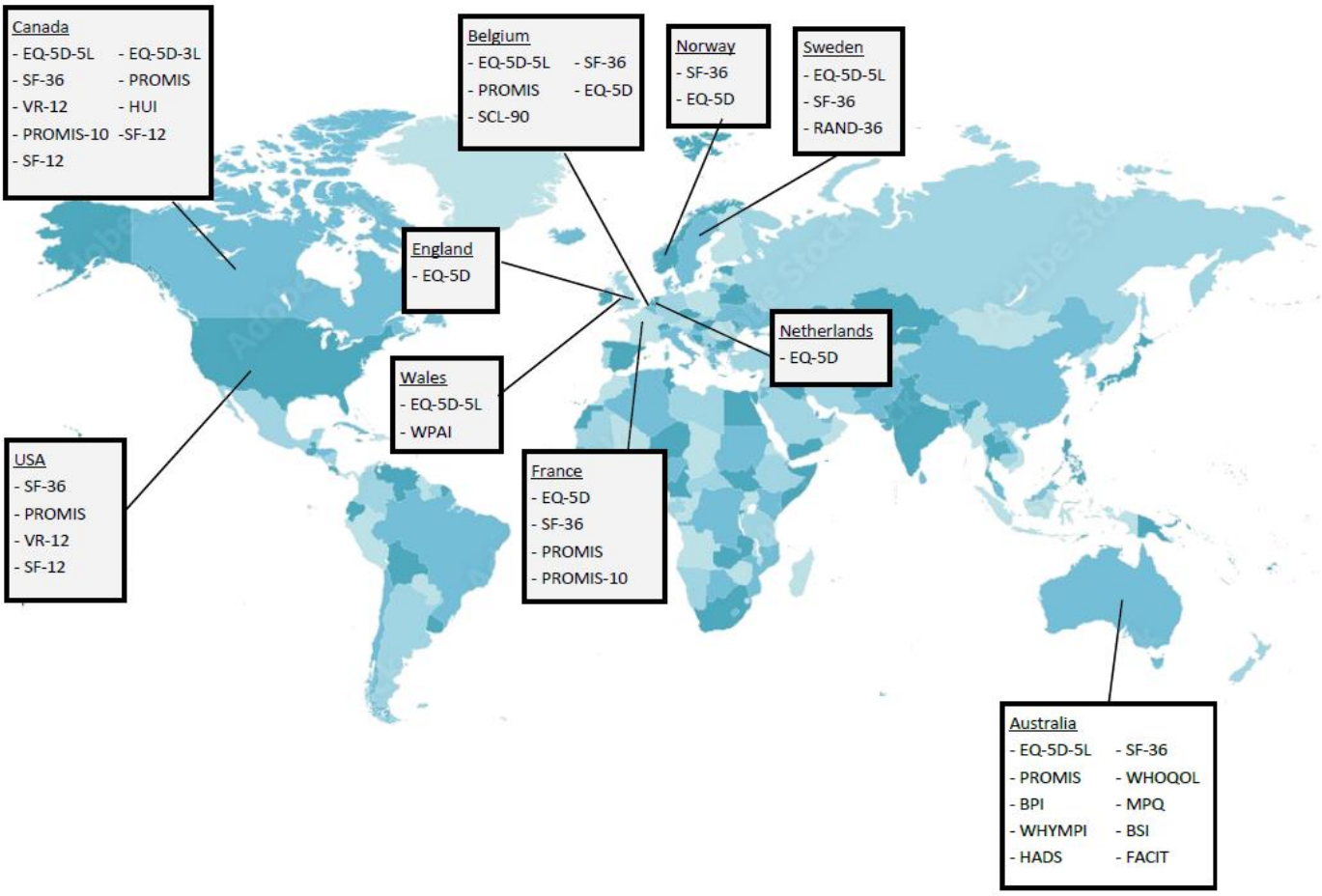

Figure 3: Generic PROMs in use in Australia and overseas. Modified from Calmus, Thuong, Morin et. al. 2021[5] Shaded areas on the map indicate different countries.

The Netherlands Approach

The Netherlands have implemented a standard set of generic PROMs utilising a working group. The Dutch Outcome-Based Healthcare Program developed a working group with a goal to align PROM data collection in medical specialist care.[6] The working group consisted of consumers, clinicians, insurers, hospitals, universities and independent clinicians.

[4] Benson. 2020
[5] Calmus, Thuong, Morin et. al. 2021
[6] Voshaar, Terwee, Haverman et. al. 2022

Support was received from a project team with expertise in PROMs and health disparities.[6] An overview of their approach is outlined in Table 1:

Table 1: The Netherlands Approach to Generic PROM/s Selection

Step	Tasks Completed
Determine goal and scope of subcommittee	• Determined key concepts • Determined selection criteria
Selection and operationalisation of PROMs	• Identified generic PROM tools for inclusion and exclusion • Reviewed other published PROM domain frameworks • Ranked generic PROM tools with subcommittee and consumer advocacy group members
Selection of PROMs a) Identification of PROMs	• Long-list of generic PROM tools compiled
Selection of PROMs b) Initial assessment	• Three expert researchers assessed all generic PROM tools on the long-list for face validity and eliminated those that did not meet initial criteria
Selection of PROMs c) Criteria assessment	• Remaining generic PROM tools underwent detailed review of quality criteria – content validity, feasibility to implement, measurement properties, possibility to convert to Item Response Theory • Stakeholder feedback received on final list of generic PROM tools

The subcommittee also formulated recommendations on how the standard set of generic PROM tools should be used by specialist care providers in The Netherlands.[6]

The Canadian Approach

The Canadian Institute of Health Research provided support to researchers in 2013 in selection of a PROM for integrated care.[2] The steps included:

1. Compilation of a long-list of generic PROM tools
2. Shortlisting of generic PROMs with inclusion of generic, quantitative measures designed for adult populations
3. Descriptive overview of shortlisted generic PROMs – including official translations, respondent burden, tool costs and dimension coverage
4. Review of PROM performance – psychometric and decision-making
5. Additional information – example of use in primary and community care, PROM related activity in other jurisdictions
6. Workshop and recommendations – review of evidence and identification of preferred tool/s.[2]

The above two countries have been specifically included within this report as they had recently published methodology relating to generic PROM selection.

Australian Context

A generic PROM tool is currently in use in New South Wales (NSW).[7] The NSW Agency for Clinical Innovation (ACI) underwent the following process in selecting a generic PROM:

1. Environmental scan to determine current state and workflows
2. Literature and evidence reviews
3. Statewide workshops – undertaking a co-design process with clinicians, managers, consumers and carers
4. Usability workshops and data discussions
5. Pilot of the PROMIS-10 Generic PROM tool
6. Collation of feedback and refinement approach
7. Endorsement of the PROMIS-29 Generic PROM tool.[7]

[7] Agency for Clinical Innovation. No date

When accounting for national and international approaches, the following steps are recommended as part of the PRM selection process[2,3,6,7]

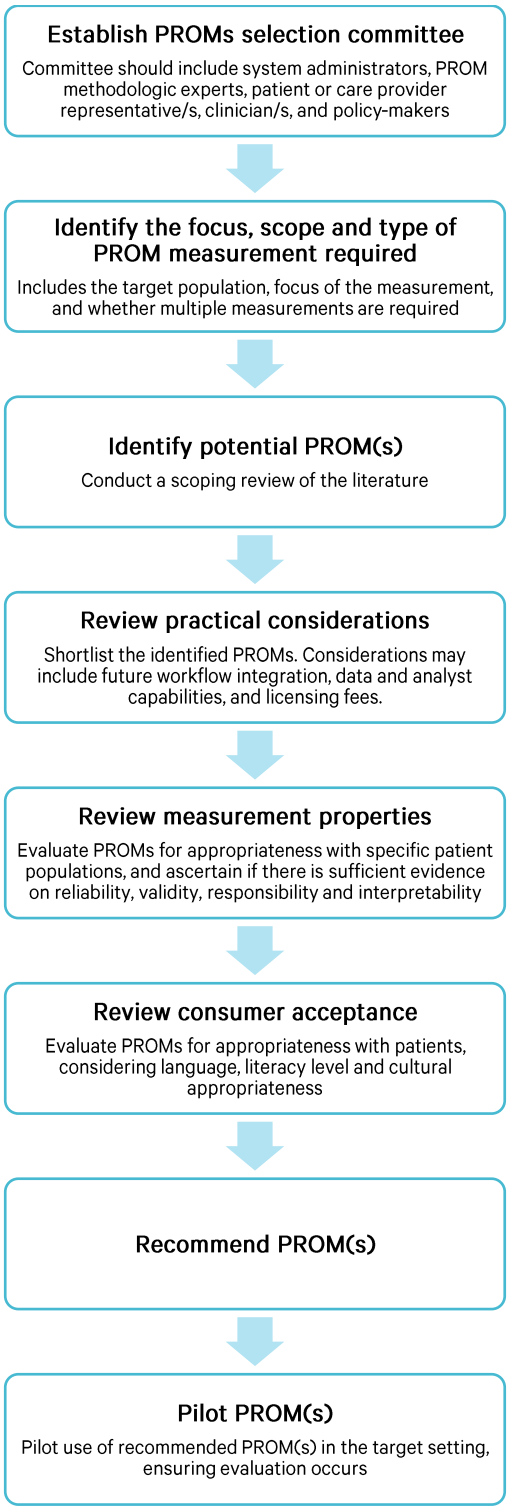

Figure 4: Flow chart showing recommended PRM selection process, synthesised from the literature.

Statewide PRM Program – Generic PROM Selection Methodology

PRM Program - Generic PROM Subcommittee

The PRM Program Board endorsed the formation of a Generic PROM Subcommittee in 2022. The purpose of the Generic PROM Subcommittee is to provide a recommendation to the PRM Program Board of a generic PROM for adoption and use in South Australia's public health system (SA Health). The aim of the program is to offer the selected generic PROM tool for usage by clinical services from 2024 onwards, noting usage is not mandatory.

The Subcommittee was convened in March 2023 with the following aims:

- Review local, national, international use of generic PROM tools
- Develop principles and criteria for selection of generic PROM tools
- Develop draft and final reports for the PRM Program Board.

Subcommittee membership consists of clinicians, health economists, consumers and researchers with knowledge and experience in patient reported measures. From the formation of the Subcommittee, strong consideration for consumer involvement, not just in tool selection, was provided. A list of all Subcommittee members is provided in Appendix 1.

Requirements for South Australia

The Subcommittee initially outlined several requirements for the selection of a preferred generic PROM tool, including but not limited to:

- Ability to measure a broad set of outcomes
- Ability to compare across conditions and consumer groups
- Allowance for standardisation across the health system and population
- Complementing the use of condition-specific PROMs.

Approach to Generic PROM Tool Selection

The below approach was developed by the Generic PROM Subcommittee after discussion and consideration of national and international approaches. The Subcommittee recognised that significant work had recently occurred in local and international contexts that was transferable to the South Australian context; therefore we did not seek to redesign the selection methodology as part of generic PROM selection for South Australia.

The methodology was adapted to increase consumer involvement throughout the PROM selection process.

Step	Associated Task	Person/s Responsible	Completion Time
Review of literature	Build on and update literature review based on NSW ACI literature review	PRM Implementation Manager – with input from Subcommittee	1 month
Generic PROM tool selection processes and outcomes	Review NSW generic PROM tool selection processes and outcomes and determine SA selection methods based on above processes	Generic PROM Subcommittee	2 months
Generic PROMs selection pool	Specify generic PROMs selection pool ('long-list')	PRM Implementation Manager – with input from Subcommittee	2 months
PROMs tool scoring	Determine scoring mechanism for generic PROMs tools	Generic PROM Subcommittee	2 months
Shortlist tools	Application of scoring criteria to generic PROMs 'long-list'	PRM Implementation Manager with input from Subcommittee	1 month
Consumer preferencing	Consumers to select preferred generic PROM from shortlisted tools	PRM Implementation Manager – with input from Subcommittee	2 months
Clinician consultation	Clinicians to provide consultation on generic PROM selected by consumers	PRM Implementation Manager – with input from Subcommittee	1 month
Final tool selection	Collation of consumer and clinician feedback	PRM Implementation Manager	1 month
Preparation of final report for PRMs Program Board	Generation of report with final recommendations	PRM Implementation Manager – with input from Subcommittee	2 months
Program Board endorsement	Presentation of Generic PROM Subcommittee Final Report	PRM Implementation Manager with approval from Subcommittee	1 month

Generic PROM Tools – Long-list

The initial list of generic PROMs comprised tools listed on the Australian Commission on Safety and Quality in Health Care website (https://www.safetyandquality.gov.au/), and included additions from Subcommittee members. The original list contained 46 tools, including paediatric and condition or domain-specific tools. Prior to finalising the list, it was decided by the Subcommittee that paediatric, condition and domain-specific tools be excluded from the shortlisting

process, as they do not meet the definition for a generic PROM. This left a long-list of 13 generic PROMs, as seen in Appendix 2.

Principles for Shortlisting

The below principles and definitions for shortlisting were developed from discussions amongst the Generic PROM Subcommittee and evidence from the literature.

Note: letters A-H do not represent weighting or preference for proposed principles. Additionally, a tool does not have to score highly or meet all the below criteria to be shortlisted.

Table 2: Generic PROM Subcommittee – Shortlisting Principles

	Principles	Description	Rating (red, yellow, green)
A	System Perspective	Enables a system-wide view and comparison across broad patient populations	
B	Economic Evaluation	Enables economic analysis – cost-effectiveness or cost-utility analyses	
C	Language and Cultural Translation	Existing translation to multiple languages and ability to be adapted to suit cultural needs	
D	Future Proof	Aligns with digital systems evolution, emerging survey technologies, and trends in PROMs development	
E	Cost Effective	Licensing and cost of use are manageable from a system and service perspective	
F	Psychometric Properties	Ability of the tool to measure what it claims to measure – including validity, reliability and responsiveness	
G	Clinical Relevance	Able to be meaningfully integrated into clinical decision-making processes and provides actionable insight	
H	Consumer Relevance	Relevant, understandable, and manageable for consumer and/or carers	

Approach to Shortlisting

The recommended approach to shortlisting, as agreed upon by the Subcommittee, was as follows:

- Principles A-E would be assessed by the PRM Implementation Manager
- Principle F would be assessed by two members from the Subcommittee with experience in psychometric validity
- All assessments would be conducted under a pair or peer review process
- Assessments would be made under the 'traffic light' system
- Principles G-H would occur for shortlisted tools only.

Shortlisting Process

Shortlisting occurred from 17th July to 2nd August 2023. Four people were involved in the shortlisting process – two assessed the tools against principles A-E, and two assessed for psychometric validity. Two subcommittee members with expertise in psychometric validity assessment undertook the shortlisting.

A decision was made to conduct psychometric validity assessments against generic PROM tools assessed as suitable after the other two team members had assessed against principles A-E initially. This was endorsed by the Subcommittee Chair.

Psychometrics

Psychometrics can be defined as a branch of psychology seeking to measure behavioural and social phenomena using statistical methods.[1] Psychometric properties include validity, reliability and responsiveness and are strongly considered when assessing the overall quality of a PROM. Definitions of these properties are:

- Validity – the extent to which a tool measures what it was designed to measure.
- Reliability – the extent to which a tool performs consistently and predictably.
- Responsiveness – the ability of a tool to detect change over time.[1,8]

PROMs should undergo psychometric validation to ensure they reflect the outcomes they say they measure and can assess change over time.[2]

[8] Mokkink, Terwee, Patrick et. al. 2010

Table 3: Generic PROM Subcommittee – Shortlisting Results (Principles A-E)

Tool	Rating (red, yellow, green)					Overall Rating
	A. System Perspective	B. Economic Evaluation	C. Language and Cultural Translation	D. Future Proof	E. Cost Effective	
EQ-5D-5L						Suitable
PROMIS-10						
PROMIS-29						
PROPr (PROMIS-29+2)						
SF-12						
SF-36						
WHODAS2.0						
HUI						Marginal
HUI3						
QWB-SA						
WHOQOL-BREF						
WHOQOL-100						
AM-PAC						Unsuitable
AQoL-8D						
AQoL-7D						
AQoL-6D						
AQoL-4D						
GCOS-24						
HOWSYOURHEALTH?						
NHP						
SDS						

AM-PAC = Activity Measure Post-Acute Care; AQoL = Assessment of Quality of Life; EQ-5D = European Quality of Life-5 Dimensions; GCOS = Genetic Counseling Outcomes Scale; HUI = Health Utilities Index; NHP = Nottingham Health Profile; PROMIS = Patient-Reported Outcome Measurement Information System; QWB-SA = Quality of Well-Being scale Self-Administered; SDS = Sheehan Disability Scale; SF = Short Form; WHODAS 2.0 = World Health Organisation Disability Assessment Schedule 2.0; WHOQOL = World Health Organisation Quality of Life

Assessment of psychometric properties was then conducted on the following tools:

- EQ-5D-5L
- PROMIS-10
- PROMIS-29
- PROPr (PROMIS-29+2)
- SF-36
- SF-12
- WHODAS2.0

It was decided not to conduct psychometric assessment on tools categorised as 'marginal' as the approach was 'lowest score out.'

Table 4: Generic PROM Subcommittee – Final Shortlisting Results (Principles A-F)

Tool	Rating (red, yellow, green)						Overall Rating
	A. System Perspective	B.Economic Evaluation	C. Language & Cultural Translation	D. Future Proof	E. Cost Effective	F. Psychometric Validity	
EQ-5D-5L							Suitable
PROMIS-10							
PROMIS-29							
PROPr (PROMIS-29+2)							
SF-12							
SF-36							
HUI							Marginal
HUI3							
QWB-SA							
WHOQOL-BREF							
WHODAS2.0							
WHOQOL-100							
AM-PAC							Unsuitable
AQoL-8D							
AQoL-7D							
AQoL-6D							
AQoL-4D							
GCOS-24							
HOWSYOURHEALTH?							
NHP							
SDS							

AM-PAC = Activity Measure Post-Acute Care; AQoL = Assessment of Quality of Life; EQ-5D = European Quality of Life-5 Dimensions; GCOS = Genetic Counseling Outcomes Scale; HUI = Health Utilities Index; NHP = Nottingham Health Profile; PROMIS = Patient-Reported Outcome Measurement Information System; QWB-SA = Quality of Well-Being scale Self-Administered; SDS = Sheehan Disability Scale; SF = Short Form; WHODAS 2.0 = World Health Organisation Disability Assessment Schedule 2.0; WHOQOL = World Health Organisation Quality of Life

The tools assessed as 'suitable' were:

- European Quality of Life-5 Dimensions 5 Level – EQ-5D-5L
- Patient Reported Outcome Measurement Information System (PROMIS):
    - PROMIS-10
    - PROMIS-29
    - PROPr (PROMIS-29+2)
- Short Forms:
    - SF-12
    - SF-36

Members of the shortlisting group recommended further reduction of the above list of tools to take to consumer and clinical representatives for final selection. This was discussed with the Subcommittee Chair and it was decided to have the Subcommittee select the final top tools. PROMIS-10 was not selected for progression to consumer or clinician feedback due to perspective and experiences shared from interstate delegates.

At the Generic PROM Subcommittee meeting held 2nd August 2023, the Subcommittee members endorsed the final top tools as:

- EQ-5D-5L
- PROMIS-29
- SF-12 (pending further investigation into the potential costs).

Following subcommittee endorsement of the above list, contact was made with SF-12 license owners to enquire about licensing fees. The estimated costs provided by the owners far exceeded the program funding allocation and so with the subcommittee approval SF-12 was removed from consideration. In addition, SF-12 scoring is not able to be conducted within the ZEDOC system – consumer data is sent overseas in order to be assessed.

The final two shortlisted generic PROMs were the EQ-5D-5L and the PROMIS-29. Permission to use each PROM digitally for the purposes of consumer engagement was granted by licensees in August and September 2023.

Consumer Engagement

In line with the PRM Program vision and principles, the Subcommittee had a strong focus on consumer engagement from formation. Additionally, this process provided an opportunity to empower consumers to drive and be involved in decision making; to promote consumer voice in services and decisions; and ultimately, it is consumers, not clinicians who will be completing the tool.

The purpose of consumer engagement was to involve consumers in the selection of the generic PROM at all stages of the process. Consumer representatives attended the Subcommittee meetings and contributed to decision making and endorsement of the methodological approaches. Shortlisted PROMs were also provided to a sample of health consumers, who had the opportunity to indicate their preferred generic PROM.

Generic PROM Preferencing

The Subcommittee endorsed the following consumer engagement plan:

- Consumers to participate in review of the EQ-5D-5L and the PROMIS-29 and to indicate a preference
- Exclusions: consumers <18 years of age
- Inclusions: diversity of clinical conditions; consumers from all LHNs; digital competency not required; range of cultural groups, gender and ages
- Use of ZEDOC solution to administer each PROM, and collect preferences and other demographic information
- Target: maximum 100 consumers; proportionate to LHN population
- Consumers to be reimbursed for their time and additional support able to be provided by PRM team
- Information workshops to be provided to consumers prior to participation

- Data and details to be removed from ZEDOC at end of process.

The intent of consumer engagement was to have a representative sample of the South Australian population. Consumers were engaged through liaison with the LHN Consumer Engagement/Experience Leads. The Leads were provided with information relating to the PRM Program background, Subcommittee work, reason for consumer preferencing and number of consumers required from each LHN. (Note: the total number of consumers the Subcommittee was able to engage was 100, due to licensing restrictions for one of the generic PROMs). The PRMs Implementation Manager wrote communications that were provided to the Leads to send to relevant consumer groups.

Table 5: Target Number of Consumers per LHN (Based on Population)

Local Health Network (Abbr)	Current Population	% of Population	Proposed Number of Consumers
BHFLHN*	208589	11.8	12
CALHN	471358	26.6	20
EFNLHN*	40806	2.3	4
FUNLHN*	43024	2.4	4
LCLHN*	67092	3.8	4
NALHN	419297	23.7	20
RMCLHN*	69301	3.9	4
SALHN	381668	21.6	20
WCHN^	124828	7.0	8
YNLHN*	75529	4.3	4
SA Population	1771000		
Consumer Target	100		100

^includes paediatric patients
* regional LHN
BHFLHN = Barossa Hills Fleurieu LHN; CALHN = Central Adelaide LHN; EFNLHN = Eyre and Far North LHN; FUNLHN = Flinders and Upper North LHN; LCLHN = Limestone Coast LHN; NALHN = Northern Adelaide LHN; RMCLHN = Riverland Mallee Coorong LHN; SALHN = Southern Adelaide LHN; WCHN = Women's and Children's Health Network; YNLHN = Yorke and Northern LHN

Four virtual workshops were provided to consumers throughout the week of the 25th of September 2023. The workshop content included an introduction to PROMs, the generic PROM shortlisting process, and what the consumer role in preferencing would be. Consumers were asked to complete the EQ-5D-5L, PROMIS-29 and a post-PROM evaluation survey within ZEDOC. The evaluation survey was developed with input from Subcommittee members and collected information including basic demographic data and can be found in Appendix 3. The aim of the evaluation survey was to understand health literacy and health system attendance for the consumers participating in this process. This, in conjunction with the consumer generic PROM preference, would allow the Subcommittee to understand generic PROM preferences across consumer groups.

Consumers elected to receive survey invitations via email or SMS and then completed EQ-5D-5L, PROMIS-29 and an evaluation survey within ZEDOC. Enrolment in ZEDOC occurred in an alternating fashion, so that consumers received either EQ-5D-5L or PROMIS-29 as their first tool to complete. The consumers were also asked to choose one PROM as their top preference and provide a reason why. Consumers were encouraged to provide any feedback on use of the ZEDOC solution.

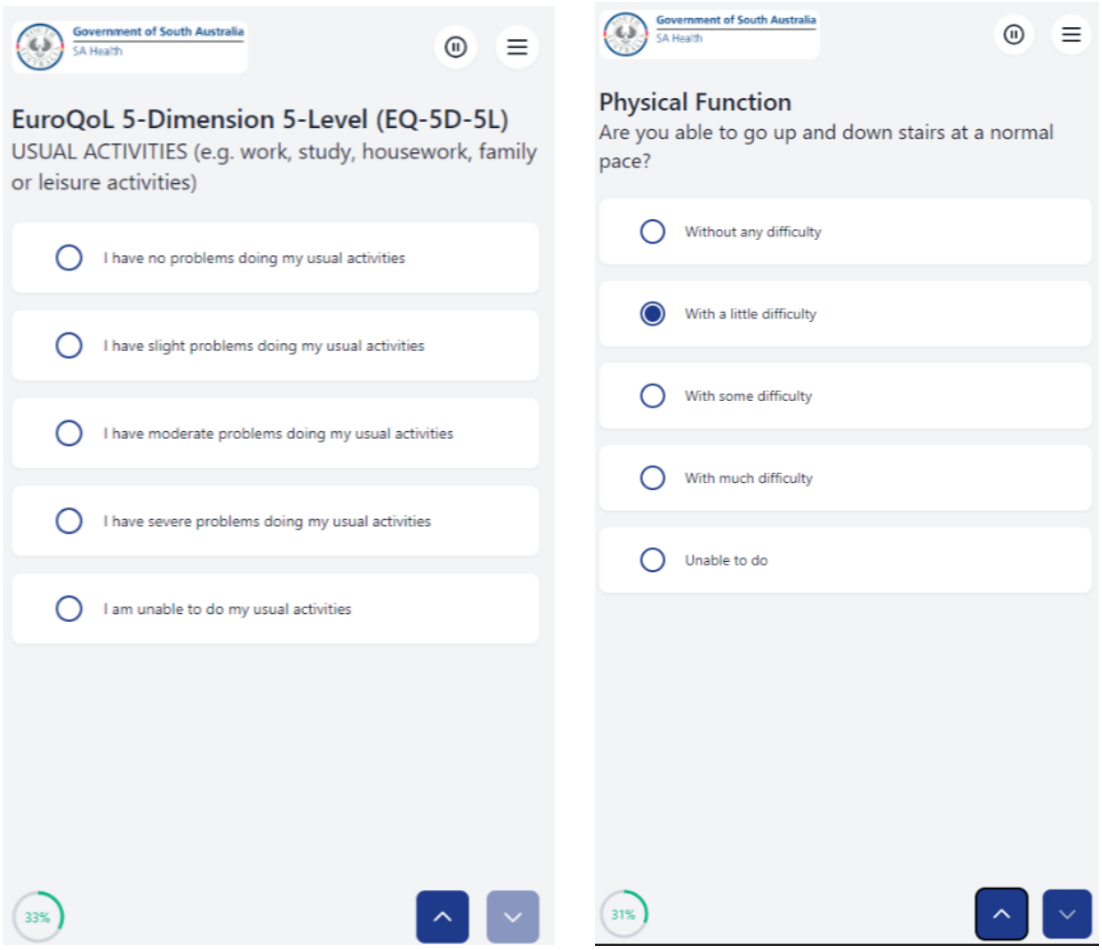

Figure 5: EQ-5D-5L and PROMIS-29 – appearance with ZEDOC Digital Solution

Consumer Engagement - Results

Table 6: Consumer Participation Across Local Health Networks

Local Health Network (Abbr)	Number of Participating Consumers
BHFLHN*	2
CALHN	18
EFNLHN*	1
FUNLHN*	1
LCLHN*	3
NALHN	9
RMCLHN*	2
SALHN	8
WCHN	4
YNLHN*	4
Total	52

* regional LHN
BHFLHN = Barossa Hills Fleurieu LHN; CALHN = Central Adelaide LHN; EFNLHN = Eyre and Far North LHN; FUNLHN = Flinders and Upper North LHN; LCLHN = Limestone Coast LHN; NALHN = Northern Adelaide LHN; RMCLHN = Riverland Mallee Coorong LHN; SALHN = Southern Adelaide LHN; WCHN = Women's and Children's Health Network; YNLHN = Yorke and Northern LHN

Two rounds of consumer engagement occurred to ensure consumers from all Local Health Networks (LHNs) were able to participate. To encourage consumers to participate, virtual workshops were offered out of hours, with multiple chances to attend. Additionally, when low numbers of consumers were registering interest, the scope of consumer types was increased to increase participation.

Table 7: Consumer demographic Information - comparison with Australian Bureau of Statistics Census Data

Generic PROM	n	%	Australian Bureau of Statistics – Census Data[9]	n	%
Participants	52	-	Participants	1,781,516	-
Surveys Completed	52	100%		-	-
Age Group					
18-24	3	5.8	15-24	208,326	11.7
25-44	7	13.5	25-44	461,947	25.9
45-64	29	55.8	45-64	451,788	25.4
65-84	13	25	65-84	309,000	17.3
85 or over	0	0	85 or over	47,325	2.7
Gender					
Male	19	36.5	Male	878,592	49.3
Female	32	61.5	Female	902,924	50.7
Non-binary	1	1.9	Gender diverse	-	-
Prefer to self-describe	0	0	Prefer not to say	-	-
Language other than English					
Yes	5	9.6	Other	317,287	17.8
No	47	90.4	English	1,382,951	77.6
Indigenous status					
Aboriginal	6	11.5	Aboriginal	40,592	2.3
Torres Strait Islander	0	0	Torres Strait Islander	994	0.1
Both Aboriginal and Torres Strait Islander	1	1.9	Both Aboriginal and Torres Strait Islander	967	0.1
None	45	86.5	-	-	-

Table 8: Population Distribution - comparison with SA Population Survey

Generic PROMs	n	%	South Australian Population Health Survey[10]	n	%
Metropolitan	39	75%	Metropolitan	6,335	71.6
Regional	13	25%	Regional	2,507	28.4

Consumer demographic information has been compared with the Australian Bureau of Statistics (ABS) Census and the SA Population Survey (SAPS) to demonstrate that the consumer sample utilised for generic PROM preferencing is comparable with the wider South Australian population. As indicated in Tables 7 and 8 above, across demographic groups the generic PROM consumers are comparable with the SA population.

[9] Commonwealth of Australia. 2022.
[10] Wellbeing SA. 2021.

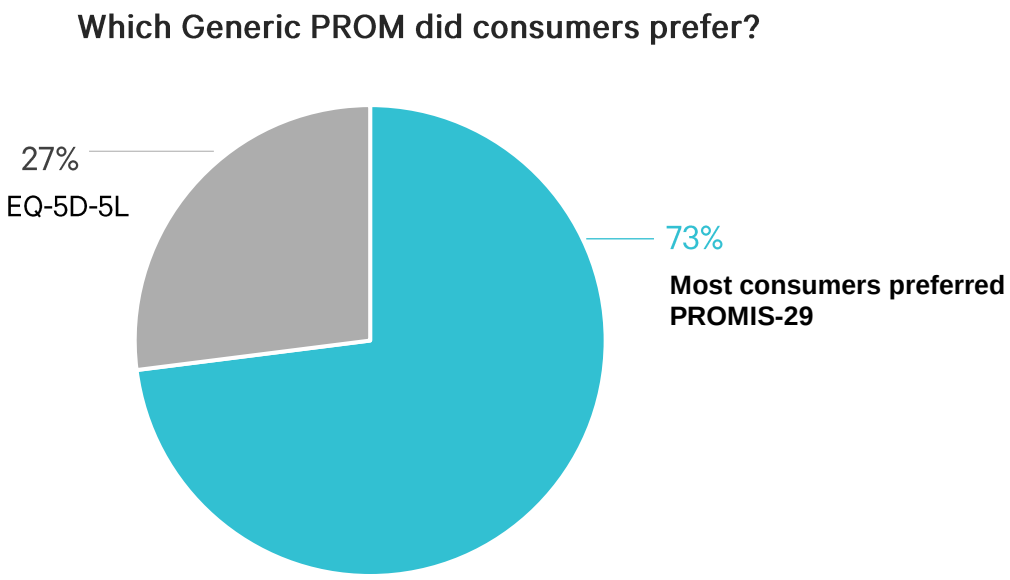

Figure 6: Pie chart showing which Generic PROM consumers preferred. 73% of the consumers surveyed preferred PROMIS-29.

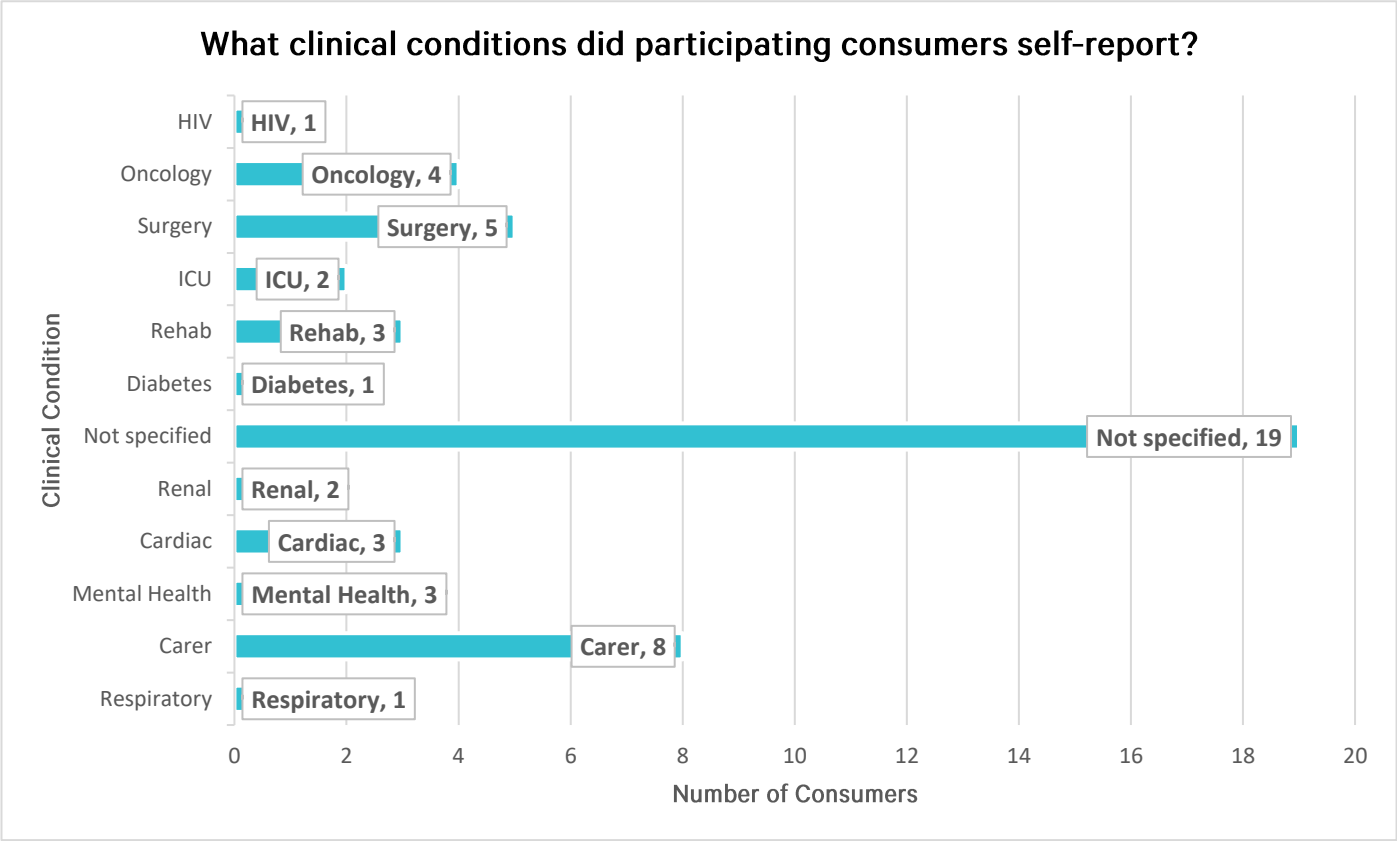

Figure 7: Bar graph showing clinical conditions self-reported by consumers who participated in the Generic PROM preferencing process.

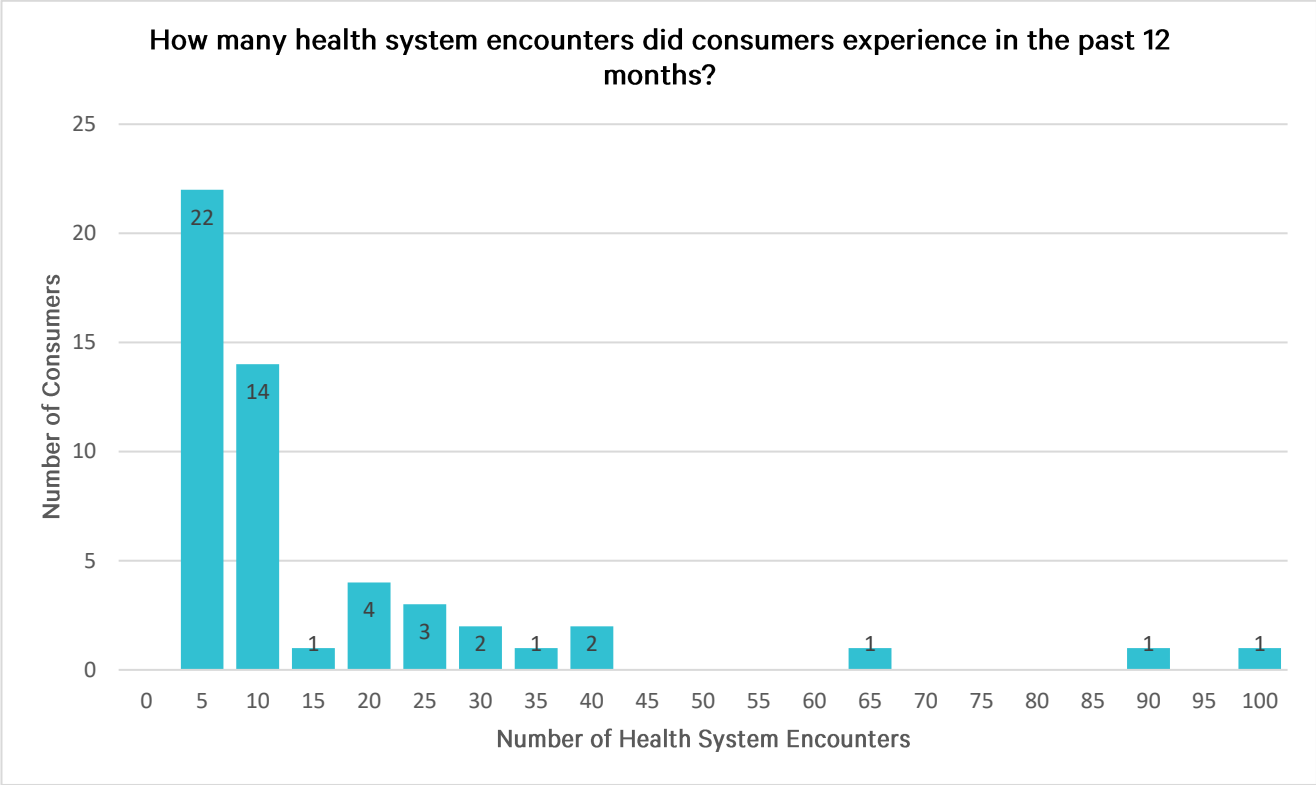

Figure 8: Column graph showing number of health system encounters experienced by consumers who participated in the Generic PROM preferencing process. Most consumers had between 5-10 health system encounters in the past year.

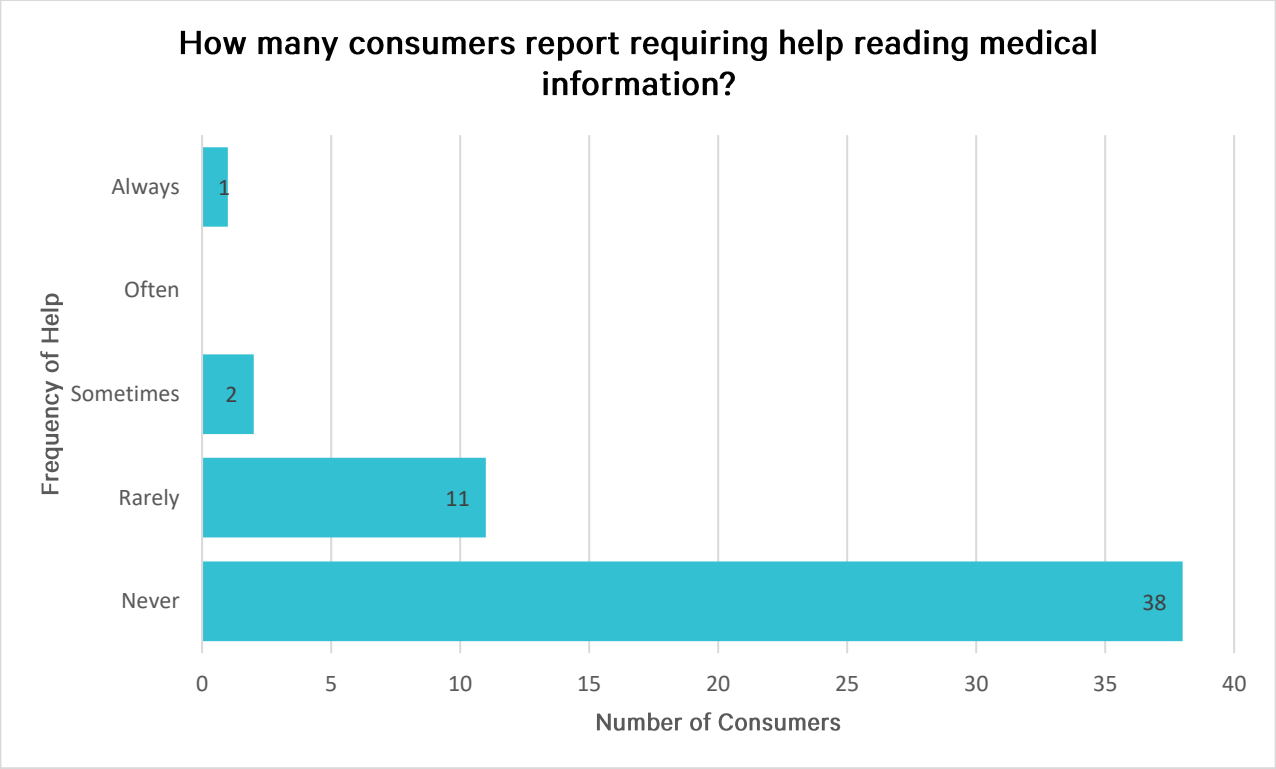

Figure 9: Bar graph showing consumer responses to the question 'How often do you need to have someone help you when you read instructions, pamphlets or other written material from your doctor or pharmacist?' Most consumers reported not requiring assistance.

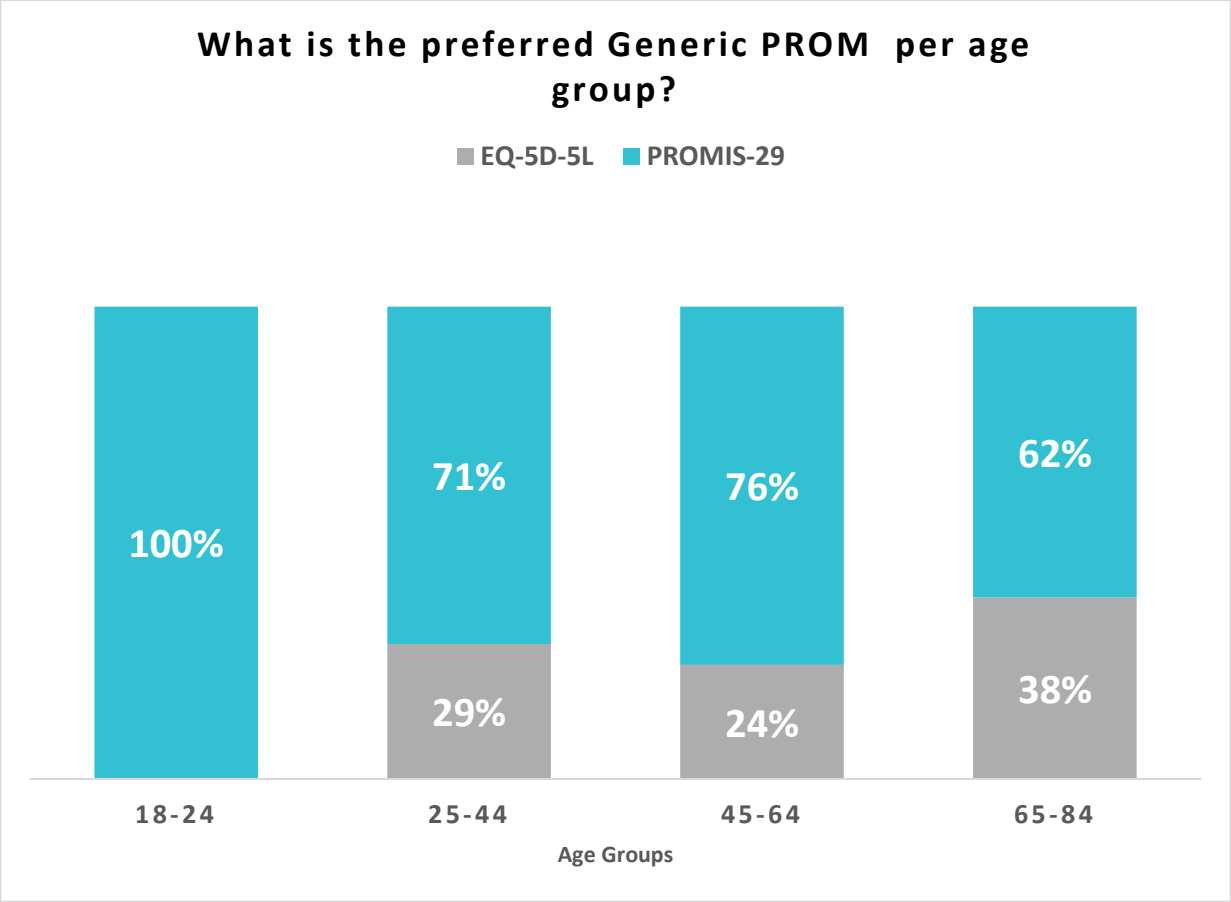

Figure 10: Stacked column graph showing Generic PROM Preference – per age group. PROMIS-29 is the preferred Generic PROM across all age groups surveyed.

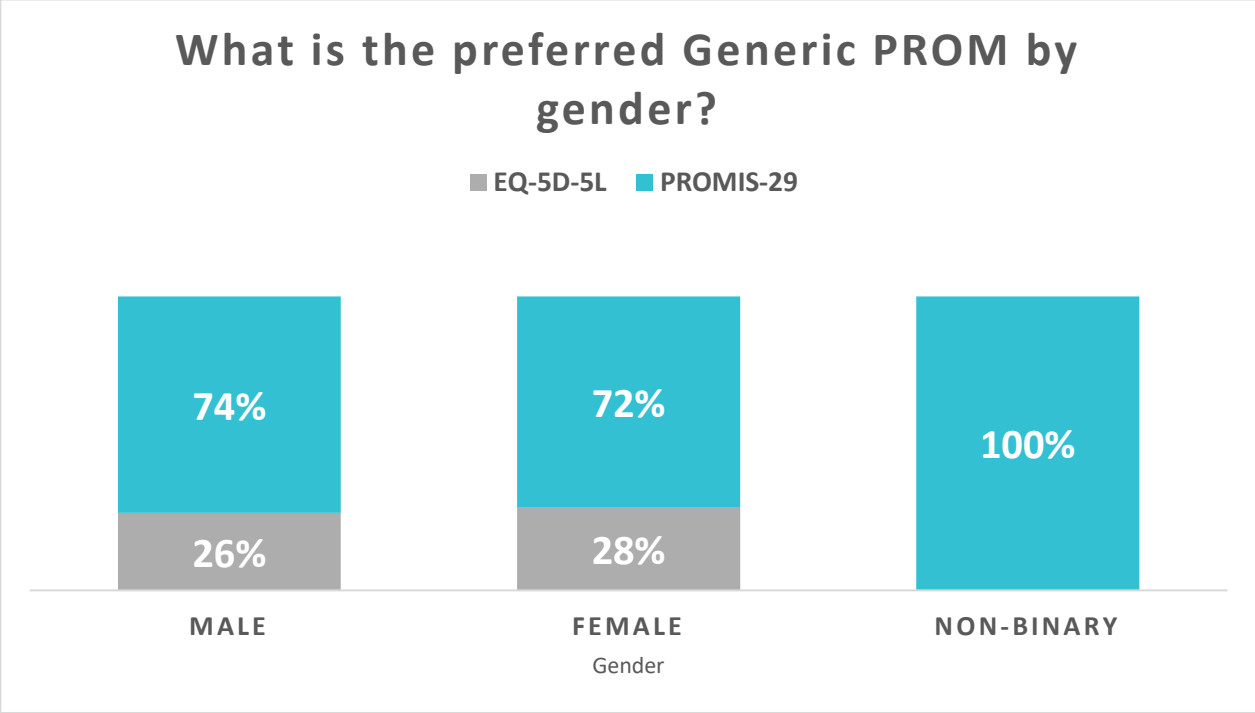

Figure 11: Stacked column graph showing Generic PROM Preference – by gender. PROMIS-29 is the preferred Generic PROM across all gender groups surveyed.

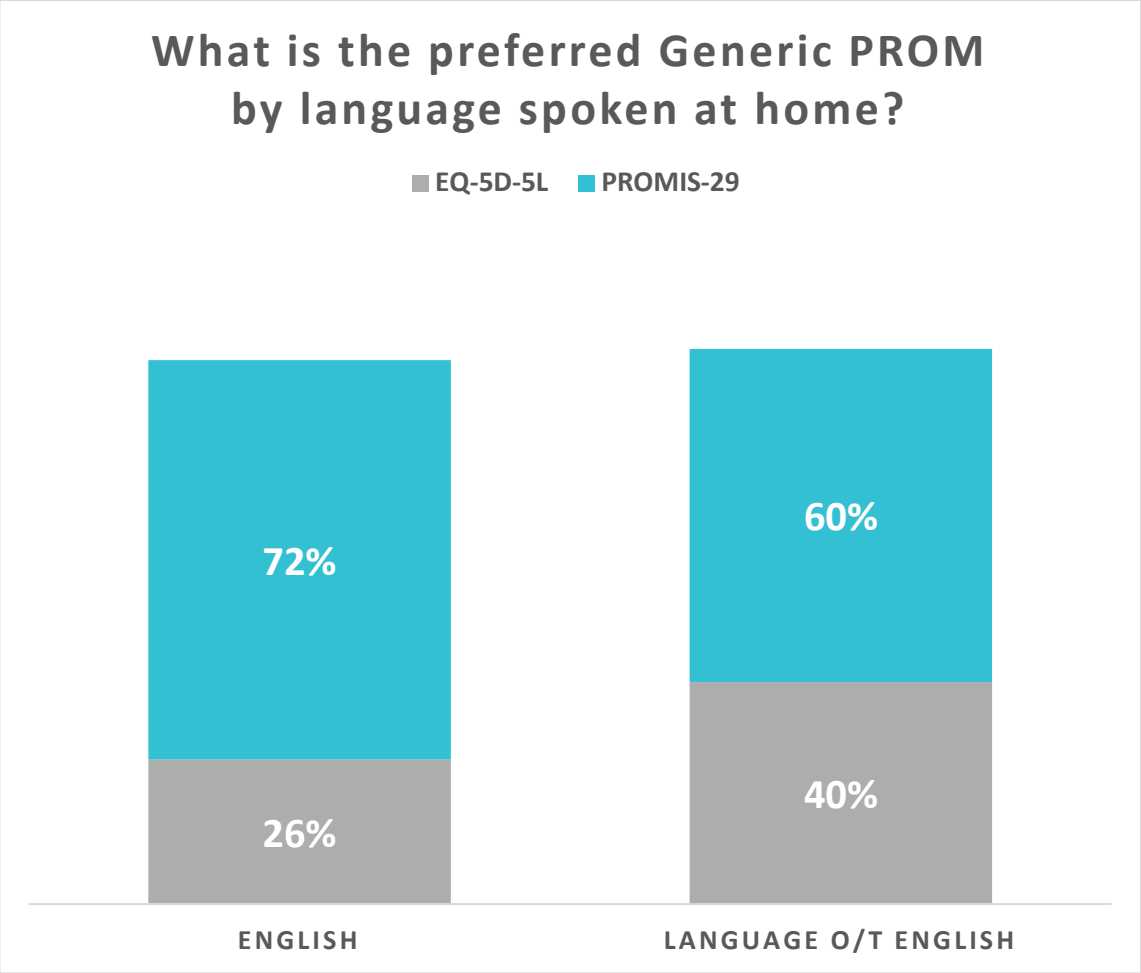

Figure 12: Stacked column graph showing Generic PROM Preference – by language spoken at home. PROMIS-29 is the preferred Generic PROM across all groups surveyed.

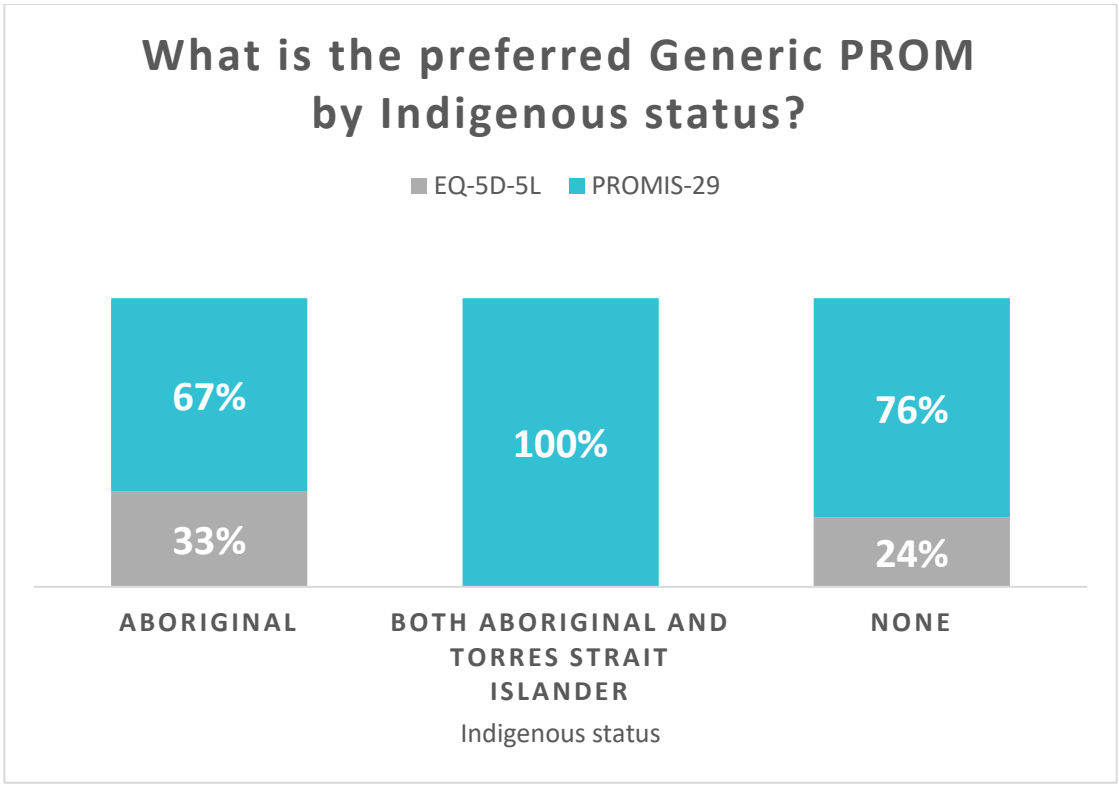

Figure 13: Stacked column graph showing Generic PROM Preference – by Indigenous status. PROMIS-29 is the preferred Generic PROM across all groups surveyed.

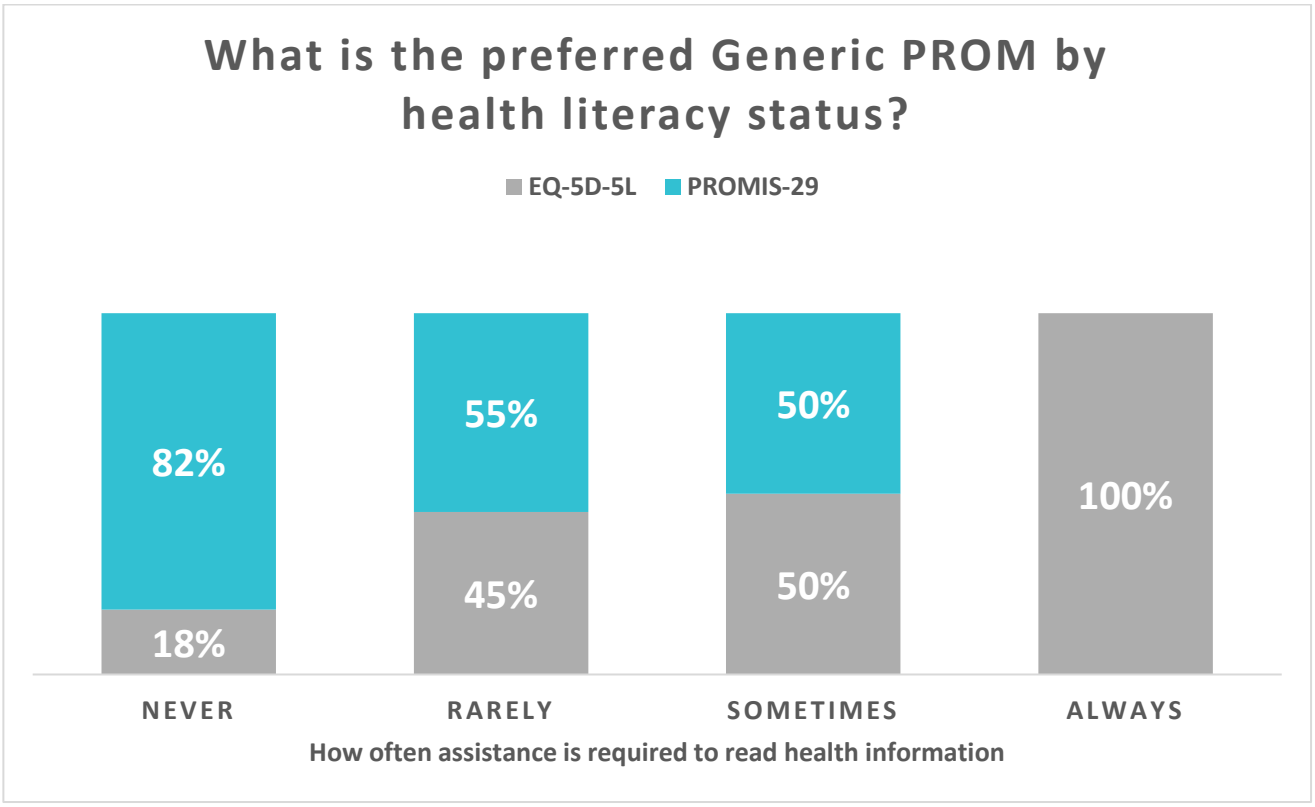

Figure 14: Stacked column graph showing Generic PROM Preference by health literacy level. Preference for the PROMIS-29 decreases as support required to read and understand health information increases.

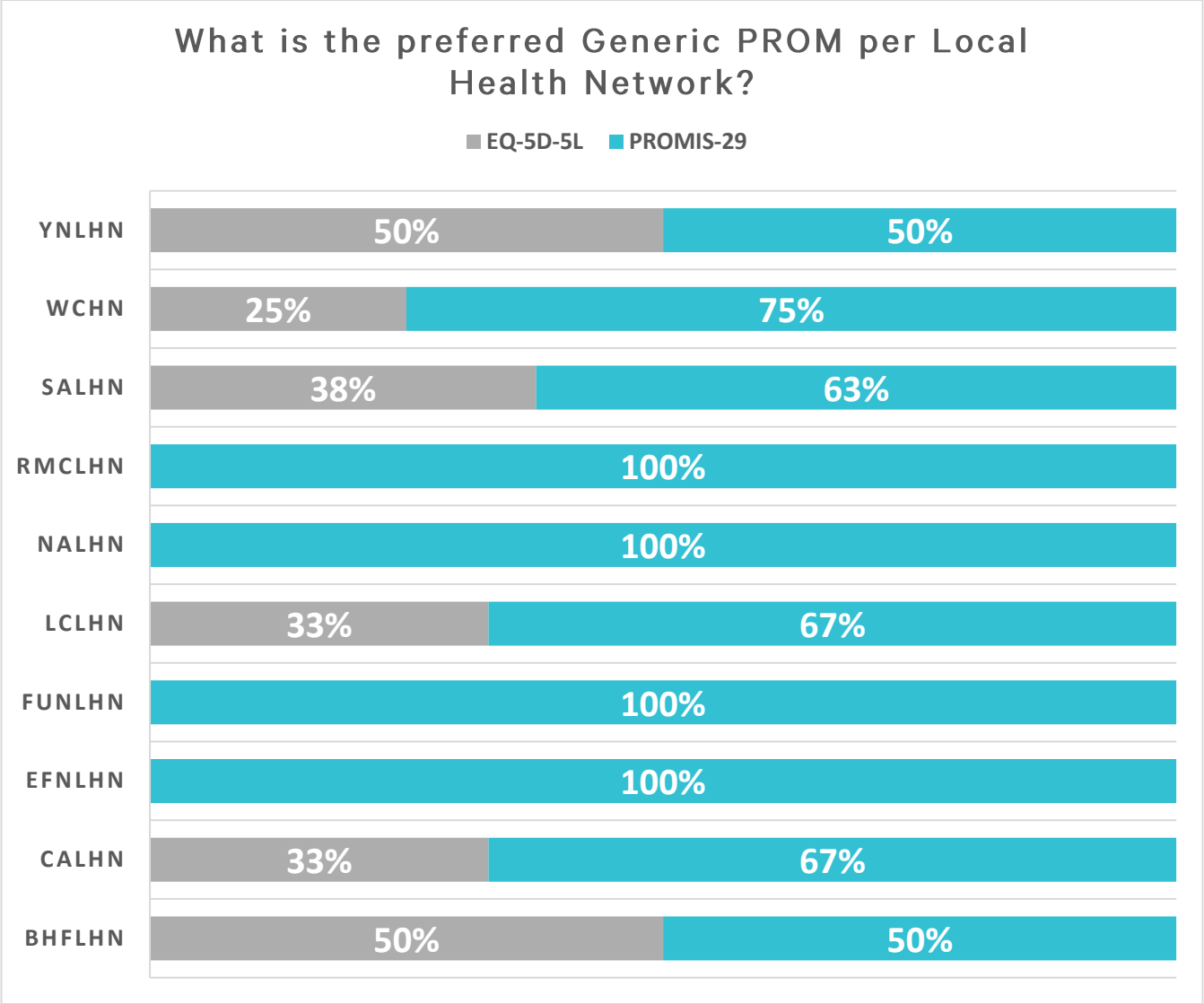

Figure 15: Stacked bar graph showing Generic PROM Preference by Local Health Network. PROMIS-29 was the preferred Generic PROM across most Local Health Networks.

BHFLHN = Barossa Hills Fleurieu LHN; CALHN = Central Adelaide LHN; EFNLHN = Eyre and Far North LHN; FUNLHN = Flinders and Upper North LHN; LCLHN = Limestone Coast LHN; NALHN = Northern Adelaide LHN; RMCLHN = Riverland Mallee Coorong LHN; SALHN = Southern Adelaide LHN; WCHN = Women's and Children's Health Network; YNLHN = Yorke and Northern LHN

Thematic Analysis

Consumers were asked to provide a reason, in writing, for their preferred generic PROM. Key themes from consumer comments are summarised below. Full written feedback provided by all consumers can be found in Appendix 4.

EQ-5D-5L Positive Comments	PROMIS-29 Positive Comments
• Easy to use • Simple • More subjective • Better questions • More direct • Quicker to complete	• Larger scope to draw from (7 days) • More spectrum of general health matters • Comprehensive • More detailed questions • More specific questions • Clearer questions • Seems helpful to discuss with health professional
EQ-5D-5L Negative Comments	**PROMIS-29 Negative Comments**
• Scale was difficult to use/interpret • Did not explain clearly what was required • Too brief	• 29 questions can be long • Repetitive • Not relevant for consumers with pain

Overall, the strong consumer preference across all demographics was for the PROMIS-29. As stated above, PROMIS-29 was preferred by consumers as it was more comprehensive, detailed and specific. This was despite the PROMIS-29 being a longer tool than the EQ-5D-5L.

Clinician Engagement

The primary objective of clinician engagement was to inform clinicians of the preferred generic PROM as selected by consumers and provide information on how the generic PROM could be incorporated into clinical practice. The engagement also provided an opportunity to build awareness of the PRMs Program.

Clinician engagement was endorsed by the Generic PROM Subcommittee and encompassed two methods: written communications and virtual workshops. Written communications were disseminated through the wider health system, to capture as many clinicians as possible, and virtual consultation sessions allowed for a more detailed discussion with stage 1 PROM services.

Written Communications

A fact sheet was developed, outlining the generic PROM shortlisting process and consumer preference. The fact sheet also contained information on clinical use of the PROMIS-29. Clinicians were invited to provide feedback on the nomination of the PROMIS-29 as the preferred generic PROM. The fact sheet was disseminated along with relevant communications via the following channels:

- PRM Research Collaborative members
- LHN Communication teams.

The fact sheet and a summary was also uploaded onto the PRMs website along with associated posts on CEIH social media (Twitter and LinkedIn) linking to the website summary.

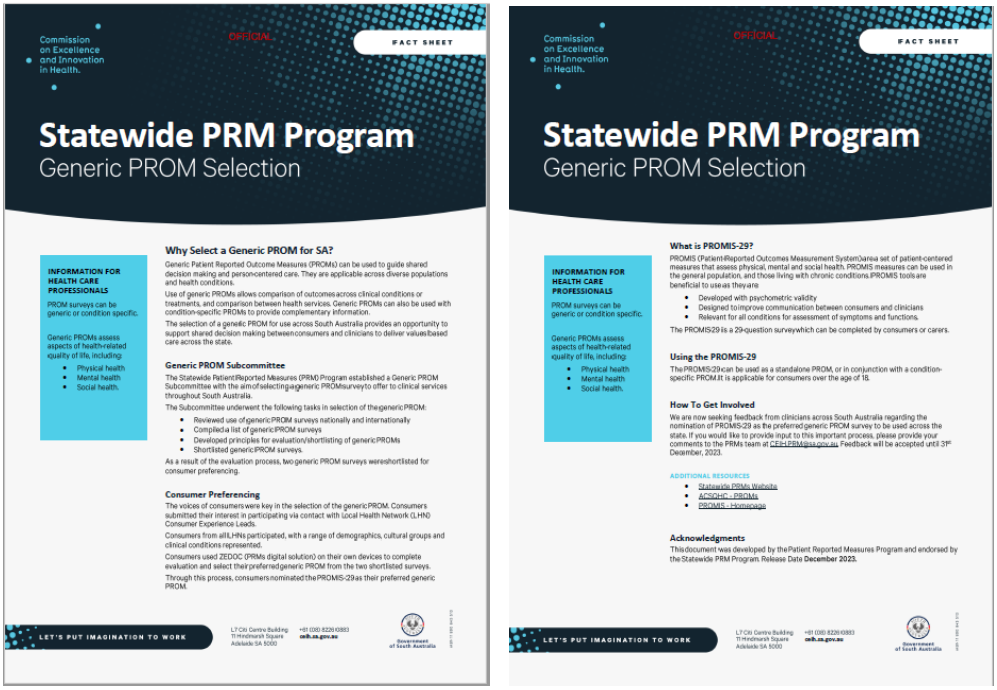

Figure 16: Communications fact sheet for Clinicians

Virtual Consultation Sessions

Workshop-style engagement occurred with selected implementing services. Sessions were approximately 30 minutes in duration and covered the following:

- Role of the Generic PROM Subcommittee
- Shortlisting methodology
- Consumer Participation
- Consumer Preferencing and Results
- Clinical Applications of PROMIS-29
- Discussion and Feedback
- Next Steps.

Three workshops were delivered between 20th December 2023 and 4th January 2024.

Clinician Feedback

Whilst this process targeted feedback by clinicians, feedback was received by both clinical and non-clinical staff, via email and verbally.

Overall, feedback from clinicians was positive and supportive regarding future use of PROMIS-29. Clinical specialties that provided feedback included:

- Medical (Rheumatology, Oncology, Radiation Therapy)
- Surgical (Plastics)
- Nursing (South Australian Medical Imaging)
- Paramedic

Specifically, clinicians commented on the following:

- Advantages of selecting a generic PROM that matches what other states use

- Advantages of using a generic PROM in areas with broad scope of disease; or have a multi-system or functional impact
- Potential future benefits for Computer Adaptive Testing-Item Response Theory (CAT-IRT)
- Potential integration of the PROMIS-29 with condition-specific PROMs
- Welcoming of a generic tool allowing comparison across populations
- A fantastic indicator to clinicians on status of an individual's quality of life
- Straightforward and easy to understand questions
- Helpful to have clear preference data from consumers; having consumer engagement from the start means that use of the tool is more likely to succeed in the long run

Additional comments and feedback:

- Consider the PROMIS-29 a screening tool and recommend clearly defined cut offs to define those who require more detailed assessments
- Recommendation for use of the Problem Checklist (tool not included in shortlisting)
- PROMIS-29 not appropriate for use in cancer care
- Request for a generic cancer PROM
- Communication with LHN Chief Executive Officers from start of process to get more engagement
- Ordering of responses (for one tool) is not consistent for every question

Three clinical services stated they would be happy to use PROMIS-29 with their condition-specific PROM in the future.

Feedback from non-Clinicians

Non-clinical staff who provided feedback were members of the PRM Program Board and non-clinical members of the PRM Research Collaborative.

Positive feedback included:

- Aligns well with the biopsychosocial models and follows domains to be reviewed from a developmental perspective
- Comprehensive measure that covers a breadth of quality-of-life domains

Additional comments and feedback:

- Designed for those 18+ years with chronic conditions
- Further work required on preferred language, learning style and barriers to communication
- Query regarding language translations and
- Concerns using longer tool on literacy level
- Terminology used and whether this is current and equitable (e.g. use of the term 'vacuuming/yard work')
- Not a preference-based measure and therefore cannot obtain utility scores or directly apply scores in calculating Quality Adjusted Life Years or Cost Utility Analyses

Responses Provided to Feedback

Respondents were provided the following points to provide further context to their feedback:

- The generic PROM will be optional, not mandatory and does not preclude use of other tools e.g. EQ-5D-5L
- Development of future resources, for example a 'decision guide' for clinical staff is planned
- Supporting use of PROMIS-29 with condition-specific PROMs
- Future work to occur in selection and implementation of generic PROM in paediatric populations
- Future work in minor amendments to language

- Initial implementation of the generic PROM will be in English; future langage translations are planned
- The goal in implementation is for consumers to report quality of life; future work on economic analysis could occur

Feedback received from clinical staff indicates they are supportive of the recommendation for the PROMIS-29 to be the generic PROM for South Australia.

This finalises the assessment of the PROMIS-29 against the principles developed by the Generic PROM Subcommittee.

Table 9: PROMIS-29 Rating against Generic PROM Subcommittee Principles

	Principles	Description	Rating (red, yellow, green)
A	System Perspective	Enables a system-wide view and comparison across broad patient populations	
B	Economic Evaluation	Enables economic analysis – cost-effectiveness or cost-utility analyses	
C	Language and Cultural Translation	Existing translation to multiple languages and ability to be adapted to suit cultural needs	
D	Future Proof	Aligns with digital systems evolution, emerging survey technologies, and trends in PROMs development	
E	Cost Effective	Licensing and cost of use are manageable from a system and service perspective	
F	Psychometric Properties	Ability of the tool to measure what it claims to measure – including validity, reliability and responsiveness	
G	Clinical Relevance	Able to be meaningfully integrated into clinical decision-making processes and provides actionable insight	
H	Consumer Relevance	Relevant, understandable, and manageable for consumer and/or carers	

PROMIS-29 - Advantages and Uses

The PROMIS tools were designed to enhance communication between clinicians and consumers.[11] The suite of tools were created to be relevant across multiple conditions for the management of symptoms and functions. The PROMIS tools are available in multiple formats and languages.

PROMIS-29 measures change from the perception of the consumer. It enables consumers to raise issues and discuss their concerns and engage in conversations about their care and treatment decisions.

PROMIS-29 also promotes shared decision making and identifies domains where the consumer may benefit from additional support or referral.[11]

Broadly, PROMIS-29 assesses:

[11] HealthMesures. 2023

- Physical function
- Pain interference
- Fatigue
- Sleep disturbance
- Depression
- Anxiety
- Participation in social roles and activities.[11]

It can also be a useful screen for disability, identify healthcare disparities, and improve population health.

PROMIS-29 is scored using T-score metrics, allowing for comparison across domains, health problems and with the general population. When used with a condition-specific PROM, PROMIS-29 can capture more common health related quality of life domains affecting the consumer, but are unrelated to their clinical condition.[11]

PROMIS-29 is validated in the general population, and multiple clinical conditions, including:

- Cancer
- Inflammatory bowel diseases
- Chronic kidney disease
- Burns
- Haemophilia
- Musculoskeletal diseases
- Systemic Lupus Erythematosus
- Aortic Dissection
- Elderly consumers with chronic conditions.[11]

PROMIS tools also have capability to add CAT-IRT. This allows higher precision, lower respondent burden, and can reduce the question set to 4-6 items. Additionally, PROMIS tools allow the ability to calculate Quality Adjusted Life Years for economic evaluation.

Generic PROM - Intended Use

To achieve system level impacts of the usage of a generic PROM, the recommended tool/s will need broad uptake across the South Australian health system. The Statewide PRMs Program will support the uptake of the PROMIS-29 by:

1. Undertaking a program of education around values based healthcare and the use of PRMs throughout SA Health services
2. Recommend the PROMIS-29 to clinical services, in addition to condition/cohort specific tools
3. Limit the usage of other generic PROMs within the ZEDOC solution unless usage is clinically justified and supported by the PRM governance group.

Recommendations

Following a shortlisting process, consumer preferencing and clinician feedback, the PROMIS-29 has emerged as the most appropriate generic PROM for use by South Australian clinical services.

Based on the assessment and consultation that has occurred, the Generic PROM Subcommittee recommends:

4. Endorsement of the PROMIS-29 as the preferred generic PROM tool for consumers aged 18+ years within South Australian clinical services
5. Implementation of the PROMIS-29 within appropriate clinical services utilising ZEDOC
6. Further refinement of preferred condition/demographic-specific PROMs for South Australia occurs.

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Appendix 1: Generic PROM Subcommittee – Membership List

Name	Position	Job Title
Ian Brownwood	Chair	Health Economist and Senior Consultant, Health Policy Analysis Ltd, New South Wales
Professor Julie Ratcliffe	Member	Professor of Health Economics, Flinders University, South Australia
Doctor Tamara Crittenden	Member	Research Co-ordinator, Flinders University, South Australia
Professor Catherine Hill	Member	Head of Unit, Rheumatology, The Queen Elizabeth Hospital, South Australia
Doctor Claudia Bull	Member	Research Fellow, University of Queensland, Queensland
Doctor Rasa Ruseckaite	Member	Senior Research Fellow, Monash University, Victoria
Alison Williams	Member	Consumer Representative, South Australia
Sadie Goddard-Wrighton	Member	Consumer Representative, South Australia
Melissa Tinsley	Member*	Associate Director, IDEA Team, Agency for Clinical Innovation, New South Wales
Ron Tenenbaum	Member*	Chief Executive Officer, The Clinician, New Zealand
Megan Scott	Member*	Director, Patient Reported Measures Program, South Australia
Caroline Bartle	Member*	Implementation Manager, Patient Reported Measures Program, South Australia

*non-voting members

Appendix 2: Generic PROMs Long-list

Name	Year	Country Developed	Description
Activity Measure Post-Acute Care (AM-PAC)	2004	USA	Tested in acute hospital, inpatient rehab, post-acute care, hip fracture, stroke, cancer, older patients, orthopaedics, medically complex cases
European Quality of Life-5 Dimensions 5 Level (EQ-5D-5L)	1990	Europe	Descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 5 levels: no problems, slight problems, moderate problems, severe problems and extreme problems
Nottingham Health Profile (NHP)	1981/ 1985	UK	Originally created as a standardised tool to survey health problems and measure medical or social interventions. Originally generated based on extensive discussions with patients
Patient-Reported Outcome Measurement Information System (PROMIS) – PROMIS-10, PROMIS-29 and PROPr	2010	USA	Set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children
Sheehan Disability Scale (SDS)	1983	USA	Developed to assess functional impairment in three inter-related domains; work/school, social and family life
Short Form (SF-36; SF-12)	1992	UK	SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. 36 questions that cover eight domains of health; Limitations in physical activities because of health problems, Limitations in social activities because of physical or emotional problems, Limitations in usual role activities because of physical health problems, Bodily pain, General mental health (psychological distress and well-being), Limitations in usual role activities because of emotional problems, vitality (energy and fatigue), General health perceptions
World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0)	2010	International	A generic assessment instrument for health and disability. Used across all diseases, including mental, neurological and addictive disorders. Applicable in both clinical and general population settings. Applicable across cultures, in all adult populations.
World Health Organization Quality of Life; (WHOQOL-BREF; WHOQOL-100)	1998	International, inc. Australia	WHOQOL is a quality-of-life assessment developed by the WHOQOL Group with fifteen international field centres, simultaneously, in an attempt to develop a quality-of-life assessment that would be applicable cross-culturally
Assessment of Quality of Life (AQol)		Monash University	Health-related multi-attribute utility quality of life instruments. Initially they were designed for use in economic evaluation studies. However, their use is broader and need not be limited to economic or health related work. To date, four AQoL instruments have been developed.
Genetic Counseling Outcomes Scale (GCOS-24)	2011	UK	A 24-item outcome measure for clinical genetic services specifically focusing on an experience of empowerment among patients.
Health Utilities Index (HUI)	2015	Canada	Describes health status, measures within-attribute morbidity and HRQoL, and produces utility scores. There are three versions - HUI, HUI2 and HUI3. Translated into 35 languages. HUI is a family of generic preference-based systems for measuring comprehensive health status and HRQoL. Health dimensions include vision, hearing, speech, ambulation/mobility, pain, dexterity, self-care, emotion, cognition.
Quality of Well-Being scale Self-Administered (QWB-SA)	2012	USA	Measures HRQoL, monitors health of populations over time, evaluates efficacy and effectiveness of clinical therapies of practices using preference-weighted self-administered measure. Preference-weighted measure of health status and overall well-being over the previous 3 days in four domains: mobility, physical activities, social activities, symptom/problem complexes. Translations available.
HowsYourHealth	1997	USA	Research shows basic information tailored to the needs of the respondent and their doctor or nurses is most likely to make communication better, place everyone on 'the same page' and increase confidence with self-care

Appendix 3: Consumer Generic PROM Selection Evaluation Survey

Section 1: Demographics

1. What is your age group?
   Answer type: single select
   a. 18-24
   b. 25-44
   c. 45-64
   d. 65-84
   e. 85 or over
2. What is your gender?
   Answer type: single select and free text
   a. Male
   b. Female
   c. Non-binary
   d. Prefer to self-describe – *free text field when selected*
3. Do you use a language other than English at home?
   Answer type: single select and free text
   a. Yes – *free text field when selected*
   b. No
4. Do you identify as Aboriginal or Torres Strait Islander?
   Answer type: single select
   a. Aboriginal
   b. Torres Strait Islander
   c. Both Aboriginal and Torres Strait Islander
   d. None
5. How many encounters have you had with the health system in the last 12 months?
   Answer type: scale from 1-100+; increments of 1
6. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacist?
   Answer type: single select
   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Always

Section 2: Survey Evaluation

Please mark the survey which you felt best reflects each statement. You may select yes, no or unsure.

1. The questions were easy to understand.
   Answer type: drop down – yes, no, unsure
   a. EQ-5D-5L
   b. PROMIS-29
2. I found the survey questions to be meaningful to me.
   Note: meaningful could mean that the questions were important, useful, significant, or purposeful to you.
   Answer type: drop down – yes, no, unsure
   a. EQ-5D-5L
   b. PROMIS-29
3. The survey asked questions that allowed me to provide enough information on my quality of life.
   Answer type: drop down – yes, no, unsure

   a. EQ-5D-5L
   b. PROMIS-29
4. The information and survey were clearly presented on the screen of my device.
   Answer type: drop down – yes, no, unsure
   a. EQ-5D-5L
   b. PROMIS-29
5. The time it took me to fill in the survey was acceptable.
   Answer type: drop down – yes, no, unsure
   a. EQ-5D-5L
   b. PROMIS-29
6. The steps to access the surveys on my device were easy to follow.
   Answer type: single select
   a. Yes
   b. No – *if 'no' selected, question 7 appears.*
7. If no, what would have made it easier to follow?
   Answer type – free text field
8. Based on your experience today, please select your top survey preference. You may select one survey only.
   Answer type: single select – tick box
   a. EQ-5D-5L
   b. PROMIS-29
9. Why did you vote this way?
   Answer type: free text field

Appendix 4: Consumer Generic PROM Written Feedback

Preferenced survey	Reason	Other info/data
PROMIS-29	Larger scope to draw from e.g. seven days instead of today. If just focussing on one day doesn't not give enough allowances for fluctuations in health.	
PROMIS-29	The Promis 29 seemed to give more of a spectrum of general health matters over a 7-day period. Where the Euro was that day. I couldn't work out the scaling question there was no clear instructions to slide and select or tap screen etc...I actually emailed Caroline thinking I'd done something wrong. 29 questions obviously do take a little longer to get through and some of the sequencing changed which confused me (but maybe I was going to fast paced). I'm curious as to where a question might include the perspective of a carer, e.g. my father might have been inclined to rate more positively himself but if there was a question how do your loved ones/carers perceive you it might be rated differently for example and may offer a useful perspective.	Also emailed feedback: Just one more comment on the PROMIS – they had mostly provided past tense questions then there was one question referencing present tense – I feel fatigued – rather than I felt fatigued. It's a little thing but might trip some people up.
EQ-5D-5L	It was easy	
PROMIS-29	I found this survey to be very comprehensive and the questions were very specific. I feel that this survey would be able to capture the consumers overall health and quality of life.	
PROMIS-29	I felt like I could be more specific responses as there were more number options and I felt I had more choice.	
EQ-5D-5L	Much simpler, the scale from 1-100 in correlation with the format of the other questions was difficult and the second survey was repetitive	
PROMIS-29	Thought providing a snapshot of the past 7 days was more helpful than just a snapshot of one day as more detail would enable the health professional to better understand how I was "travelling". Giving more detail made me feel that the health professional was genuinely interested in how I was coping with life - made me feel heard. Giving more detail helped me reflect more on how I was travelling so might help me to have a more constructive conversation with the health professional.	
PROMIS-29	The survey chosen, being the first one, had more questions which allowed me to give more information which I felt covered more of my whole experience. My perception was that the questions focused on one subject or issue at a time and therefore easier to provide a thoughtful response much quicker. As opposed to the second survey which seemed to ask double barrelled questions (for the want of a better term) e.g. do you feel tired because you are anxious? These questions I felt took longer to consider and were	

Preferenced survey	Reason	Other info/data
	'harder' to think about. The irony being that the longer survey was easier on the mind and time.	
PROMIS-29	A more comprehensive cross section of my daily experiences to indicate current challenges.	
PROMIS-29	The questions were clearer and more detailed, so it felt like I was giving more accurate and useful information about my personal situation.	
PROMIS-29	Questions related to health issues mostly	Scale button needs highlighting
PROMIS-29	The method required to complete Promis was clearly and simply stated. Importantly the action was consistent throughout. The range of questions was more comprehensive and pertinent; they covered both physical and emotional health issues. For me, personally, this caused me to be more discerning about myself. Therefore, I think it would be more helpful to the health practitioner.	Additional feedback: EQ-5D-5L's Best Health Measure did not explain clearly what was required.; i.e. to move the scale up or down to record one's own ap0preciation of one's health. Whilst this can be seen a nit picking, for someone nervous about using a computer or completing important personal information on the web this can be disconcerting, even off-putting. I needed a simple direction on what to do there. On the other hand, Promis's directions were clear, and the action required was consistent throughout; the range was comprehensive addressing both physical and emotional health.
PROMIS-29	I feel this survey was a bit more in depth.	
EQ-5D-5L	The questions in the aEQual 5 were relevant to me. More subjective.	
EQ-5D-5L	Better questions	
EQ-5D-5L	I found the promos survey too long and repetitive	
PROMIS-29	This servant asked me questions I can relate to also easy to understand and answer without feeling like I am being judged. The questions were straight forward with easy yes no answers.	
PROMIS-29	I believe that there was more to respond to that gave me satisfaction in assessing my health needs and wants.	
EQ-5D-5L	Questions were more direct and not repetitive.	
PROMIS-29	Although it was a longer survey which might be better shortened a little. It was easy to go through the questions without having to read like in the other survey.	I didn't like having to read all the questions. Liked the first survey better - reading only one question. (First survey was PROMIS-29)
PROMIS-29	This survey was more comprehensive.	
PROMIS-29	the questions were more relevant to me with auto immune issues, it felt more about my general overall health than my mental health. In any discussion about my general health answers on the 2nd questionnaire, I am sure the health professional would be able to raise	

Preferenced survey	Reason	Other info/data
	and discuss the mental health repercussions at that point. A person suffering from ill health may not appreciate that they are suffering from depression as a result of disappointment, frustration, lack of energy, withdrawal, anxiety with their health issues etc so may not correctly answer the first questionnaire. The second questionnaire gives the health professional an opportunity to ask questions on the rates and levels of pain, lethargy etc and the effect that has on the patient. Defiantly the second questionnaire. Thanks for the opportunity to have a say.	
EQ-5D-5L	I could answer q's with a quicker response rate	
PROMIS-29		The question about how many interactions with health professionals you were only able to give exact number, I think it should be a number range. As people with lots of health issues may go many times but won't remember how many but could give an approximate range
PROMIS-29	I found that the questions were more involved & gave more options to give a more accurate answer.	
PROMIS-29	The potential answers are shorter in length, despite there being more questions, it is easier to digest.	
EQ-5D-5L	Because the questions seemed to relate to issues I am concerned about	
PROMIS-29	Yes	
PROMIS-29	It just seems to flow well and easy print	
PROMIS-29	MORE COMPREHENSIVE, MORE DEMOGRAPHICS EASY TO ANSWER	
PROMIS-29	It was more involved and found it easier to use. The questions suited me more as a consumer.	
EQ-5D-5L	Was more meaningful to me as I went through, the exercise although both were straightforward.	
EQ-5D-5L	The other survey was not consistent. The questions asked in the last seven days, but not all of the questions.	
PROMIS-29	I felt there was more content in the first survey and covered more areas of concern and daily living needs.	First survey was PROMIS-29
PROMIS-29	It was based on a time frame of 7 days. Same as a DASS 21 for Mental Health Evaluations. My only issue is with pain scales. Those of us with chronic everyday pain need a different scale. Not truly reflecting what we live with.....our pain tolerance is higher.	
EQ-5D-5L	Felt easier and more comfortable	
PROMIS-29	The survey seemed like it covered a more holistic view of where things were at in my life now to provide that information to a clinician.	

Preferenced survey	Reason	Other info/data
	The other survey was too brief, and didn't seem like it was worth the effort of doing it for such limited information to be shared.	
PROMIS-29	I would be happy with either survey. However, I though PROMIS asked a few more questions which would help to assess a person's health and wellbeing.	
PROMIS-29	Questions were more specific with less room for uncertainty on how to answer	
EQ-5D-5L	The shorter survey with direct questions appealed to me, and was very clear. Doing a shorter survey that was so quick to complete felt like I'd achieved something in such a short amount of time.	Additional feedback via email: When I started the Euro survey it wasn't clear where to press to advance the survey. A little note like "click blue down arrow to continue" could be helpful. Information on how to drag the dot in the health scale question would also be beneficial. I figured it out fairly easily but making things as easy as possible for elderly or less tech savvy patients might be an idea. The second PROM seemed very repetitive with the questions on fatigue and depression, I feel like you might lose some patients who decide they don't want to finish the survey.
PROMIS-29	Having more questions enables me to be able to give a more thorough indication of how my day to day life is	
PROMIS-29	I felt the questions were more extensive - if I had physical or emotional or mental issues in the last 7 days I feel they would have been visible to a practitioner to then probe further.	
EQ-5D-5L	I found the questions very straight forward and relevant to my situation.	
PROMIS-29	I think the longer survey covered more dimensions of health and wellbeing although I preferred the scale of 1-100 for gauging health. I think too that a similar 100 scale is needed for separate dimensions of anxiety and depression because can have one without the other. Also question that asks "are you able to 'run' errands is a bit ambiguous because it might be interpreted as being able to run doing errands when it really means 'able to undertake or perform the errands' .. so suggest change the wording	
PROMIS-29	more information was asked which I felt was more beneficial	
PROMIS-29	This survey was a little more comprehensive.	

Preferenced survey	Reason	Other info/data
EQ-5D-5L	It was quick & easy & captured ability to live a normal life. The PROMIS had a large focus on pain which is likely relevant to many but not really to me. What I don't know is whether the PROMUS provides more useful info to healthcare providers. I feel like something in between might work best?	
PROMIS-29	I feel the Proms survey covered the most with in-depth follow up questions. However, I can see that some Consumers will find it annoying "repeating" a question several times. When I initially launched into both survey's I felt the information slides had a lot of "dead space" and I wasn't sure if more information would automatically flow down in segments. Both surveys felt fine besides the dead space.	
PROMIS-29	The survey I selected was the one I felt covered all the bases and I related most to; both surveys seemed good. Could be it was the variety and depth of the questions in the one I selected just seemed more natural to me and easy to respond to. The one I did not choose had a scale of 0 - 100 on my health which I actually found difficult to reply to because … it seemed like a more complicated question I think, a large scale to try and lean into. From my point of view I chose the one that felt most relatable, but the margin between the two is very fine, if I were presented with the survey I did not select I think I would basically handle it without stress. Best of luck to you in your continued work. I have enjoyed this experience. Thank you.	
PROMIS-29	I found that the more questions were adding to the information. The other was more brief and not so comprehensive.	
PROMIS-29	the questions were more meaningful to me	
PROMIS-29	Found it easier to follow, less wordy, the slide button on the other survey was more challenging on my iPhone had to zoom in. The promise survey certainly felt the. Right fit.	

Document Revisions

No.	Date	Description	Person
R0.1	28/11/2023	Draft version	Caroline Bartle, Skye Hayes
R0.2	02/01/2024	Updated draft	Caroline Bartle
R1.0	04/01/2024	Final draft version 1.0	Caroline Bartle, Skye Hayes
R2.0	22/01/2024	Final draft version 2.0	Caroline Bartle, Skye Hayes, Megan Scott
R3.0	02/02/2024	Final draft version 3.0	Caroline Bartle
1.0	07/02/2024	Final version 1.0	Caroline Bartle
2.0	09/02/2024	Final version 2.0	Caroline Bartle
3.0	12/02/2024	Final version 3.0	Caroline Bartle