

# Pathways to Community Living Initiative

---

Final Evaluation Report

The authors acknowledge the mental health professionals, consumers and families who have contributed to resources produced by the Pathways to Community Living Initiative (PCLI), as these documents provided useful reference material for this report. We also extend our thanks to the stakeholders who offered their time and expertise through participating in interviews, surveys and other data collection processes to inform the PCLI evaluation. We acknowledge the extensive work and vigilant methodology employed by InforMH and the Ministry PCLI team to produce the consumer outcomes datasets.

We acknowledge the contributions of Malcolm Masso and Tim Coombs to the evaluation design. We would also like to thank staff from the funding body, especially the Ministry PCLI team led by Robyn Murray and Kate Jackson, and wider Mental Health Branch, NSW Ministry of Health and the Local Health District PCLI program managers, senior coordinators and executive leads, for their vision, energy and ongoing commitment to this evaluation.

We particularly acknowledge the lived experience of people with a mental illness; your preferences, wishes, needs and aspirations are at the heart of this program, your perspective is essential to defining and achieving the goals of the PCLI.

Williams K, Kobel C, Westera A, O'Shea P, Rahman M, Morris D and Thompson C (2021) Pathways to Community Living Initiative – Final Evaluation Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong, Wollongong.

# Foreword



This is the final report on the independent evaluation of the first years of the Pathways to Community Living Initiative (PCLI) by the Australian Health Services Research Institute (AHSRI), University of Wollongong.

NSW Health is pleased to have been working with Professor Kathy Eagar, Director of AHSRI

and her team from 2017 until December 2021 to progress this evaluation, and acknowledges the commitment, diligence and rigour demonstrated by the evaluators over this time. There has been a significant investment by AHSRI in its engagement with the Ministry and with the Local Health District mental health services, consumers, families and carers as well as with community-based service partners.

The PCLI is a major system reform program with a focus on people experiencing severe and persistent mental illness (SPMI) and exceptionally complex needs who have experienced long-stays in inpatient services or who are at risk of long stays or recurrent hospitalisations. In 2015, when the program was established, NSW had over 380 patients who were long-stay, many of whom had been in our hospital system for over ten years; some much longer. Through the PCLI, NSW Health has led a comprehensive and person-centred approach to working with these individuals, and developed strong partnerships with community-based services. This has enabled the majority of these individuals to successfully transition to the community, and created pathways to community-based care that will help prevent long-stays and provide improved care and support in the future.

The evaluation details the major components of this state-wide reform program. These include additional clinicians within multidisciplinary teams based within Local Health Districts (LHDs), cross-sector partnerships, and strategic leadership and resources provided by the NSW Ministry of Health, combined with strong local executive leadership and program management.

This final report - Report 7 - presents the summative findings of the mixed methods evaluation activities and formative information to guide continuing reform within mental health services. This includes administrative data, cost of care estimates, program documents, participant observation, staff surveys, and semi-structured interviews with a variety of stakeholders including patients, family, carers, PCLI clinicians and program managers, and mental health service staff.

Overall, the evaluation demonstrates that:

- People with severe mental illness and complex care needs can be managed successfully in community settings if suitable supports are provided.

- People who transitioned to community living through the PCLI reported feelings of safety, independence and freedom.
- The PCLI has contributed to improved quality and sustainability of transitions to community for this small group of patients.
- Transitions from hospital to aged care (for those with significant issues of ageing) resulted in substantial reductions in costs of care.
- The PCLI has contributed to positive changes in clinical practice and organisational culture in mental health services.

The evaluation identified a number of important contributors to the program's success in promoting and embedding recovery orientation in mental health services, such as:

- well-documented and clear processes to guide and improve transition planning;
- engagement with patients, family and carers;
- the role of the PCLI multidisciplinary teams in building capacity and bridging gaps between services and sectors;
- collaborative efforts to build medical leadership in rehabilitation psychiatry; and
- the establishment of networks to share knowledge and promote good practice across NSW.

NSW Health appreciates the key recommendation from the evaluation that 'ongoing work is needed to embed these changes' and acknowledges that 'transitioning vulnerable people out of hospital successfully will always require the flexibility and expertise for cross-sector working and well-resourced community mental health services.'

As the evaluators have summarised: *The ultimate test of success and sustainability was encapsulated by one person very early in the program. Interviewed in 2017, this person said the PCLI was not about the housing itself, or even about the clinical and functional supports available. It was about giving people the chance to have ordinary, everyday interactions with others, who may or may not also have a mental illness. Then they are truly living in the community.*

I welcome this report.



**David Pearce**  
**Executive Director**  
Mental Health Branch  
NSW Ministry of Health



# Pathways to Community Living Initiative

---

Final Evaluation Report

# Contents

<b>Foreword</b>	<b>3</b>
<b>Glossary of terms and abbreviations</b>	<b>12</b>
<b>Executive Summary</b>	<b>14</b>
Background	14
Methods	15
Findings	15
Recommendations	18
Conclusion	19
<b>Structure of Report</b>	<b>20</b>
<b>Part 1</b>	<b>21</b>
<b>1 Introduction</b>	<b>22</b>
1.1 Scope and structure of this report	22
1.2 Background	22
1.2.1 Recovery orientation	22
1.2.2 The target population	23
1.2.3 Program design and delivery	23
1.2.4 Strategic objectives and outcomes	24
1.2.5 Quadrant framework for implementation	24
<b>2 Evaluation methods</b>	<b>27</b>
2.1 Evaluation design	27
2.1.1 Ethical approval	28
2.1.2 Evaluation questions	28
2.2 Routine administrative data	29
2.2.1 Data sources	29
2.2.2 Data preparation and linkage	29
2.2.3 Data analysis: consumer outcomes	30
2.2.4 Data analysis: costs of care	31
2.3 Survey of inpatient staff	33
2.3.1 Materials	33
2.3.2 Procedure	33
2.3.3 Participants	33
2.3.4 Analysis	33
2.4 Qualitative methods	34
2.4.1 Consumer and carer interviews	34
2.4.2 Key informant interviews	35
2.4.3 Data preparation and coding	35
2.4.4 Carer and consumer interview analysis	36
2.4.5 Key informant interview analysis	36
<b>3 Program achievements</b>	<b>37</b>
3.1 Transitions to community living	38
3.2 Success factors	39
3.3 Consumer and carer experiences	39

3.4	Service development	40
3.5	Reform of mental health services	41
3.6	Sustainability	41
3.7	Value for money	42
3.8	System efficiency	42
<b>Part 2</b>		<b>43</b>
<b>4</b>	<b>Consumer outcomes</b>	<b>44</b>
4.1	Data quality, availability and completeness	44
4.2	Profile of the PCLI cohort at baseline	47
4.2.1	Health status at baseline	49
4.3	Transitions to community living	53
4.3.1	Factors predicting transition	54
4.4	Health outcomes following transition from hospital	57
4.4.1	Stage One health outcomes	57
4.4.2	Stage Two health outcomes	58
4.5	Consumer journeys after transition	59
4.5.1	Presentations to hospital emergency departments	59
4.5.2	Mental health related readmissions	60
4.5.3	Community mental health service use	61
4.5.4	Consumer profile in MH-RAC network services	61
<b>5</b>	<b>Consumer and carer experiences</b>	<b>64</b>
5.1	Vignettes: pre-transition histories	65
5.2	First-hand accounts by consumers and carers	66
5.2.1	Experiences of the transition process	66
5.2.2	A home in the community	68
5.2.3	Health and wellbeing	70
5.2.4	Social participation and meaningful occupation	73
5.3	Lived experience reflections	75
5.3.1	Level of consumer participation in decision making at the transition stage	75
5.3.2	Tensions between choice and duty of care	75
5.3.3	Accommodation issues	76
5.3.4	Hospital reform	76
5.4	Key informants' perceptions of consumer and carer experiences	76
5.4.1	Consumer engagement	76
5.4.2	Carer engagement	79
5.4.3	Perceived benefits for consumers and carers	79
<b>6</b>	<b>Provider and system change</b>	<b>82</b>
6.1	Availability of expertise and skills	82
6.1.1	Staffing enhancements	82
6.1.2	Training	83
6.1.3	Coaching and mentoring	83
6.1.4	Consultation and empowerment	83

6.2	Collaboration within health services	84
6.3	Community support	85
6.3.1	‘Getting to Know You’ processes	85
6.3.2	Matching people with the right supports	86
6.3.3	Monitoring and follow-up assessments	87
6.3.4	Capacity building with disability providers	88
6.3.5	Functional partnerships across mental health and aged care	88
6.4	Culture of recovery	90
6.4.1	The challenge of culture change	90
6.4.2	Progress towards a recovery culture	91
<b>7</b>	<b>Economic evaluation</b>	<b>94</b>
7.1	Costs of hospital-based care	94
7.2	Costs of aged care services	95
7.3	Costs of disability-related support	97
7.4	Total costs	97
7.5	Summary of cost comparison	98
<b>Part 3</b>		<b>99</b>
<b>8</b>	<b>Sustainability</b>	<b>100</b>
8.1	Embedding PCLI processes	101
8.1.1	Strategic leadership and governance	101
8.1.2	Defining the target group	102
8.1.3	Infrastructure and tools to inform clinical care	102
8.1.4	Sustainable practice change	104
8.1.5	Strengthening community mental health care	104
8.2	Policy alignment	105
8.2.1	Mental health care reform	105
8.2.2	Reform agendas in aged care and disability sectors	106
8.2.3	Value-based health care	106
8.3	Stage Two service developments	108
<b>9</b>	<b>Discussion</b>	<b>110</b>
9.1	Leadership	110
9.2	Collaborative monitoring and measurement	111
9.3	History and context	112
9.4	Clinical engagement and co-direction	112
9.5	Consumer and carer engagement	113
9.6	Cross-sector engagement and capacity building	114
9.7	Conclusion	114
<b>References</b>		<b>115</b>
<b>Appendix 1: Staff survey results</b>		<b>121</b>
<b>10 Responses to the Round 2 staff survey</b>		<b>123</b>
10.1	Differences within the Round 2 sample	124
10.2	Differences between Round 1 and Round 2	125
10.3	Summary	126
<b>Appendix 2: PCLI program logic</b>		<b>127</b>
<b>Appendix 3: Consumer outcomes analysis – additional tables</b>		<b>128</b>



# Figures

Figure 1	Structure of this report.....	20
Figure 2	PCLI quadrant framework for program implementation .....	24
Figure 3	Evaluation components and evaluation questions.....	28
Figure 4	PCLI Program Logic.....	37
Figure 5	Consumers with MH-OAT baseline assessment by year of transition .....	46
Figure 6	Consumers with PCLI baseline assessment by year of transition .....	46
Figure 7	LCQ responses .....	51
Figure 8	Predictors of discharge from hospital .....	54
Figure 9	Comparison of ACFI scores .....	63
Figure 10	Multilevel factors in implementation and sustainability (Stirman et al., 2012).....	100
Figure 11	Proposed Specialist Living Support models for Stage Two .....	109

# Tables

Table 1	PCLI toolkit –selected mental health measures .....	25
Table 2	Stage One MH-RAC services.....	26
Table 3	PCLI Evaluation Framework .....	27
Table 4	Ethics applications –PCLI evaluation.....	28
Table 5	GGFCE chain price index .....	32
Table 6	Number of assessments by time point .....	45
Table 7	Consumers with paired assessments (before and after transition).....	47
Table 8	Profile of consumers by stage and cohort .....	48
Table 9	Overview of tools used in the consumer outcomes evaluation.....	49
Table 10	Transition status by stage and cohort.....	53
Table 11	Factors predicting discharge from hospital.....	55
Table 12	Additional factors predicting discharge from hospital for Stage One.....	56
Table 13	Health outcomes after transition for Stage One.....	58
Table 14	Health outcomes after transition for Stage Two.....	59
Table 15	Emergency department presentations after discharge from hospital.....	60
Table 16	Hospital readmissions after discharge from hospital .....	60
Table 17	Profile of consumers in MH-RAC .....	62
Table 18	Consumer engagement: themes and change over time .....	77
Table 19	Ambulance service activity and expenditure .....	95
Table 20	Daily ACFI subsidy.....	95
Table 21	Overview of partnership agreements.....	96
Table 22	Home care package subsidy.....	96
Table 23	Overview of care cost by type .....	97
Table 24	Cost of index stay compared to living in community .....	98
Table 25	Round 2 staff survey results .....	121
Table 26	Overall staff views of the PCLI in Round 1 and Round 2.....	125

Table 27	Differences between Round 1 and Round 2 survey responses .....	126
Table 28	K10 at baseline.....	128
Table 29	LSP-16 at baseline.....	128
Table 30	HoNOS at baseline.....	128
Table 31	HoNOS 65+ at baseline .....	129
Table 32	RUG-ADL at baseline.....	129
Table 33	RAS-DS at baseline .....	130
Table 34	LCQ at baseline –consumers reporting good to excellent .....	130
Table 35	CAN-C at baseline.....	130
Table 36	CANE at baseline .....	131
Table 37	M-DAD at baseline .....	131
Table 38	DemQOL at baseline .....	132



# Glossary of terms and abbreviations

ACFI	Aged Care Funding Instrument
Ax	Assessment (baseline)
CAC	Clinical Advisory Committees: weekly client review meetings comprising representatives of RACF, LHD PCLI and community mental health teams.
CAN-C	Camberwell Assessment of Need clinical version
CANE	Camberwell Assessment of Need for the Elderly
CLS	Community Living Supports
CMO	Community Managed Organisations
CNC	Clinical Nurse Consultant
CRAM	Clinical Risk Assessment and Management
DemQOL	Dementia Quality of Life
eMR	Electronic Medical Record
FTE	Full Time Equivalent
HASI	Housing and Accommodation Support Initiative – a NSW program to support people with a severe mental illness to live and participate in the community
HASI Plus	Housing and Accommodation Support Initiative Plus - a NSW program to provide extra support (16 -24 hour/day) for people with severe or persistent mental illness
HI	Health Infrastructure
HIE	Health Information Exchange. The NSW Health Information Exchange (HIE) is the primary and official source of all data relating to hospitals in NSW, including admitted patients, emergency department presentations and community health services provided by LHD / Specialty Health Network (SHN), mental health assessments and outcomes collections. Data from LHD / SHNs Patient Administration Systems (PAS), Community Ambulatory (CHAMB) and Mental Health Outcome and Assessment Tools (MHOAT) collections are routinely entered into the HIE. The data are used for funding purposes, reporting of Health Service Performance Agreements and other reporting.
HNE	Hunter New England
HoNOS	Health of the Nation Outcome Scales
HoNOS 65+	Adaptation of HoNOS for use with older people with a mental illness
Index Stay	The PCLI index stay was defined as the hospital inpatient stay that ended in transition into the community. For consumers who had not yet transitioned, the index stay was defined as the current stay.
InforMH	Information for Mental Health unit in System Information and Analytics (SIA) Branch of Ministry of Health. InforMH is responsible for collecting, distributing and supporting performance related reports on mental health services in NSW.
Initial Cohort	A group of around 380 mental health consumers who had been in hospital for over 365 days at the start of the PCLI. Information provided by the Ministry PCLI team shows that as at 31 December 2014 the estimated number of long-stay patients was 387. At the time of the first census in June 2015 there were 350 consumers in the initial cohort.
K10	Kessler 10 Depression scale
KI	Key informant; stakeholder interviewed by the evaluation team
KPI	Key performance indicator
LCQ	Living in the Community Questionnaire
LHD	Local Health District
LOS	Length of Stay
LSP-16	Abbreviated Life Skills Profile
M-DAD	Modified Disability Assessment for Dementia
MDC	Major Diagnostic Category
MDT	Multidisciplinary Team
MHACPI	Mental Health Aged Care Partnerships Initiative
MH-OAT	Mental Health Outcomes Assessment Tool collection, a set of tools collected by all mental health services every three months while admitted, every six-months post discharge, mandated nationally: K10, HoNOS, HoNOS 65+, LSP-16 and RUG-ADL.

MH-RAC	Mental Health – Residential Aged Care
MH-RAC Network	Network of Ministry and LHD PCLI staff, OPMH coordinators, and representatives of participating residential aged care facilities
Ministry	Ministry of Health
Ministry PCLI team	Staff working in the Ministry of Health to provide strategic leadership for the PCLI.
MOU	Memorandum of Understanding
MRN	Medical Record Number
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
OPMH	Older People's Mental Health
OT	Occupational Therapist
PAS ID	Patient Administration System Identification
PCLI	Pathways to Community Living Initiative
PCLI Collaborative Group	PCLI governance group meeting weekly to focus on the practical aspects of implementation. Comprises Ministry PCLI team and representatives from LHDs, contractors, and others as required.
PCLI Practice Network	Network of Ministry and LHD PCLI program managers, clinicians and peer workers
PCLI program managers	Staff responsible for implementation of the PCLI within the LHDs that comprise the six primary implementation sites
PCLI Steering Committee	Governance group for PCLI program, meets three times annually and comprises representatives of the Ministry PCLI team, LHDs, Mental Health Discipline Leads and other content experts
PHSREC	Population and Health Services Research Ethics Committee
PPE	Personal Protection Equipment
PRN	Pro Re Nata (as required), relates to the use of psychotropic medications
PTSD	Post-Traumatic Stress Disorder
PUG	Project User Group: team within Ministry that facilitates co-design of services through input from consumer and carer representatives on the service, functional and design requirements for the PCLI SLS services
RACF	Residential Aged Care Facility
RANZCP	Royal Australian and New Zealand College of Psychiatrists
RAS-DS	Recovery Assessment Scale - Domains and Stages
RFI	Request for Information
RFT	Request For Tender
RN	Registered Nurse – Degree level educated nurse, provides clinical leadership role in aged care
RUG-ADL	Resource Utilisation Groups – Activities of Daily Living
Second Wave	Consumers 'in scope' for the PCLI since 1 July 2015 because their length of stay exceeded 365 days or they were considered at risk of a long stay
SHN	Specialty Health Network
SIL	Supported Independent Living, NDIS-funded disability services provided by CMOs
SLS	Supported Living Services. Stage Two clients only.
SPMI	Severe and Persistent Mental Illness
Stage One	Service development and clinical service enhancements targeted at those individuals in the PCLI cohort who experienced significant issues of ageing.
Stage Two	Service development and clinical service enhancements targeted at individuals who are younger (18 years and upwards) without significant issues of ageing.
SWMHIP	state-wide Mental Health Infrastructure Program
WNSW	Western New South Wales

# Executive Summary

---

The Pathways to Community Living Initiative (PCLI) is a major mental health reform program led by the NSW Ministry of Health ('the Ministry') in collaboration with NSW Local Health Districts (LHDs). It is a key component of the whole-of-government enhancement of mental health care under the *NSW Mental Health Reform 2014-2024*. The PCLI represents a transformational change in the care of people with severe and persistent mental illness (SPMI) and complex needs who are, or are at risk of becoming, long-stay inpatients in NSW hospitals.

This is *PCLI Evaluation Report 7*, the final report of the independent evaluation conducted by the Centre for Health Service Development, University of Wollongong, between January 2017 and October 2021. The report presents the summative findings of the mixed methods evaluation activities and formative information to guide continuing reform within mental health services.

## Background

---

Personal recovery –having a meaningful, satisfying life even while experiencing the symptoms of mental illness –is a difficult struggle for some people. This is the case for people with SPMI and complex needs, who present particular challenges for delivery of mental health care and support services in the community. For many years it was assumed that the best place for these people was in a long-stay ward. Long hospital stays led to institutionalisation which compounded the difficulties of a return to community living. Because of their exceptionally high care needs, this group has not benefitted equitably from previous deinstitutionalisation efforts. The PCLI has sought to change this by introducing new inpatient and community mental health processes, care pathways and community-based supports.

The PCLI approach aims to support people with SPMI and complex care needs who have been in hospital for more than 365 days ('long-stay patients') to move into the community and to reduce the risk of future long-stay admissions. Stage One consumers are long-stay patients with significant issues of ageing, many of whom are eligible for support within the Australian Government's aged care programs, in particular residential aged care. These people generally require ongoing support from NSW Older People's Mental Health (OPMH) services or an OPMH clinician. Stage Two PCLI consumers are long-stay patients without significant issues of ageing, many (but not all) of whom are able to access specialist accommodation and support services with funding under the National Disability Insurance Scheme (NDIS). These consumers generally require ongoing support from community mental health services delivered by LHDs.

Two cohorts of consumers have been supported by the PCLI. The initial cohort consists of individuals who had been in hospital for more than 365 days at the census date of 30 June 2015. The second-wave cohort comprises individuals whose long hospital stay began after this date. Both cohorts include a mix of Stage One and Stage Two consumers.

A state-wide team supports local implementation. The program is led by the Ministry PCLI team, LHD executive leads, and PCLI program managers. Primary implementation sites are six Local Health Districts (LHDs): Hunter New England (HNE); Northern Sydney (NS); South-Western Sydney (SWS); Sydney; Western New South Wales (WNSW); and Western Sydney (WS). The mental health services in these LHDs house most of the long-stay patients in NSW public hospitals. Additional LHDs are: Nepean Blue Mountains (NBM), Central Coast (CC), Illawarra Shoalhaven (IS) and South-Eastern Sydney (SES) plus St Vincent's Specialist Health Network. Recently, the program has extended to include all the rural LHDs across NSW, with a senior clinician and rural program coordinator based at Murrumbidgee LHD. The PCLI steering committee includes consumer and carer representatives.

Each LHD has been allocated funding for senior clinical positions to support the implementation of the PCLI at the local level. Most now also employ PCLI-funded peer workers. At the time of the evaluation, the Ministry has approved enhancement funding for the full-time equivalent (FTE) of 48.8 positions, including 18.3 FTE Stage One and 26.5 FTE Stage Two team members (in January 2022 additional funding to LHDs increased this to 73.64 FTE positions including 18.3 FTE Stage One and 55.34 FTE Stage Two). Under the partnership agreements with the MH-RAC facilities, the PCLI provides additional funding to improve aged care staffing and preparedness to support people with SPMI and significant ageing-related needs. Planning is underway as part of the Statewide Mental Health Infrastructure Program (SWMHIP) for additional community-based services for people with SPMI and complex needs who do not have significant ageing-related issues.

# Methods

---

This is a mixed methods evaluation, using routinely collected administrative data from the Health Information Exchange (HIE) and the PCLI database, two surveys of inpatient mental health service staff, and qualitative data from semi-structured interviews with consumers, carers, PCLI program managers

and executive leads, PCLI peer workers and clinicians, leaders in OPMH and community mental health services, and inpatient and community mental health service staff members. Full details of the evaluation methods can be found in Chapter 2.

# Findings

---

In this section, an outline of the findings is presented for each evaluation question, based on the PCLI Program Logic Framework. These outcomes are important achievements and also interdependent facilitators of the anticipated impacts of the program beyond the timeframe of this evaluation. A full summary of findings can be found in Chapter 3, with detailed results in Chapters 4-7.

## How successful was the PCLI in transitioning people from hospital into the community?

Two thirds of PCLI consumers (674/1004, 67%) were transitioned to the community by the end of December 2020: 156/227 (69%) in Stage One and 518/777 (67%) in Stage Two. Almost one-fifth (19%) of Stage One consumers and around one-third of Stage Two consumers remained in hospital at 31 December 2020. Thirty-five (3%) consumers had died in hospital, most of whom were people with significant ageing-related issues.

Stage One consumers with reduced capacity in 'late loss' activities of daily living (RUG-ADL total score and toileting domain) were more likely to be discharged. For those assessed with the LSP-16, poorer general functioning and higher disability predicted discharge. Similarly, reduced capacity in instrumental and basic activities of daily living (M-DAD) was associated with higher likelihood of discharge. Although this might seem counterintuitive, it makes sense given the nature of the cohort. People experiencing greater disability and requiring greater assistance with activities of daily living would seem more suited to life in an aged care facility than those who were still relatively mobile and capable of self-care.

For Stage Two, people who were younger, had shorter length of stay, lower severity of mental health disorder (HoNOS), greater general functioning and lower disability (LSP-16) or lower psychological distress (K10) were significantly more likely to be transitioned into the community. The usual destinations for Stage Two consumers offer a range of disability supports but no 24/7 clinical support (although people are linked with community mental health services for regular follow-up). It appears that services are ensuring that Stage Two consumers are as clinically well as possible, and equipped for daily living, before arranging their transition.

Following discharge, Stage One consumers' general functioning and disability (LSP-16) improved on average, but cognition and physical health deteriorated (HoNOS 65+ impairment) and there was loss of function in activities of daily living (RUG-ADL total, bed mobility, transfers and eating). Changes in K10 and HoNOS were not significant. Stage Two consumers on average showed a decline in general functioning and disability (LSP-16) and deterioration in cognition and physical health (HoNOS impairment). Changes in K10, other HoNOS subscales, and HoNOS total were not significant. With the data available it is not possible to differentiate between the effects of ageing and mental illness and the impacts of change in accommodation and service provision. Consumers who completed the follow-up assessments may not be representative of all PCLI consumers. This is a limitation of the study.

Following transition to the community, the goal of the PCLI is to avoid further long-stay mental health care admissions and also to avoid a cycle of very frequent admissions; both these situations reveal a lack of community supports. Because of the severity of their mental illness, it is generally accepted that PCLI consumers will need occasional inpatient treatment. About 20% of Stage One and 33% of Stage Two consumers required mental-health-related readmissions, most resulting in stays of four weeks or less. Twenty-one consumers went on to have another hospital stay longer than 365 days. At 31 December 2020, 7 (4%) of Stage One and 45 (9%) of Stage Two consumers who had previously transitioned were current admitted patients.

Only a small proportion of transitioned consumers (7% of Stage One and 8% of Stage Two) presented to hospital emergency departments (ED). Almost all (31/33) Stage One presentations to ED did not have a primary mental health diagnosis recorded. Three-quarters of Stage Two ED presentations were accounted for by nine consumers; excluding these, there were only 45 presentations among more than 500 people. These findings indicate community management of mental illness is generally working well. Almost all consumers (90% of Stage One and 96% of Stage Two) had received at least one follow-up contact with mental health community teams.

## What factors predicted success?

Successful transitions hinged on planning and preparation. The process of transition to community begins with understanding the person's goals, capacities and support needs, which are matched carefully with appropriate providers and services, and capacity building with the providers around the person's specific needs. It continues beyond discharge from hospital with a short period of monitoring and continued capacity building by the PCLI team while handing over responsibility to the community or OPMH case manager for longer-term care and follow-up assessment. At the MH-RAC partner facilities, the post-transition support from PCLI Stage One teams is ongoing, due to the continuing relationship between the aged care and health services fostered by the formal partnership arrangements. Although discharges to community from long-stay units were happening (and still are happening) without the PCLI, the program has undoubtedly contributed to improved quality and sustainability of transitions.

The additional funding available under the PCLI delivered a robust foundation for reform. The key elements are dedicated program management roles, networks of highly skilled clinicians and enhancements to aged care partners. The program managers are a vital point of contact, facilitating communication and enactment of the Ministry's strategic priorities within LHDs and ensuring fidelity to program processes while contextualising implementation to the operational needs of their LHDs. The senior clinicians have contemporary expertise and have demonstrated sophisticated stakeholder engagement, influencing and capacity building skills. The senior peer workers bring the consumer perspective to the fore, acting as advocates and guides for people while gently but persistently encouraging recovery-oriented practice among clinical colleagues.

Underpinned by strong local executive leadership, the program has introduced clearly defined processes and resources to guide changes in practice. PCLI clinicians have been supported through the provision of training, networking opportunities and regular meetings to facilitate consistency across the program and to consult and brainstorm around emerging issues. The teams have been positioned within each LHD according to local priorities, and their collective activities have helped cement the program as a state-wide initiative, providing impetus and authority. The collaborative approach also underpins the capacity building and workforce development activities within health services and community partners. These investments will need to continue in order to embed the culture change that has started, and to ensure the goal of transition planning is 'everyone's business'.

## What was the consumer/family/ carer experience?

Overall, consumers and carers reported positive experiences of the PCLI. They were grateful for the opportunity for a more satisfying life while retaining valued clinical care and functional supports. Carers and some consumers were impressed by the detailed transition planning and the personalised care delivered by PCLI teams. Some carers said they would have preferred more information and to have been more involved in decisions relating to transition.

When consumers and carers talked about the new accommodation and supports in the community they identified features which made those places feel like home: a private space where a person can have their own things; feeling safe and socially connected; being treated with dignity and respect by staff; having opportunities to live more independently and freedom to make choices and decisions about their lives.

Consumers told the evaluation team that their mental health and well-being have improved since transition. Some reported declined physical health, either due to ageing or to lifestyle choices which had led to weight gain or increased smoking. Consumers did not lack knowledge of healthy behaviours and had insight that their freedom of choice might sometimes lead to poor choices. For staff of aged care and high support NDIS homes (SIL or Supported Independent Living) there was an evident tension between encouraging healthy behaviours while supporting independence and freedom. Given the high prevalence of chronic illness and early mortality among people with SPMI, this issue was highlighted as an area of particular concern by lived experience workshop participants who reviewed and reflected on the consumer and carer data.

Carers reported improvements in their own health and well-being. Transition into the community provided opportunities for consumers to reconnect with family and make some new social connections. With psychosocial support, consumers are going out in their communities to engage in regular activities. Some consumers are engaging in training, or volunteer or paid work. COVID-19 and subsequent lockdowns have made social participation more challenging.

Key informants (KIs) observed benefits of transition for consumers including improved quality of life, improvements in function, greater social participation, and better mental and physical health. Benefits for carers were also reported, particularly increased family engagement and improved relationships. Carers had pleasant spaces where they could visit, and it was easier to spend time with the consumer in a relaxed and informal way. For most, initial anxiety about the transition had given way to relief and gratitude that a better life was possible for their person.

A greater focus on active rehabilitation and meaningful occupation following transition may be beneficial, both in general and particularly for older consumers who are not eligible for NDIS community access funding. Aged care providers noted that PCLI Stage One consumers were generally more mobile and less physically dependent than the average aged care resident and therefore in greater need of activities and social engagement.



## Have high quality and responsive new services been established?

For Stage One consumers and those in Stage Two with relatively stable needs, the program has built on existing infrastructure such as the Commonwealth's residential aged care program and the National Disability Insurance Scheme (NDIS), supplemented by new inputs (funding, clinical expertise) and processes (assessments, clinical governance processes). However, many existing aged care and disability providers are limited in terms of their operational models and staffing capabilities, and are not suitable for people with very complex needs and comorbidities due to drug and alcohol use, intellectual or cognitive impairment, and behaviours of concern. The PCLI has developed new service models for these consumers.

Stage One service developments are already well established. These are the MH-RAC partnerships between the NSW Ministry of Health and aged care providers, which are supported by the Stage One clinicians and program managers in participating LHDs. In the main, successful partnerships have been fostered through trusting, respectful and responsive relationships, a willingness to learn from experience and model fidelity.

For Stage Two, there has been extensive investment in evaluating existing models of care, analysing consumer data, and stakeholder consultation to identify the requirements for new services to cater to this cohort. Procurement processes (with Health Infrastructure and the SWMHIP) are underway for top-tier housing providers to build new services and NGOs to operate them, with three levels of care.

## Has practice in existing services been reformed?

The introduction of the PCLI challenged the prevailing 'custodial', 'over-protective' and 'paternalistic' culture in mental health long-stay wards and has contributed to culture change. Staff survey findings indicate a substantial minority are not completely convinced, as shown by neutral responses to questions about change. It is arguably more worthwhile to concentrate change management efforts with this group rather than with the tiny minority who resist change.

The capacity for the PCLI to achieve long-term change requires a cultural shift to the more contemporary and hopeful approach that acknowledges the rights of consumers to experience personal recovery. This mindset has underpinned the PCLI from the outset and throughout its implementation. The program has empowered staff who wanted to see recovery orientation enacted in routine practice but were previously frustrated by systemic and cultural barriers. It has done so by encouraging multidisciplinary involvement, placing senior peer workers in positions where they can advocate for consumers, and designing person-centred processes for assessment and planning. The PCLI challenges everyone involved to be accountable for outcomes, to avoid long stays and to quantify and manage risks associated with discharge. It has equipped mental health services to unpack consumers' capacities and preferences, assemble community-based, tailored supports, and reenergise rehabilitation psychiatry by demonstrating

what is possible.

Most LHDs have embedded aspects of the program within operational and clinical governance processes, such as earlier commencement of discharge planning, engagement by inpatient units with community teams, and within at least one site, mandating community follow-up for at least two years. Practice change is occurring, although it is incomplete and still requires extensive input from PCLI staff through ongoing monitoring and capacity building.

The collaborative underpinnings of the program have included the development of networks and communities of practice between PCLI clinicians and peer workers, through them, facilitated linkages with broader mental health and community service providers. The networks have been an important source of information about different models of care operating across the state, as well as an opportunity to workshop issues, problem-solve and learn from each other. Importantly, they have also provided an informal 'quality control' element for consumers transitioning across LHDs in terms of identifying suitable community service providers and supporting 'at risk' consumers who may be moving between LHDs.

## Was the model sustainable?

The PCLI has been underpinned by key factors identified in the implementation science literature that are known to promote sustainable change: alignment with policy frameworks that articulate contemporary aspirations for mental health service provision; dedicated investments to enhance capacity within health; leveraging opportunities available within the community sector such as residential aged care and the NDIS; strategic leadership and robust governance arrangements; and a variety of effective mechanisms for communication and networking.

Sustainability of the PCLI is premised on the capacity of community aged and disability services to support consumers in partnership with community mental health teams. This has been aided by the inclusion of clinical oversight processes and capacity building activities with staff within these partner services. KIs continue to raise concerns about the systemic limitations within aged care and disability services. It is clear that there will be an ongoing need for the provision of specialist clinical and behavioural supports from highly skilled community mental health teams.

The ability of LHDs to adapt the targeting of consumers according to context and/or emerging challenges has been one of the program's strengths. The changing profile of consumers in terms of complexity, comorbidity and risk comes with additional challenges for community mental health, aged care and disability services. At this point there is still considerable value in the Ministry's having oversight of the strategic planning and resourcing of the PCLI, while continuing to foster strong executive support and clinical governance at LHD level.

Overall, there is cause for optimism about the prospects for sustainability of the PCLI. The program is aligned with the overarching principles of value-based health care through an explicit focus on shared decision making with consumers and carers, workforce development within hospitals, and boosting resources and capacity in community service providers.

## Did the PCLI result in value for the money spent?

An economic evaluation was conducted of Stage One. Stage Two was out of scope as PCLI service developments for Stage Two are not yet operational. Based on discussions with the Ministry PCLI team, the scope was limited to Stage One consumers who had been discharged from hospital at 31 December 2020 (n=156). The PCLI Stage One has resulted in a substantial reduction in the costs of care, with a total reduction of \$32.8M annually for 156 Stage One consumers who have transitioned to residential aged care or home care. Across the Stage One cohort the average cost of care incurred while living in the community was \$143,459, amounting to a 59.4% reduction compared to the average cost during their index stay. Costs were lowest for consumers who transitioned to a generalist RACF and highest for consumers who transitioned to an SRACF with NDIS support. Transition to community living led to large reductions in average costs regardless of discharge destination, ranging between 37.0% and 72.5% savings compared with hospital-based care.

## How has the PCLI improved efficiency in systems/services/workforce?

There is ample evidence that the processes, structures and resources of the PCLI have addressed historical barriers to discharge from long-stay wards. The program has created well-documented and clear processes to guide transition planning, improving upon the existing procedures. There is now greater availability of skills and expertise, through the presence of senior clinicians in the PCLI positions and through the capacity building they constantly undertake with inpatient and community mental health staff and external providers. The unique bridging role of the PCLI clinician – sitting between inpatient and community, capacity building in both, and acting as a conduit for essential information – has helped break down ‘silos’ and improve efficiency within mental health services. Community mental health teams are better prepared to take on case management and monitoring of people with SPMI and complex needs at the point of discharge so that they have continuity of care. Aged care and disability providers have greater willingness and ability to work with these consumers, thus expanding the available options. Finally, a distinguishing feature of the PCLI is the strength and variety of networks it has established across NSW to build expertise and share knowledge around complex care mental health rehabilitation in inpatient and in community settings.

## Recommendations

---

It is recommended that the Ministry:

1. Retains the PCLI as a distinct and named program, with state-wide leadership and control over resources, until there is sufficient evidence that PCLI processes are embedded in LHDs and structural barriers to recovery-oriented practice are addressed at state level.
2. Retains the distributed leadership model that is in place for the foreseeable future.
3. Strongly supports LHDs to use the routine assessment tools (MH-OAT) at baseline and follow-up for demonstrating outcomes, along with a small selection of PCLI-specific, person-centred tools that provide insight into personal recovery and quality of life.
4. Continues to make the full PCLI assessment suite available for clinical purposes. Incentivise clinicians to use these tools through providing ongoing improvements to the PCLI database, facilitating training, and exploring and addressing sources of clinician resistance.
5. Recognises that a shift is occurring in the program that should be formalised through adjustment to the stated goals of the PCLI, including how activity is tracked and how outcomes are measured, to reflect the increasing focus on complex care rehabilitation.
6. Integrates audit and quality improvement processes to track the sustainability of the health and well-being and social integration of transitioned individuals.
7. Continues efforts to build a strong professional identity for rehabilitation psychiatry.
8. Continues to invest resources into LHDs to strengthen multidisciplinary input to care planning with complex patients.
9. Maintains support, resources and strategies to assist providers to maintain social connections during COVID.
10. Encourages a focus on consumers’ physical health care needs when they leave hospital through supporting access to GPs and programs to self-manage chronic health conditions and healthy lifestyle opportunities, as this is a group with significantly increased morbidity associated with chronic health issues.
11. Considers providing funding for post-transition activities in MH-RAC partnerships and proposed PCLI Stage Two service models that will assist people to continue working towards personal recovery, meaningful occupation and social integration.
12. Continues to ensure that the additional positions funded through the PCLI are designed and used by the LHDs in the most appropriate ways to support complex care rehabilitation and community transition of people with SPMI and complex needs.

# Conclusion

---

The evaluation of the PCLI has spanned over four years. During this time, the five 'simple rules' of transformational change in large health care systems (Best et al., 2012) have been a useful framework for reflecting on program implementation and can provide a succinct guide for the future. Of these elements, the most critical appear to be the strategic overview from the Ministry PCLI team, the financial and other resources for LHDs, and the encouragement of culture change towards recovery orientation in inpatient mental health services. Efforts to establish a positive identity for psychiatric rehabilitation are also likely to be transformative.

The overarching goal of the PCLI is to achieve system reform that delivers improved outcomes for consumers, that is sustainable and embeds continuous improvement within health services. Early in the program, one KI said that although deinstitutionalisation was not new, 'maybe we are doing it in a way that is much more thorough than has been done before'.

The PCLI is occurring within the complex system of NSW Health mental health care delivery. Systems have emergent properties and can take on a life of their own, so effecting change is not linear. It would be advantageous for future evaluations of the PCLI to focus on this systems perspective, as it is not a traditional health program fixed in scope and timeframe. The PCLI has built on the NSW mental health reform agenda, and will continue to adapt in response to aged care and disability policy changes and shifts in the current service delivery framework.

As time progresses there will be fuzzy boundaries around what the PCLI is as opposed to what are actually organic developments in the NSW mental health system. This makes it important to keep track of progress as the program's reform agenda is not yet ready to be left alone to the invisible forces of the broader health system. Ongoing work is needed to embed these changes. Transitioning vulnerable people out of hospital successfully will always require the flexibility and expertise for cross-sector working and well-resourced community mental health services.

The ultimate test of success and sustainability was encapsulated by one person very early in the program. Interviewed in 2017, this person said the PCLI was not about the housing itself, or even about the clinical and functional supports available. It was about giving people the chance to have ordinary, everyday interactions with others, who may or may not also have a mental illness. Then they are truly *living* in the community.

# Structure of Report

The report is structured in three main sections to aid the reader in finding information (Figure 1).

**Figure 1 Structure of this report**

<b>Part 1</b>	<b>Background and summary of findings</b>
<b>Chapter 1 – Introduction</b>	Provides essential background on the target population, program design and resources, strategic objectives, and implementation.
<b>Chapter 2 – Evaluation methods</b>	Describes quantitative and qualitative data sources and analysis methods.
<b>Chapter 3 – Program achievements</b>	Summarises findings from Section 2 around the evaluation questions.
<b>Part 2</b>	<b>Evaluation findings in detail</b>
<b>Chapter 4 – Consumer outcomes</b>	Presents detailed findings from administrative datasets including a description of PCLI consumers, health status at baseline, health outcomes, predictors of discharge, and journeys after transition from hospital.
<b>Chapter 5 – Consumer and carer experiences</b>	Presents detailed findings on consumers’ and carers’ experiences of transitions and subsequent community living, based on analysis of interviews with consumers and carers, secondary analysis by lived experience workshop participants, and key informant accounts.
<b>Chapter 6 – Provider and system change</b>	Presents detailed findings from analysis of interviews with key informants (KIs) and two surveys of inpatient mental health service staff members, regarding changes in practice and culture in mental health services.
<b>Chapter 7 – Economic evaluation</b>	Presents detailed analysis of the costs to government of care for consumers in the community compared with ongoing hospital stays.
<b>Part 3</b>	<b>The future of the PCLI</b>
<b>Chapter 8 – Sustainability</b>	Presents findings from KI interviews, surveys and document analysis on the prospects for sustaining the PCLI. This chapter has a formative focus.
<b>Chapter 9 – Discussion</b>	Discusses findings around the ‘five simple rules’ of large-system transformational change in health care and provides recommendations based on evidence from the evaluation and published literature.

---

# Part 1

Introduction

Evaluation methods

Program achievements



# 1 Introduction

---

The Pathways to Community Living Initiative (PCLI) is a coordinated state-wide mental health reform program led by the Ministry of Health in collaboration with NSW Local Health Districts (LHDs). The PCLI represents a transformational change in the care of people with complex mental health needs who are, or are at risk of becoming, long-stay inpatients in NSW hospitals.

The program aims to support people with **severe and persistent mental illness** (SPMI) and complex needs who have been in hospital for more than 365 days to move into the community, and to reduce future long-stay admissions, by changing practice in inpatient and community mental health settings and providing care pathways and community-based support.

## 1.1 Scope and structure of this report

---

This is *PCLI Evaluation Report 7*, the final report. The period of this report covers the extensive work invested in service development for PCLI Stages One and Two and actions taken to support and sustain the individual planning, assessment and transition mechanisms over the life of the PCLI. It builds on lessons from previous reports about large-system transformational change in health care (Best et al., 2012). It presents summative conclusions on the program to date and formative information to guide ongoing work.

The report is divided into three sections to aid the reader in finding essential information. **Part 1** contains this introductory chapter which provides background about the target population, the program design and resources, and the strategic objectives, followed by a chapter describing the evaluation methods. Chapter 3 presents a summary of program achievements, organised around the evaluation questions

and bringing together the summative findings from all the components of the evaluation. Detailed findings are presented in **Part 2** of the report. Chapter 4 contains outcomes for PCLI consumers based on analysis of administrative data. Chapter 5 presents findings on the experiences of consumers and carers based mainly on first-hand accounts. Chapter 6 presents findings from interviews with key informants regarding changes in practice, services and the mental health system. Chapter 7 presents the results of the economic evaluation. These four summative chapters are followed by **Part 3**, which has a formative evaluation purpose, aiming to contribute to the ongoing implementation and impact of the PCLI beyond the life of this evaluation project. Chapter 8 focuses on sustainability and future development, and Chapter 9 concludes the report with a discussion and recommendations structured around the ‘simple rules’ of large-system transformational change in health care (Best et al., 2012).

## 1.2 Background

---

This section of the introduction contains background information to provide essential context for the findings of this report. For details about the history and early development of the PCLI, see *Evaluation Report 1* (Thompson, Williams & Masso, 2018).

The PCLI is a component of the decade-long whole-of-government enhancement of mental health care under the NSW Mental Health Reform 2014-2024. The program aims to support people with SPMI who have been in hospital for more than 365 days to move into the community (**‘long-stay patients’**), and to reduce future long-stay admissions, by changing practice in inpatient and community mental health settings and providing care pathways and community-based support. Planning for the PCLI began in mid-2014 and the program was launched in mid-2015.

### 1.2.1 Recovery orientation

The *National Framework for Recovery-Oriented Mental Health Services*, which provides guidance on embedding recovery philosophy in service delivery, defines recovery as:

*Being able to create and live a meaningful and contributing life in a community of choice, with or without the presence of mental health issues. (Commonwealth of Australia, 2013)*

Personal recovery may be a struggle for many people (Australian Health Ministers’ Advisory Council, 2013). This is the case for people with SPMI and complex needs, and for many years it was assumed that the best place for these people was in a long-stay ward. Long hospital stays led to institutionalisation which compounded the difficulties of a return to community living.

The PCLI clinical enhancements and service developments have focused on long-stay patients with complex needs, who previously had limited options for transitions to community. Australian research has acknowledged that people with SPMI present particular challenges for service delivery in the community (Morgan et al. 2017). People with SPMI may be systematically excluded from effective care in community settings if their high support needs cannot be met (Davis et al., 2012; Irmiter et al., 2007; Novella, 2010).

## 1.2.2 The target population

PCLI consumers have SPMI and complex needs and have had, or are at risk of experiencing, long stays in hospital. Most have a primary diagnosis of psychosis. Their severe, treatment-resistant symptoms, combined with physical problems, cognitive impairment, developmental disorders, and/or substance misuse, affect all aspects of daily functioning (Killaspy et al., 2013).

The PCLI is designed to provide resources and build capacity within the mental health system and across the aged care and disability sectors to meet the exceptionally complex and high needs of this small group of people.

Within the target population for the PCLI there are two distinct sub-groups:

**Stage One** consumers are long-stay patients with significant issues of ageing and include some people aged younger than 65 years, because people with complex mental illness who have been hospitalised for extended periods tend to experience poorer physical health and earlier ageing than the general population. Because of their ageing issues, they are:

- Eligible for aged care funded support from the Australian Government for care in residential aged care homes or in the community (accessed via the Aged Care Assessment Teams (ACAT) processes); and/or
- Treated by NSW Older People's Mental Health (OPMH) services or an OPMH clinician.

**Stage Two** consumers are long-stay patients without significant issues of ageing. The PCLI assessments, literature reviews, and consultations with consumers, carers and clinicians have helped understand the specific needs of this cohort.

For monitoring and reporting purposes, the PCLI also distinguishes between the **initial cohort** who had been in hospital for more than 365 days at the first census date of 30 June 2015, and the **second-wave cohort** who came into scope for the PCLI after this date due to long stays or risk of long stays. Both cohorts include a mix of Stage One and Stage Two consumers.

## 1.2.3 Program design and delivery

At establishment the PCLI was described as a project; however, its complexity has since been acknowledged, along with the breadth and depth of work required to develop, implement and sustain the partnerships and practice changes at its core. The PCLI is therefore more accurately described as a program of work. Program management is not simply 'a scaled-up version of project management', but consists of:

*...the integration and management of a group of related projects with the intent of achieving benefits that would not be realised if they were managed independently (Lycett et al., 2004, p.289)*

Planning for the PCLI began in mid-2014 and the program was launched in mid-2015. The program is delivered using a distributed leadership approach which comprises:

- The **Ministry PCLI team** - the PCLI program manager, the Director of OPMH, senior project officers, the clinical lead, the consumer lead, and the information lead (from InforMH, the Information for Mental Health unit in System Information and Analytics Branch of the Ministry of Health). It provides strategic direction and resources to support LHDs with implementation and manages the contracts with the external aged care partners.
- LHD **executive leads**, and PCLI **program managers** (funded by the Ministry) to form part of a state-wide team supporting the program's implementation at the local level.
- For Stage One, the OPMH coordinators/service managers have also played important roles in supporting the PCLI clinical teams and the program implementation. For Stage Two, the support role for clinicians has sometimes been undertaken by medical leadership, community mental health team leaders or allied health leaders.

**Primary implementation sites** for the PCLI are six Local Health Districts (LHDs): Hunter New England (HNE); Northern Sydney (NS); South-Western Sydney (SWS); Sydney; Western New South Wales (WNSW); and Western Sydney (WS). The mental health services in these LHDs house most of the long-stay mental health consumers in NSW public hospitals.

Additional LHDs are: Nepean Blue Mountains (NBM), Central Coast (CC), Illawarra Shoalhaven (IS) and South-Eastern Sydney (SES) plus St Vincents Specialist Health Network. Most recently, the program has extended to include all the rural LHDs across NSW, with a senior clinician and rural program coordinator based at Murrumbidgee LHD.

Each LHD has been allocated funding for senior clinical positions to support the implementation of the PCLI at the local level. Most now also employ PCLI-funded peer workers. At the time of the evaluation, the Ministry has approved enhancement funding for the full-time equivalent (FTE) of 48.8 positions, including 18.3 FTE Stage One and 26.5 FTE Stage Two team members (and from January 2022, 73.64 positions including 18.3 FTE Stage One and 55.34 Stage Two). Under the partnership agreements with the MH-RAC facilities, the PCLI provides additional funding to improve aged care staffing and preparedness to support people with SPMI and complex needs. Recurrent funding levels for 2020-21 are provided in Chapter 7.

## 1.2.4 Strategic objectives and outcomes

An early planning document (NSW Health, 2016) set out the strategic outcomes of the PCLI at completion, which shaped the program itself and the evaluation:

- Long-stay patient transitions
  - The number of long-stay patients in mental health facilities in NSW will have decreased.
  - Individuals will have transitioned successfully to homes in the community with individually tailored ‘wraparound’ clinical and support services, permanent accommodation options, and improved health outcomes.
- Improved care pathways
  - A gap analysis and a future service spectrum will have been delineated for people with enduring mental illness across all settings and sectors.
  - Services will be supported to implement a re-configuration of existing resources, and/or additional service pathways.
  - Services will have developed a contemporary model of care across non-acute inpatient and community to further embed a recovery approach.

## 1.2.5 Quadrant framework for implementation

The strategic objectives of the PCLI were later conceptualised as a quadrant framework, around which activities of implementation were organised (Figure 2). This framework was based on the PCLI Program Logic Framework endorsed by the Steering Committee in 2017.

**Figure 2 PCLI quadrant framework for program implementation sites (and recently at newer sites)**



### 1.2.5.1 Program processes

Program processes include leadership and governance mechanisms, such as the PCLI Steering Committee which comprises representatives from each participating LHD, discipline leads, consumer and carer representatives, and members of the Ministry PCLI team. Steering committees and working groups have also been established at each of the six primary implementation sites (and recently at newer sites). There are several task-focused state-wide committees. Weekly meetings of the PCLI Collaborative Group bring together the program managers from each primary implementation site with the Ministry PCLI team, with others (e.g., the evaluation team, senior PCLI staff from other LHDs, staff of InforMH) joining the meetings at regular intervals. These provide an ongoing mechanism for discussion of issues relating to implementation.

Communication and workforce development are other important tasks within this quadrant. The PCLI Practice Network meetings are interactive events which enable the PCLI clinicians and peer workers to share knowledge and contribute to program development. These replaced the earlier Dialogue Days. A communication plan and materials have been developed. A commissioned evidence check (Matheson & Carr, 2015) early in the program identified workforce development as an essential element in order to promote a recovery orientation among staff. One of the first tasks was a training needs analysis, followed by development and roll-out of staff training. Ongoing workforce development is provided at LHD level as required.

### 1.2.5.2 ‘Getting to Know You’

‘Getting to Know You’ refers to the individual transition planning processes promoted by the PCLI. Tailored assessments for individual consumers are a key element of successful transition from hospital, according to national and international evidence (NSW Health, 2015). PCLI-specific assessment tools (including, but not limited to, those listed in Table 1) are intended to be integral to the transition process and were selected by a group of senior practitioners to complement the national, mandated Mental Health-Outcome Assessment Tool (MH-OAT) collection. Baseline assessments provide insight into the health status of consumers in hospital, and follow-up assessments provide an opportunity to monitor health outcomes after transition.

In 2016, during the early implementation phase, the use of these tools in comprehensive assessment of PCLI consumers was a key performance indicator (KPI) in Ministry/ Chief Executive Service Agreements for participating LHDs. However, the stated purpose of the tools is to encourage person-centred, multidisciplinary care. The assessments have also been used at the aggregate level to guide service development.

These processes are supported by two guidance documents created by an expert panel, the *Planning, Assessment and Follow-Up Guide* (NSW Health, 2020a) to lead staff through stakeholder engagement and the use of the PCLI assessment tools for care planning, and the *Journey to Home Guide* (NSW Health, 2020b) for patients and families.



In a coup for the program, a policy directive was introduced (the *NSW Health PD2019\_045 Discharge Planning and Transfer of Care for Consumers of NSW Health Mental Health Services*) which requires LHDs to follow the PCLI processes for long-

stay patients. This provides the PCLI with a useful mechanism for direct governance, helping to ensure that long-stay patients across NSW have access to the 'Getting to Know You' processes.

**Table 1 PCLI toolkit – selected mental health measures**

Tool	Purpose
Recovery Assessment Scale–Domains and Stages (RAS-DS)	What does the person value? How do they feel they are tracking with their recovery?
Camberwell Assessment of Need (CAN-C) and CANE Elderly	What is going well? What type of help and support does the person need?
Living in the Community Questionnaire (LCQ)	How much is the person participating in community life and what would they like to change?
Modified Mini Mental State (3MS), WASI-II, RBANS Neurological Functioning, Trail Making Test A and B	What are the person's cognitive strengths and limitations?
Modified Disability Assessment for Dementia (MDAD), Large Allen's Cognitive Levels Screen 5 (Allens)	What is the person's level of functional cognition?
PCLI Risk Screening Assessment, Historical Clinical and Risk Management Tool (HCR-20)	What risks need to be considered and what management strategies might be needed?

Source: NSW Health, 2020a

### 1.2.5.3 Stage One service developments

The PCLI Stage One service development activities built on previous efforts, particularly modelling and evaluation of mental health aged care partnerships and accommodation options. The development of the OPMH services (formerly Specialist Mental Health Services for Older People; SMHSOP) over the past 10-15 years provided a foundation (NSW Health, 2006) as did the establishment of two pilot services within residential aged care facilities in NSW funded under the Mental Health Aged Care Partnership Initiative, which subsequently provided the evidence base for one of the three Stage One service models (Health Outcomes International, 2011; Health Policy Analysis, 2013). Development began in 2015 and was shaped by planning documents that provided policy context and governance, first the *NSW Service Plan for SMHSOP 2005-2015* (NSW Health, 2006), and later the *NSW Older People's Mental Health Services Service Plan 2017-2027* (NSW Health, 2017).

Stage One consumers who require aged care have three options for community living, two of which are delivered via formal partnerships supported by contracts and funding with the Ministry and service level agreements with LHDs (Table 2). Participating services in the partnerships have been brought together for mutual support and quality improvement in collaboration with the Ministry, through the Mental Health-Residential Aged Care (MH-RAC) network.

#### **Mental Health Aged Care Partnership Initiative (MHACPI)**

units are discrete, secure, purpose-designed transitional units within aged care homes. Under the partnership arrangement, the Ministry provides funding for additional, specialised aged care staffing and the LHD provides regular clinical support from the Stage One/OPMH team. Under the PCLI, three MHACPI units have been established within the Hunter New England, Northern Sydney and Nepean Blue Mountains LHDs, each with capacity for 10 people. The MHACPI units are regarded as transitional because once consumers have adapted to their new living arrangements, they are offered the opportunity to move to a less intensive care setting within the existing care home or elsewhere. When this occurs, ongoing support is provided through OPMH services as needed.

**Specialist residential aged care facilities (SRACFs)** are purpose-designed aged care facilities providing specialist models of care for people with complex, chronic mental illness. To provide supported places for Stage One consumers, the Ministry has partnered with three SRACFs within the Western NSW, Western Sydney and central Sydney LHDs, providing funding for additional, specialised aged care staffing within the facilities. Transition follow-up is also provided by the PCLI Stage One/OPMH teams in the respective LHDs, with ongoing support through the OPMH services once the person is settled.

**Table 2 Stage One MH-RAC services**

Facility name	Service type	Provider	Places	Location	OPMH services
Governor Phillip Manor	MHACPI	RSL Lifecare	10	Penrith	Nepean Blue Mountains, Western Sydney
Tobruk Unit	MHACPI	RSL Lifecare	10	Narabeen	North Sydney <sup>1</sup>
Charles O'Neill Court	MHACPI	Catholic Health Care	10	Mayfield (Newcastle)	Hunter New England
Benjamin Short Grove	SRACF	Mission Australia	10	Orange	Western NSW
Marian Nursing Home	SRACF	Southern Cross Care	30	Parramatta	Western Sydney
Annie Green Court	SRACF	Mission Australia	10	Redfern	Sydney

1. As of April 2022 this MHACPI is currently out for re-tender by the Ministry.

#### Generalist or mainstream residential aged care facilities (RACFs)

are also accommodation and care options for Stage One consumers. Many, but not all, have pre-existing relationships with local OPMH services and inpatient long-stay units due to their history of supporting consumers with mental illness. Specialist clinical mental health transition and consultation-liaison support is provided by OPMH services.

#### 1.2.5.4 Stage Two service developments

For Stage Two consumers at the highest levels of complexity and need, under the Statewide Mental Health Infrastructure Program (SWMHIP), the Ministry is planning for 230 places in **Specialist Living Support (SLS) services** for NSW. These are expected to be built and maintained by top-tier community housing providers and run by non-government organisations (NGOs) with 24/7 staffing and suitable expertise in a joint service delivery model with LHDs. A Request for Procurement has recently been issued. Further information about the planned Stage Two service developments can be found in Section 8.3.

Many Stage Two consumers across the initial and second-wave cohorts have already transitioned to the community utilising existing disability accommodation and support providers with funding through the **National Disability Insurance Scheme (NDIS)**. Depending on the needs and preferences of the consumer and their family, they have access to a variety of community living options, including the NDIS Supported Independent Living (SIL) group homes, public housing, private homes, and as well to the Housing and Accommodation Support Initiative (HASI) Plus program run by NSW Health.

#### 1.2.5.5 Information and evaluation

Activities in the information and evaluation quadrant have included the development of the PCLI Program Logic Framework, which has provided a foundation for the commissioned program evaluation (see Chapter 2 for details).

Bandwidth scores for individual consumers on the PCLI assessment tools, described above, are entered by the LHDs into a purpose-built database to serve as a data collection for monitoring and evaluation. When the tools were introduced,

each LHD had a spreadsheet for keeping track of the assessments for each consumer. As the PCLI cohort grew, an Access database was developed and rolled out to the primary implementation sites. There were issues with data security and the lack of reporting capabilities, which led to the engagement of consultants ARTD in mid-2017. Since then, ARTD has been involved with the Ministry PCLI team in the development and ongoing improvement of an integrated database.

Now, the PCLI database is an online portal with expanded functionality providing access for all LHDs. The primary purpose of the database is to monitor the consumer journey through PCLI processes including the collection of data from the suite of assessment and care planning tools selected for use within the program. The database was built as an administrative and project coordination tool for LHD PCLI project managers for the primary purpose of the administration, implementation and monitoring of the PCLI. The data contain details of the current episode of inpatient care, including hospital admission dates, and local Medical Record Numbers (MRNs) to allow linkage to other routinely collected data items for those episodes. The PCLI database is registered as a state-wide data asset where it is held by a NSW Health entity and where its data collection is mandatory by law or policy.

Three other data sources are also used for analysis and reporting. InforMH extracts a quarterly long-stay census from the Health Information Exchange (HIE) which is reported back to LHDs. This provides data for reporting on a quality indicator for the PCLI in the performance agreement meetings with the Ministry. A six-monthly data and information report is collated by each participating LHD on staff recruitment and transitions, reported back to the Ministry via LHD chief executives. Quarterly reports from the PCLI-funded MH-RAC partners are also utilised for monitoring and reporting.

A key mechanism for governance and information sharing in this quadrant is the PCLI Data and Information Management Group which has an ongoing role in ensuring that data are collected and available for health planning, reporting and evaluation. It assists with resolving issues relevant to data collection. This group meets monthly, with representation from the Ministry PCLI team, InforMH, ARTD and the evaluation team. There is a monthly data and information meeting led by the Ministry with PCLI program managers and coordinators and InforMH.

# 2 Evaluation methods

In January 2017, the Centre for Health Service Development (CHSD), University of Wollongong, was engaged to evaluate the PCLI, with the following goals:

- To help consumers, carers, clinicians, managers and policy makers assess the impact of the PCLI and the extent to which it is meeting its objectives;

- To identify opportunities to refine the PCLI, and
- To inform future investment and practice (Masso et al., 2017).

## 2.1 Evaluation design

The design of the evaluation was guided by the PCLI Evaluation Framework developed by the NSW Ministry of Health and endorsed by the PCLI Steering Committee (Table 3).

**Table 3 PCLI Evaluation Framework**

Level	Activities (Implementation)	Outcomes (1-2 years)	Outcomes (3-5 years)
<b>Consumers</b>	Individualised engagement, screening and assessment. Transition to community living.	Improved experience (engagement, choice and control).	Improved wellbeing, quality of life, physical health, mental health and social participation.
<b>Family/carer/ guardian</b>	Engagement with families and carers.	Improved experience (engagement, choice and control).	Engagement with care/cared persons. Satisfaction with quality, security and safety of care.
<b>Providers/ partners/ staff</b>	Workforce redesign. Workforce development.	Improved expertise and skills.	Functional partnerships established. Improved availability of relevant expertise and skills.
<b>System/service</b>	Coordination, communication, cultural change. Enhanced services. Development of contemporary model of care.	Improved collaboration. Culture of recovery. Contemporary models of care established. Improved information sharing.	Improved collaboration. Culture of recovery. Sustainable continuous improvement of service.

**Note:** The term 'consumer' will be used to describe the individuals targeted by the PCLI when there is a need to distinguish them from other people, such as carers or staff.

The PCLI Evaluation Framework is based on the assumption that for an innovation to 'work', it has to do so at multiple levels: consumers, providers and the care delivery system (Masso et al., 2016). The care delivery system encompasses three elements:

- the 'social' aspect (e.g., the networks and relationships between providers);

- the 'organisational' aspect (e.g., management structures, resources, processes); and
- the broader system of health and aged care within which the PCLI exists.

## 2.1.1 Ethical approval

For the purposes of ethical approval, the evaluation was divided into three components. The evaluation of consumer outcomes component uses NSW Health datasets and involves data linkage and consequently was submitted to, and approved by, the NSW Population and Health Services Research Ethics Committee (PHSREC). The other components did not require

approval by the NSW PHSREC (according to advice received in March 2017) as they did not require access to patient records. Instead they were submitted to, and approved by, the relevant University of Wollongong Human Research Ethics Committees (Table 4).

**Table 4 Ethics applications – PCLI evaluation**

No.	Name	Participants	Ethics committee	Timing of approval
1	Evaluation of provider/system change	Staff working either in the health system or for organisations providing accommodation services in the community	University of Wollongong and Illawarra Shoalhaven Local Health District Health and Medical Human Research Ethics Committee	July 2017
2	Evaluation of consumer and carer experience	Consumers and carers	University of Wollongong and Illawarra Shoalhaven Local Health District Social Sciences Human Research Ethics Committee	May 2018
3	Evaluation of consumer outcomes	No participants – the study involves secondary analysis of data collected by NSW Health	NSW Population & Health Services Research Ethics Committee	June 2018

A fourth component – the economic evaluation – utilised summarised data from the evaluation of consumer outcomes and did not require separate ethical approval. Progress reports are submitted annually, as required, to renew the ethics approvals.

## 2.1.2 Evaluation questions

This report includes new data on all four evaluation components and addresses the evaluation questions associated with each of these components (Figure 3).

**Figure 3 Evaluation components and evaluation questions**

<b>Component 1</b>	<b>Evaluation of consumer outcomes</b>
Question 1	How successful was the PCLI in transitioning people from hospital into the community?
<b>Component 2</b>	<b>Evaluation of consumer and carer experience</b>
Question 1	How successful was the PCLI in transitioning people from hospital into the community?
Question 3	What was the consumer/family/carer experience?
<b>Component 3</b>	<b>Evaluation of provider/system change</b>
Question 2	What factors predicted success?
Question 4	Have high quality and responsive new services been established?
Question 5	Has practice in existing services been reformed?
Question 6	Was the model sustainable?
<b>Component 4</b>	<b>Economic evaluation</b>
Question 7	Did the PCLI result in value for the money spent?
Question 8	How has the PCLI improved efficiency in systems/services/workforce? Includes consideration of benefits to individuals (e.g., quality of life, physical health, mental health and wellbeing).

## 2.2 Routine administrative data

This section describes the methods for the consumer outcomes and economic evaluation components of the evaluation. The primary consumer outcome measure was discharge from hospital. The secondary outcome measures were scores from 11 tools from the PCLI suite of assessment tools entered into the PCLI database and the Mental Health Outcome and Assessment Tools (MH-OAT) entered into the Health Information Exchange (HIE), chosen based on their relevance for the evaluation and expected frequency of use in the PCLI.

### 2.2.1 Data sources

There were three data sources: the PCLI database, the HIE and MH-RAC provider reporting. Data extraction was designed in consultation with (and approved by) the Ministry PCLI team. MH-RAC reporting data were separate from HIE and PCLI data and could not be linked.

The PCLI database served as the ‘source of truth’ in defining the PCLI cohort; that is, all consumers in the PCLI database were included and consumers who are not entered into the PCLI database were excluded. During data checking, any inconsistencies between the PCLI database and the HIE were resolved with assistance from the Ministry PCLI team and InforMH.

The HIE is the official source of all data relating to hospitals in NSW, including admitted patients and community health services provided by LHDs/Specialty Health Networks (SHN), mental health assessments and outcomes collections. Data from Patient Administration Systems (PAS), Community Ambulatory (CHAMB) and MH-OAT collections are routinely entered into the HIE. The data are used for funding purposes, reporting of Health Service Performance Agreements and other reporting. As such, the HIE is considered the ‘primary’ source of consumer-level data for the evaluation, with the exception of the definition of the PCLI cohort. All consumer-specific data, stay data and MH-OAT data were sourced from the HIE, whereas the PCLI-specific assessment tool data were sourced from the PCLI database.

The evaluation makes use of the definitions and concepts embedded in the HIE. This includes the concepts of ‘stay’, ‘admission’, ‘discharge’ and ‘length of stay’. These data items (concepts) are consistently collected and reported across all hospitals in NSW.

Another data source for consumer outcomes and costs of care following discharge was available for a sub-group of Stage One consumers. The partnership agreements between NSW Health and the MH-RAC providers require quarterly reporting of selected resident characteristics to the Ministry PCLI team. The data obtained by the evaluation team contained de-identified person-level information for all consumers who had transitioned to a PCLI-funded MH-RAC facility. No such data were available for generalist RACFs. This information provided an additional perspective to the consumer journey after transition which supplemented the HIE data and informed the economic evaluation.

The long-stay census data extracted quarterly from the HIE by InforMH is not used in the evaluation, because inclusion criteria differ from those used in the PCLI database, and thus these two sources inevitably include slightly different (although overlapping) cohorts. The six-monthly data and information reports are collated by the Ministry PCLI team from reports provided by participating LHDs as part of their reporting requirements. LHD records have traditionally been kept on spreadsheets and may or may not match the records entered into the PCLI database. As far as the evaluation team is aware, there have been no attempts to reconcile these sources with each other or with the PCLI database. As the PCLI database is registered as a state-wide data asset and its data collection is mandatory it is considered to be the most reliable source of the three, and is therefore preferred for the purposes of the evaluation.

### 2.2.2 Data preparation and linkage

Data from the PCLI database was provided to InforMH by the Ministry PCLI team with identifying information such as: Hospital ID, LHD/SHN and PAS ID/Medical Record Number. InforMH used the identifying information to perform data linkage and then removed all such identifiable information and added a pseudo identifier which uniquely identifies each consumer in all tables provided. This was performed to facilitate data analysis for the evaluation team and to adhere to ethical requirements for privacy and confidentiality of personal and health data.

The identification of PCLI consumers in the HIE was performed by InforMH based on the consumers in the PCLI database. We acknowledge the extensive work and vigilant methodology employed by InforMH to produce the datasets.

The final data from the PCLI database were extracted in June 2021 (different components on different dates) and from the HIE on 17 June 2021. The final data extract was supplied to the evaluation team on the same day. Extensive data quality checks were carried out to investigate the robustness of the data. Data queries were reported to InforMH and every effort was made to resolve issues. Data were supplied in SAS data format and statistical analysis was conducted using SAS 9.4 statistical software.

The HIE does not include PCLI-specific items such as identification of PCLI Stage One versus Stage Two consumers, initial cohort or second-wave cohort, nor does it distinguish between time points for the PCLI assessments. These items are only available in the PCLI database.

It was essential to identify the **index stay** correctly: that is, the stay that ended in transition into the community. For consumers who had not yet transitioned, the index stay was the current (ongoing) stay. The discharge date from the index stay was used as the reference point for our analyses (i.e., date of transition). All inpatient stays, ED presentations, community visits and outcomes assessments occurring after

that date were regarded as belonging to the follow-up period and included accordingly in the economic evaluation and the outcomes analyses. The last assessment data before the reference point were considered as baseline health status.

When the index stay could not be identified from the available information, the evaluation team worked with the Ministry PCLI team and InforMH to identify the correct index stay manually.

### 2.2.2.1 Development of the analysis datasets

The data provided to the evaluation team by InforMH contained information on 1,004 PCLI consumers. The HIE inpatient dataset originally provided was an episode-level dataset where each row represented one episode. In the HIE emergency department (ED) dataset each row represented one presentation. In the HIE ambulatory care dataset each row originally represented an activity of a provider and it was converted to a service event level dataset.

A consumer-level dataset was derived from the inpatient dataset by retaining only the index stay information. The index stay discharge date was then used to identify whether hospital-based activity (inpatient stays, ED presentation, community care) belonged to a time period preceding baseline period, the baseline period or the follow-up period.

For the 11 assessment tools, only valid assessments were retained (i.e., where 'collection status' was 'Complete or partially complete'). Where multiple assessments were recorded on the same day, the last one was retained. For MH-OAT tools in the HIE, based on the admission and discharge dates of the index stay, assessments were deemed to belong to the 'baseline' or 'follow-up' time period. For PCLI-specific assessment tools, assessment during Baseline Ax or T0 were regarded as 'baseline' and assessments at any time point after discharge (T1, T2, T3 or T4) were regarded as 'follow-up'. The last assessment prior to discharge was retained as the 'baseline' and the first assessment after discharge was retained as the 'follow-up' assessment.

## 2.2.3 Data analysis: consumer outcomes

Following quality checks, descriptive statistics and appropriate measures of central tendency and measures of spread were produced. As appropriate, paired t-tests and Wilcoxon Signed Rank tests (non-parametric equivalent), were used to examine differences in scores between the baseline and the follow-up measure. P-values smaller than 0.05 ( $p < 0.05$ ) were considered statistically significant. All differences have been calculated as 'follow-up score minus baseline score', so depending on the assessment tool a negative difference may indicate an improvement (positive outcome) or a deterioration (negative outcome).

In most cases, the findings are presented separately by stage (Stage One and Stage Two), and in some instance stages are further stratified by cohort (initial and second-wave).

### 2.2.3.1 Standardisation of subscales

Where subscale scores have different ranges, the scales were standardised to represent a percentage score (i.e. range 0 to 100). The calculation of standardised scores is as follows:

$$\text{Standardised score} = (\text{actual score} - \text{lowest possible score}) / (\text{highest possible score} - \text{lowest possible score}) \text{ multiplied by } 100.$$

As an example, the standardised scores for the HoNOS (and HoNOS 65+) behaviour and impairment subscales are calculated as follows:

- Behaviour subscale contains three items, all rated on a five-point scale from 0 to 4, therefore the possible range is 0 to 12. If a consumer was rated '2' for item 1, '4' for item 2 and '1' for item 3, their total score for the 'behaviour' subscale would be 7 (2+4+1). The standardised score would be calculated as  $(7-0) / (12-0) * 100 = 58.3$ .
- Impairment subscale contains two items, both rated on a five-point scale from 0 to 4, therefore the possible range is 0 to 8. If a consumer was rated '3' for both items, their total score for the 'impairment' subscale would be 6 (3+3). The standardised score would be calculated as  $(6-0) / (8-0) * 100 = 75.0$ .

If the unstandardised scores were compared one may conclude that the consumer had less symptom severity related to 'impairment' than 'behaviour'. The standardised scores allow a direct comparison of the scores by adjusting for the difference in scales, allowing the accurate conclusion that the consumer had more problems related to 'impairment' than 'behaviour'.

### Logistic regression

The standard approach to identify and quantify consumer characteristics which predict the likelihood of being discharged from hospital (a dichotomous variable) is to use a logistic regression model. The basic idea behind logistic regression is to model the logarithm of the odds for an event (discharge from hospital) based on values of independent predictors (consumer characteristics at baseline). The model can be written as:

$$\log\left(\frac{p}{1-p}\right) = \beta X$$

Here  $p$  represents the probability of the event ('discharged') and  $1-p$  represents the probability of the non-event ('ongoing').  $X$  represents the set of predictor variables. The estimates  $\beta$  are the effects of the predictor variables and the exponentiated value of  $\beta$  represents the odds ratio of discharge from hospital. Odds ratio greater than one are interpreted as higher likelihood of discharge, and conversely values smaller than one represent a lower likelihood.

All consumer-level characteristics that were available for at least 50% of consumers were modelled using univariate logistic regression to estimate their effect on hospital discharge. Odds ratios (OR) and 95% confidence intervals are reported. Consumers whose reason for discharge was 'death' were excluded (n=35).

## 2.2.4 Data analysis: costs of care

The main goal of the economic evaluation was to provide an estimation of costs associated with hospital care during the index stay and compare with the costs of care in the community. As access to expenditure data was limited, the analysis used a 'cost to government' approach to determine funding levels. Stage Two was out of scope as PCLI service developments for Stage Two are not yet operational. Based on discussions with the Ministry PCLI team, the scope was limited to Stage One consumers who had been discharged from hospital at 31 December 2020 (n=156). It was further defined to include four main types of costs:

- Hospital-based care (admissions, ED presentations and community mental health services);
- Commonwealth funded residential aged care;
- Partnership agreements between NSW Health and aged care providers;
- National Disability Insurance Scheme.

The following types of costs were out of scope for the analysis:

- Primary health care
- Out-of-pocket contributions by consumers
- In-kind contributions by aged care providers
- Capital funding through partnership agreements (NSW Health and aged care providers)
- PCLI program (including staffing enhancement funds provided to LHDs)
- Downstream effects to the health care system

Information and documents provided by the Ministry PCLI team were used to estimate costs of supported accommodation in the MH-RAC facilities which report regularly on the profile of their PCLI residents, including the Aged Care Funding Instrument (ACFI) scores which inform funding levels. Information on the funding agreements between NSW Health and organisations providing MH-RAC facilities was used to estimate additional costs associated with care for people with SPMI and highly complex needs.

The evaluation team did not have access to **hospital cost data**. Cost estimates for hospital-based care were based on activity based funding (ABF) principles. The Independent Hospital Pricing Authority (IHPA) produces the annual National Efficient Price (NEP) which is used in combination with price weights and other adjustments to determine the price of an activity.<sup>1</sup> Price weights are produced for admitted programs, non-admitted services and ED activity using the national classifications (IHPA, 2020a). Each inpatient episode was associated with an Australian Refined Diagnosis Related Group (AR-DRG) which classifies episodes of care into clinically meaningful groups. Inpatient stays may consist of multiple episodes.

For the index stays, the outlier *per diem* was used to represent the ongoing nature of the stays. For any hospital care after transition, the usual ABF methodology was used as it best represented the episodic nature of the care. Urgency Disposition Groups (UDGs) were used to classify ED activity. This classification is based on the patient's type of visit, end status and triage category. Non-admitted community mental health care was categorised using the Tier 2 classification. For two Tier 2 classes no price weights were available because they are not included in ABF. Instead, their national average costs were used, as reported in the *Public Sector National Hospital Cost Data Collection Reports* (IHPA, 2018; IHPA, 2019; IHPA, 2020; IHPA, 2021). As the most recent report covers 2018-19 it was necessary to assume that the average cost per service event has remained constant since then.

Values were adjusted for inflation and converted to 2019-20 dollars, and an estimation for the annual cost was derived. For example, the final episode of the PCLI Stage One index stay for one consumer was classified as 'Schizophrenia Disorders, Major Complexity' (U61A) and ended in the financial year 2016-17. The 'Long-Stay Outlier Per Diem' price weight in 2016-17 was 0.1855 and the NEP was \$4,883. The daily price was calculated as the product of price weight and NEP ( $0.1855 * \$4,883 = \$906$ ).

Cost of **patient transport by ambulance to ED** was not available. As in previous evaluations, external sources were used to estimate these costs (Access Economics, 2010; Thompson et al., 2014). Cost to government was best approximated with the amount of government grants/contributions received by NSW Ambulance. The annual *Report on Government Services* provided information about activity and revenue of ambulance services around Australia in recent years (Steering Committee for the Review of Government Service Provision, 2020). For the analysis it was assumed that the costs associated with an ambulance transport to ED was the ratio between government grants/contributions and total number of patients.

The cost of **aged care services** provided to Stage One consumers was not available. Instead, cost estimates were based on Aged Care Funding Instrument (ACFI) scores for residential aged care and government subsidy levels for home care packages.

The full NDIS began in July 2016 and is managed by the National Disability Insurance Agency (NDIA). NDIS provides funding for supports and services for persons who have a permanent and significant disability. One of the eligibility criteria is that the person is aged less than 65. NDIS funding levels are based on individually assessed needs. Information on **NDIS status, types of support and funding** for individuals was unavailable. Instead the NDIS Quarterly Report was used to inform assumptions (NDIA, 2020). Assumptions were also based on conversations with the Ministry PCLI team and residential aged care providers.

1. All relevant details (such as classifications, price weights, NEP and technical specifications) for the current financial year and all previous financial years can be found on the IHPA website (<https://www.iHPA.gov.au/>).

### 2.2.4.1 Providing a basis for cost comparison

Some costs of care are recurrent (e.g., daily ACFI or NDIS funding) whereas other costs are episodic or service-driven (e.g., all hospital-based activities). Further, some costs are incurred by all Stage One consumers (e.g., index stay) whereas others are incurred by some (e.g., ED presentations). Therefore, all costs have been converted into average cost per consumer per year. For recurrent costs, the daily amount was multiplied by 365 days. For other costs, the total number of events was multiplied by the average cost of each activity to calculate the total cost of that type of activity for all Stage One consumers (n=156) over the whole post-discharge period (on average 845 days). To calculate the average cost per consumer day, the number of person days in the post-discharge period was divided by the total costs (156 \* 845 = 131,820). This was then multiplied by 365 to calculate the average cost per consumer per year.

$$\frac{\text{frequency of activity} \times \text{cost per activity}}{156 \times 845} \times 365$$

= cost per consumer per year

For example, there were 33 ED presentations with an average cost of \$1,740 recorded. The average cost of ED presentations per consumer per year can be calculated as follows:

$$\frac{33 \times \$1,740}{156 \times 845} \times 365 = \$159$$

### 2.2.4.2 Indexation

To improve comparability of prices from different sources over several financial years (nominal dollars) all amounts are converted to 2019-20 dollars (real dollars) using the General Government Final Consumption Expenditure (GGFCE) chain price index published by the Australian Bureau of Statistics (ABS, 2020). This approach is commonly used, for example, by the Productivity Commission (Steering Committee for the Review of Government Service Provision, 2020). Table 5 shows the GGFCE chain price indexes along with our calculations to convert the chain price indexes into 2019-20 dollars. To convert nominal dollars into real dollars the nominal dollar amount is divided by the GGFCE chain price index for the corresponding financial year and multiplied by 100.

**Table 5 GGFCE chain price index**

Nominal dollars (year)	Chain price index (based on 2017-18)	Chain price index (re-based to 2019-20) <sup>1</sup>
2015-16	103.9	94.0
2016-17	102.2	94.8
2017-18	100.0	96.2
2018-19	98.5	98.4
2019-20	97.7	100.0

1. Calculated conversion to 2019-20 dollars.



## 2.3 Survey of inpatient staff

An online survey of staff at the six primary implementation sites was conducted twice during the evaluation: 2018 and 2020.

### 2.3.1 Materials

A purpose-designed questionnaire was developed to inform the evaluation's understanding of the implementation and impact of the PCLI and to identify opportunities for improvement. It focused on outcomes for providers, and covered change management, culture change and the recovery orientation of services. The questionnaire consisted of two demographic questions, 33 five-point Likert scale questions rating level of agreement with a set of statements about the PCLI (36 five-point Likert scale questions), and four open-ended questions (Appendix 1).

A scan of recent relevant literature was undertaken to ensure current best practices were employed in the design, administration and analysis of the survey. Methodological issues examined in the scan included survey distribution mode and strategies to improve response and completion rates. Based on discussions concerning appropriate distribution methods at site visits and consultation with the Ministry PCLI team and program managers, the survey was distributed electronically via invitations to staff email addresses, issued from each LHD. Prior to distribution, several individuals with a range of expertise (e.g. expertise in mental health care, survey design, etc.) pilot tested the survey, resulting in some revisions.

### 2.3.2 Procedure

The survey was developed, managed and distributed using the Qualtrics research platform (<https://www.qualtrics.com/au/>) hosted at the University of Wollongong. Many of the strengths of online survey methodologies, including convenience, timeliness, and cost-effectiveness (McInroy, 2016), were realised by its use in this study. In addition, access to the internet in the health sector is relatively high (Hegney et al., 2007), reinforcing the appropriateness of the online method. In accordance with ethical requirements, robust security and access management controls were in place.

The evaluation project manager contacted PCLI executive leads at each LHD to request their assistance in distributing the staff survey. They were asked to nominate a staff member to send the email invitations (and at least three reminder emails at weekly intervals) to staff. Templates for these emails were provided, containing site-specific web links to the survey to allow monitoring of response rates at the LHD level. They were emailed under the PCLI executive lead's name, to provide high-level endorsement of the survey. The Round 1 survey was open from 28 September 2018 to 9 November 2018. The Round 2 survey was open from 12 October 2020 to 13 November 2020. The original closing dates for the survey were extended to allow for a greater number of responses. Completion of the survey was regarded as implied consent.

### 2.3.3 Participants

The target audience for the survey was inpatient nursing, allied health, medical and peer support staff, particularly staff of units that house long-stay consumers who are eligible for the PCLI. Staff members in frontline and supervisory roles were included.

In Round 1, 338 invitations were issued and 86 individuals responded from five sites. All respondents rated at least 31 of the 33 Likert scale items. Response rates by site ranged from 20% to 31%. The overall response rate was 25.4%. In Round 2, 75 individuals responded from six sites. It was not possible to calculate response rates overall or by site for Round 2 as some sites did not track the number of invitations issued (due to workload pressures).

### 2.3.4 Analysis

Survey responses were downloaded from Qualtrics and stored in a secure environment which was only accessible by the evaluation team. Data quality checks were undertaken and data analysis was performed using Excel and SPSS version 24 (IBM, Chicago, IL, USA). Comparisons between groups were analysed using appropriate statistical tests. For these tests, the five-point Likert scale was condensed into three points – agree (strongly agree and agree), neutral, and disagree (disagree and strongly disagree). Only significant differences between expected frequencies and observed frequencies are reported. For comparisons over time, one site which did not provide any data in 2018 was excluded. Full results are provided in Appendix 2, with summaries in the text of the report.

## 2.4 Qualitative methods

Qualitative methods enable deep exploration of the ways in which people think about themselves and their environments. In qualitative research the goal is 'to provide a sufficiently detailed account and/or analysis to enable others to determine whether there are other circumstances to which the findings may be applicable' (NHMRC, 2014, p. 21). For this evaluation, the qualitative methods were designed to gain a deeper understanding of program implementation and outcomes beyond what could be provided by quantitative analyses alone, and to triangulate results across data sources, thus increasing the rigour and reliability of the findings.

The main source of qualitative data for the evaluation was a series of semi-structured interviews with individuals and groups conducted every year between 2017 and 2021. Three main groups of stakeholders were interviewed: PCLI consumers and family carers; key informants (KIs) based within LHDs and including both PCLI staff and broader mental health service staff; and aged care providers. Members of the Ministry PCLI team and the Steering Committee were also interviewed occasionally. Additional sources of qualitative data included: evaluation team observations (and note taking) during meetings and workshops; review of program documents; and site visits to LHDs and aged care facilities.

In this report, quotes from **key informants** (KIs) and **consumers and carers** are indented in blue italics. Rather than numbering interviewees, the quotes are labelled with KI role and year of interview or with 'consumer' or 'carer' and stage, as this was considered more informative. Care was taken to ensure that no individuals or sites were over-represented in the quotes used.

### 2.4.1 Consumer and carer interviews

Semi-structured interviews took place with PCLI consumers and family carers to elicit their views and experiences of the program. Consistent with international best practice (Hancock et al., 2012; Katsikitis, 2017) and policy (Australian Government Department of Health, 2010), this component of the evaluation was planned and carried out in collaboration with a lived-experience academic with expertise in qualitative research and was designed to embed consumer voices in the evaluation process. Academic consumer researchers can help build trust with participants as well as contributing to the process of destigmatising mental health disorders (Griffiths et al., 2004).

Consumers and carers are now widely understood as experts by experience (Katsikitis, 2017). The inclusion of consumer and carer voices in evaluation is consistent with the principles of mental health recovery that assume that the consumer is best suited to speak about what is helpful, unhelpful, and needed in service delivery (Hancock et al., 2012). It assists recovery by helping to address power differentials between the subjects of the study and those conducting or commissioning the study (Happell et al., 2016) and can be seen as a moral and ethical imperative (Case et al., 2014). Further, the participation of consumers ensures their interests are prioritised and thus increases the relevance and validity of results (Case et al., 2014; Griffiths et al., 2004; Hodges, 2005)

#### 2.4.1.1 Materials

Interview schedules were designed to cover the evaluation questions while remaining easy to understand. Information collected from consumers included: brief personal history; expectations of the program; early experiences of the transition process; outcomes of the transition such as social participation, choice and control, physical and mental health; engagement with family and friends; and engagement with mental health and other services. Information collected from carers included the above plus changes in the relationship with the consumer, observed changes in the consumer's life, and changes in the carer's own health and well-being.

The schedule included a series of questions based around the domains of the Adult Social Care Outcomes Toolkit (ASCOT), a validated, standardised tool that is available in an Easy Read version (Turnpenny et al., 2015). The ASCOT domains provided a theoretical framework for this section of the interview. By using these domains as a guide to interview content, we ensured that we captured highly relevant information about the consumers' experiences of, and satisfaction with, their new living arrangements.

#### 2.4.1.2 Procedure

A decision was made early in the evaluation planning not to interview consumers while they remained in hospital, to avoid unnecessary risks to a vulnerable population which might result, for example, from the intrusion of the evaluation team into the hospital setting, or by raising hopes for transitions that may not eventuate for months or years. Instead, the focus of the interviews was on transition and post-transition experiences, with some questions asking participants to recall and describe the period leading up to the transition. Because recall is less accurate with more time elapsed, we aimed to interview consumers and carers within the first year following transition where possible. The setting of the interviews was generally the consumers' homes, either in aged care facilities (for Stage One) or supported community accommodation (for Stage Two). Some carers were interviewed by telephone. Interviews with consumers were conducted by two experienced qualitative researchers, usually including the consumer researcher. The interviews were conversational in tone, leaving plenty of room to follow issues that interviewees wanted to talk about.

#### 2.4.1.3 Participants

We aimed to recruit approximately 50 individuals (35 consumers, 15 carers) to provide comprehensive coverage of diverse experiences and views. In qualitative analysis the goal is to achieve saturation rather than statistical power. Saturation refers to a point at which no new information is being added to the coding categories in data analysis by including additional cases (Bazeley, 2013). Inclusion criteria were consumers 'in scope' for the PCLI, or family carers of PCLI consumers.

Participants were sampled by LHD, according to the hospital from which they transitioned to the community. Due to privacy and confidentiality requirements, the evaluation team was not able to contact potential participants directly, but recruited indirectly via PCLI staff, by providing an easy-read flyer and Participant Information Sheets tailored to each group for distribution. This was done multiple times during the course of the evaluation, starting in mid-2018. PCLI staff helped set up appointments for interviews. Informed consent procedures were handled carefully at the initial contact, when the interview appointment was made, at the start of the interview, and throughout the interview. Several potential participants withdrew consent and declined to be interviewed when the evaluators arrived at the appointment time and place, illustrating the challenges of involving this vulnerable group in research.

First-hand accounts of transition experiences were obtained from 37 interviews with 27 consumers and 12 carers between July 2018 and May 2021. Evaluation team members also spoke informally with other PCLI consumers during site visits to aged care facilities. Stage One consumers had been transitioned to aged care facilities (mostly MH-RAC network partners) and the Stage Two consumers to group homes or, in a few cases, to individual public housing. The earlier interviews focused mainly on Stage One consumers and carers and the later were mainly Stage Two, although in most years there was a mixture of both groups. The COVID-19 pandemic had a negative impact on recruitment efforts in the later years of the evaluation.

## 2.4.2 Key informant interviews

Semi-structured interviews were conducted with key informants (KIs) who were mainly staff of mental health services (including program managers, clinicians and peer workers employed in positions funded by the PCLI) and aged care services (primarily the MH-RAC partner services). Interviews were also conducted with the Ministry PCLI team and Steering Committee members, particularly the consumer representative, to understand specific issues relating to the program implementation and outcomes. A total of 167 interviews were conducted over a five-year period covering 11 implementation sites and 9 aged care facilities.

### 2.4.2.1 Materials

Interview schedules were created at the planning stage, and submitted for ethics approval; these were revised in later years (with ethics amendments as needed) as the focus shifted from early implementation to later implementation and outcomes. Separate interview schedules were written for the various groups of KIs: PCLI-funded staff, mental health service staff, and aged care managers and staff members. Specialised schedules were also created for particular evaluation purposes (e.g., the Stage One report, the case study report). The interview schedules were designed around the evaluation questions and the PCLI program logic.

### 2.4.2.2 Procedure

The first set of interviews took place in late 2017, following the first round of evaluation site visits to the six primary implementation sites. During 2018 and 2019, interviews were conducted in person during evaluation site visits. With the advent of the COVID-19 pandemic and associated lockdowns, the interviews in 2020 and 2021 were (mostly) conducted via videoconference. All participants provided informed (written or verbal) consent for the interviews.

### 2.4.2.3 Participants

KIs were sampled purposively, targeting individuals likely to be rich sources of information relevant to the program and its evaluation. The aim of the sampling was to achieve representativeness across the range of settings in which the program was taking place while allowing for sampling of special or unique cases or to gain more in-depth data about themes emerging from data analysis.

In early 2021, the evaluation team conducted 9 new interviews involving 18 KIs including: PCLI project managers, peer workers and clinicians, and PCLI executive leads from 9 sites. Two sites were not included in this round of interviews because they had contributed extensively to the case study report in late 2020, less than six months previously, and the evaluation did not wish to create unnecessary data collection burden, particularly during the COVID-19 pandemic. The 2020 interviews from these sites were included in the dataset. This round of interviews built on four previous rounds in 2020, 2019, 2018 and 2017, providing rich, in-depth, qualitative data on which to base formative and summative conclusions.

Of the 121 earlier interviews with LHD-based KIs, 41 were selected for longitudinal qualitative analysis, creating a dataset of 50 transcripts spanning five years and 11 implementation sites. Interviews were sampled purposively: those most likely to provide an overview of progress at each time point (mainly program managers, executive leads and key PCLI clinicians) were given preference for inclusion. In addition, previous evaluation reports which included interviews with aged care providers were reviewed for key information arising from those interviews, to ensure comprehensive coverage of all stakeholder views in this report.

## 2.4.3 Data preparation and coding

Interviews were recorded (with permission) and professionally transcribed through a company that ensures security and confidentiality. Transcripts were entered into NVivo 12 Plus for data management. Three team members worked together to code, index, analyse and write up the findings. Each has had extensive experience of qualitative analysis and lengthy exposure to the PCLI, creating deep understanding of the program and its context.

KW created a first draft of the coding structure for each dataset based on the evaluation questions. Two members of the team then independently coded several transcripts to test the coding structure. The team then met to discuss and refine the structure, adding and rearranging nodes as required to establish consensus on the final analytical framework. For each dataset, two team members undertook the complete

indexing of the transcripts, adapting the analytical framework to accommodate new codes, with ongoing discussion as the work progressed. Thus, the analytical approach combined deductive, question-driven coding with inductive coding which allows freedom for discovery of unexpected ideas, issues and experiences in participants' accounts (Gale et al., 2013). The team met several times to discuss and agree on the emerging concepts and themes and how these could be organised into a coherent account. Once all the data were indexed, sections of the report were assigned to team members for analysis and writing. Draft sections were edited and integrated into the report by the lead researcher.

#### **2.4.4 Carer and consumer interview analysis**

All transcripts were pooled and re-analysed for this report. A combination of inductive and deductive approaches were used to capture information relevant to the evaluation questions while allowing for the emergence of other ideas and insights from interviews. A summary of preliminary findings was sent to a group of PCLI peer workers and the consumer and carer representatives on the PCLI Steering Committee. They were invited to participate in an online Knowledge Exchange Forum, where findings were presented and a structured discussion was facilitated by members of the evaluation team. Their lived experience reflections are reported alongside the interview findings.

#### **2.4.5 Key informant interview analysis**

For the provider/system change data, a modified framework method of analysis was used, as this is highly suited to working with large datasets where the data are derived from semi-structured interviews, multiple researchers are working on the project, and the goal is a holistic descriptive overview (Gale et al., 2013). The framework method provides a systematic way to categorise and compare accounts and search for patterns in order to develop 'themes' which capture and express important concepts in the data. Themes are broad, abstract categories which recur in the data and illustrate relations, actions, beliefs, narratives or arguments (Maxwell & Chmiel, 2014). Iterative categorisation (Neale, 2016, 2021) was used to move from codes and themes to deeper analysis and interpretation of the data as this approach is systematic, comprehensive and auditable.

# 3 Program achievements

To set the scene for the detailed presentation of evaluation findings in Part 2, this chapter summarises the achievements of the PCLI to date, organised around the evaluation questions. Where possible in the following chapters, the observed outcomes are linked with the strategic objectives in Figure 4 and to program investments, activities and outputs in the

full program logic (Appendix 2). The outcomes are important achievements in their own right, and also interdependent facilitators of the eventual impacts of the program beyond the timeframe of this evaluation. Thus, according to the program logic, the outcomes summarised here will contribute towards achieving the long-term ambitions of the PCLI.

**Figure 4 PCLI Program Logic**

Strategic objectives	Outcomes (1-2 years)	Outcomes (3-5 years)	Long-term ambition
Program management.	Consumer outcomes		Community living for people who experience complex and enduring mental illness.  Recovery-based care pathways.  Appropriate individualised high-support housing.  Appropriate individualised high mental health services and support
	Improved experience (engagement, choice and control).	Improved wellbeing, quality of life, physical health, mental health and social participation.	
Governance, partnerships and communication.	Family/carer outcomes		
	Improved experience (engagement, choice and control).	Engagement with care/cared persons. Satisfaction with quality, security and safety of care.	
Change management and workforce development.	Providers/partners/staff outcomes		
	Improved expertise and skills.	Functional partnerships established. Improved availability of relevant expertise and skills.	
Individual engagement and planning.	System/service outcomes		
	Improved collaboration. Culture of recovery. Contemporary models of care established. Improved information sharing	Improved collaboration. Culture of recovery. Sustainable continuous improvement of service.	
New service models – recovery-based care in the community.			

## 3.1 Transitions to community living

### Evaluation Question 1: How successful was the PCLI program in transitioning people from hospital to the community?

Two thirds of PCLI consumers (674/1004, 67%) were transitioned to the community by the end of December 2020: 156/227 (69%) in Stage One and 518/777 (67%) in Stage Two. Almost one-fifth (19%) of Stage One consumers and around one-third of Stage Two consumers remained in hospital at 31 December 2020. Thirty-five (3%) consumers had died in hospital, most of whom were people with significant issues of ageing.

Stage One consumers with reduced capacity in 'late loss' activities of daily living (RUG-ADL total score and toileting domain) were more likely to be discharged. For those assessed with the LSP-16, poorer general functioning and higher disability predicted discharge. Similarly, among those with cognitive impairment who were assessed with the M-DAD, reduced capacity in instrumental and basic activities of daily living was associated with higher likelihood of discharge. Although this might seem counterintuitive, it makes sense given the nature of the cohort. People experiencing greater disability and requiring greater assistance with activities of daily living would seem more suited to life in an aged care facility – the destination for almost all Stage One consumers – than those who were still relatively mobile and capable of self-care.

For Stage Two, people who were younger, had shorter length of stay, lower severity of mental health disorder (HoNOS), greater general functioning and lower disability (LSP-16) or lower psychological distress (K10) were significantly more likely to be transitioned. The usual destinations for Stage Two consumers offer disability supports but no 24/7 clinical support, although people are linked with community mental health services for regular follow-up. It appears that mental health services are ensuring that Stage Two consumers are as clinically well as possible, and equipped for daily living, before arranging transitions.

Following discharge, Stage One consumers' general functioning and disability (LSP-16) improved on average. However, there was significant deterioration in cognition and physical health (HoNOS 65+ 'impairment' scores) and loss of function in activities of daily living (RUG-ADL total, bed mobility, transfers and eating). Changes in K10 and HoNOS were not significant. Stage Two consumers on average showed a decline in general functioning and disability (LSP-16) and experienced deterioration in cognition and physical health (HoNOS impairment). Changes in other HoNOS subscales, HoNOS total and K10 were not significant. With the data available it is impossible to differentiate between ongoing effects of ageing and mental illness and impacts of the change in accommodation and service provision. The findings for health outcomes may be influenced by the fact that only a limited proportion of consumers completed the follow-up assessments, and this group may not be representative of all PCLI consumers.

Key informants observed benefits of transition for consumers including improved quality of life, improvements in function, greater social participation, and better mental and physical health. Benefits for carers were also reported, particularly increased family engagement and improved relationships. Carers had pleasant spaces where they could visit, and it was easier to spend time with the consumer in a relaxed and informal way. For most, initial anxiety about the transition had given way to relief and gratitude that a better life was possible for their person.

Following transition to the community, the goal of the PCLI is to avoid further long-stay mental health care admissions, and also to avoid a cycle of very frequent admissions; both these situations reveal an underlying lack of community supports. Because of the severity of their mental illness, it is generally accepted that PCLI consumers will need ongoing treatment, including occasional inpatient admissions. This is verified by the finding that about 20% of Stage One and 33% of Stage Two consumers required mental-health-related readmissions. Most mental health related readmissions resulted in short-term stays of four weeks or less. Twenty-one consumers (3 Stage One, 18 Stage Two) went on to have another hospital stay longer than 365 days. At 31 December 2020, 7 (4%) of the Stage One and 45 (9%) of the Stage Two consumers who had previously transitioned were current admitted patients.

Only a small proportion of transitioned consumers (7% of Stage One, 8% of Stage Two) presented to emergency departments (ED). Almost all (31/33) Stage One presentations to ED did not have a mental health diagnosis recorded as the primary diagnosis. Three-quarters of all Stage Two ED presentations were accounted for by just nine consumers; excluding these there were only 45 presentations among more than 500 people. These findings indicate that most readmissions are planned rather than precipitated by ED visits, and community management of mental illness is generally working well. Almost all consumers (90% of Stage One and 96% of Stage Two) had received at least one follow-up contact with mental health community teams.

## 3.2 Success factors

---

### **Evaluation Question 2: What factors predicted success?**

Successful transitions hinged on planning and preparation. The process of transition to community begins with understanding the person's goals, capacities and support needs, which are matched carefully with appropriate providers and services, and capacity building with the providers around the person's specific needs. It continues beyond discharge from hospital with a short period of monitoring and continued capacity building by the PCLI team while handing over responsibility to the community or OPMH case manager for longer-term care and follow-up assessment. At the MH-RAC partner facilities, the post-transition support from PCLI Stage One teams is ongoing, due to the continuing relationship between the aged care and health services fostered by the formal partnership arrangements. Although discharges to community from long-stay units were happening (and still are happening) without the PCLI, the program has undoubtedly contributed to improved quality and sustainability of transitions.

The additional funding available under the PCLI delivered a robust foundation for reform. The key elements are dedicated program management roles, networks of highly skilled clinicians and enhancements to aged care partners. The program managers are a vital point of contact, facilitating communication and enactment of the Ministry's strategic

priorities within LHDs and ensuring fidelity to program processes while contextualising implementation to the operational needs of their LHDs. The senior clinicians have contemporary expertise in their professional domains, and have demonstrated sophisticated stakeholder engagement, influencing and capacity building skills. The senior peer workers bring the consumer perspective to the fore, acting as advocates and guides for people while gently but persistently encouraging recovery-oriented practice among clinical colleagues.

The program has introduced clearly defined processes and resources to guide changes in practice. PCLI clinicians have been supported through the provision of training, networking opportunities and regular meetings to facilitate consistency across the program and also to consult and brainstorm around emerging issues. The teams have been positioned within each LHD according to local priorities, and their collective activities have helped cement the program as a state-wide initiative, providing impetus and authority. The collaborative approach also underpins the capacity building and workforce development activities within health services and community partners. These investments will need to continue in order to embed the culture change that has started, and to ensure the goal of transition planning is 'everyone's business'.

## 3.3 Consumer and carer experiences

---

### **Evaluation Question 3: What was the consumer/family/carer experience?**

Overall, consumers and carers reported positive experiences of the PCLI. They were grateful for the opportunity for a more satisfying life and greater freedom while retaining valued clinical care and functional supports. Carers and some consumers were impressed by the detailed transition planning and the personalised care delivered by PCLI teams.

Approaching the transition, consumers were more likely to be excited about leaving hospital whereas carers were more likely to be anxious. PCLI staff, treating teams and community providers alleviated concerns for consumers and carers by giving them information, reassurance and time. Most consumers were offered the opportunity to visit the community accommodation provider before making a decision regarding transition. These visits were often the main source of information about the option(s) available. Photographs and even videos were sometimes used to help consumers understand what was on offer. If they were interested and willing to be involved, carers were also involved in site visits to aged care providers or group homes. Seeing the 'home' that was being offered was, for many carers, the turning point in

the decision making process. Some carers said they would have preferred more information and to have been more involved in decisions relating to transition.

When consumers and carers talked about the new accommodation and supports in the community they were able to identify a number of features which made those places feel like home: a private space where a person can have their own things; feeling safe and socially connected; being treated with dignity and respect by staff; and having opportunities to live more independently and to make choices.

According to those interviewed, consumers' mental health and well-being has improved since transition. Some reported declined physical health, either due to ageing or to lifestyle changes which had led to weight gain or increased smoking. Consumers did not lack knowledge of healthy behaviours and had insight that poor choices could be harmful to their health. Support was available, but for staff of aged care and SIL homes there was an evident tension between encouraging healthy behaviours while supporting independence and freedom. Given the high prevalence of chronic illness and early mortality among people with SPMI, this issue was highlighted as an area of particular concern by lived experience workshop

participants who reviewed and reflected on the consumer and carer data.

Carers reported improvements in their own health and well-being. Transition into the community provided opportunities for consumers to exercise greater choice and control over their daily lives, reconnect with family and make some new social connections. With psychosocial support, consumers are going out in their communities to engage in regular activities. Some consumers are engaging in training, or volunteer or paid work. COVID-19 and subsequent lockdowns have made social participation more challenging.

A greater focus on active rehabilitation and meaningful occupation following transition may be beneficial, both in general and particularly for older consumers who are not eligible for NDIS community access funding. Aged care providers noted that PCLI Stage One consumers were generally more mobile and less physically dependent than the average aged care resident and therefore in greater need of activities and social engagement. The Ministry could consider providing small amount of additional funding for MH-RAC partners to provide activities that would promote personal recovery. Similarly, continuing mental health rehabilitation activities should be an essential part of the proposed Stage Two SLS service models.

## 3.4 Service development

### Evaluation Question 4: Have high quality and responsive new services been established?

The PCLI is fundamentally a partnership approach to supporting consumers with SPMI whose needs have not been met by traditional community services. For Stage One consumers and those in Stage Two with relatively stable needs, the program has built on existing program infrastructure such as the Commonwealth's residential aged care program and the NDIS, supplemented by new inputs (funding, clinical expertise) and processes (assessments, clinical governance processes). However, as noted above, these services are limited in terms of their operational models and staffing capabilities, and are not suitable for the many Stage Two consumers with very complex needs and comorbidities due to drug and alcohol use, intellectual or cognitive impairment, past trauma and who are a risk to themselves or others.

Consequently, there has been extensive investment in evaluating existing models of care, analysing consumer data, and stakeholder consultation to identify the requirements for new services to cater to this cohort. Procurement processes are under way for top-tier housing providers to build new services and NGOs to operate them, with three levels of care:

- step-down care with active rehabilitation and ability to 'step up' to hospital for short periods of stabilisation;
- highly structured care and very high-level clinical care and functional support with stabilising rehabilitation, for people with high needs and complex-care comorbidities;
- high-level clinical and daily living support with active community-oriented rehabilitation and relapse/harm minimisation approaches for co-occurring developmental needs and/or drug and alcohol problems.

The first model is intended as transitional care while the latter two models will allow length of stay as long as required. All will provide care in domestic settings with embedded and in-reach clinicians. The PCLI Stage Two Specialist Living Support (SLS) services are a key program under the \$700m Statewide Mental

Health Infrastructure Program. They will provide 230 places in SLS facilities in 29 locations across 9 LHDs and one Specialist Health District. It is expected that these facilities will be located near major hospitals to facilitate access to clinical expertise. The procurement process has closed and tenders are being formally evaluated. This is a significant achievement resulting from extensive planning, preparation and consultation over the past five years, and from the alignment of the PCLI with broader NSW Health strategic priorities.

As documented in *PCLI Evaluation Report 5* (Williams et al., 2020), Stage One service developments are already well established. These are the MH-RAC partnerships between the NSW Ministry of Health and aged care providers, supported by Stage One clinicians and program managers in participating LHDs. In the main, successful partnerships have been fostered through trusting, respectful and responsive relationships and a willingness to learn from experience, and model fidelity which ensures access to a bespoke environment and dedicated staffing to meet the needs of people with a primary diagnosis of mental illness with issues of ageing. However, there continue to be challenges associated with model fidelity and the capacity to ensure services are consistently of a high quality due to systemic limitations within the aged care sector such as funding constraints, declining clinical capacity, and staff turnover. The systems and processes of the PCLI provide a framework to support the partnership arrangements and promote the sustainability of transitions. *PCLI Evaluation Report 5* concluded that the MH-RAC partnerships had contributed to positive outcomes for Stage One consumers.



## 3.5 Reform of mental health services

---

### **Evaluation Question 5: Has practice in existing services been reformed?**

The introduction of the PCLI challenged the prevailing 'custodial', 'over-protective' and 'paternalistic' culture in mental health long-stay wards and has contributed to culture change. Staff survey findings indicate a substantial minority are not completely convinced, as shown by neutral responses to questions about change. It is arguably more worthwhile to concentrate change management efforts with this group rather than with the tiny minority who resist change.

The capacity for the PCLI to achieve long-term change requires a culture shift to the more contemporary, and hopeful, approach that acknowledges the rights of consumers to experience personal recovery. This mindset has underpinned the PCLI from the outset, and was embedded throughout its implementation. The program has empowered a group of staff who wanted to see recovery orientation enacted in routine practice but were previously frustrated by systemic and cultural barriers. It has done so by encouraging multidisciplinary involvement, placing senior peer workers in positions where they can advocate for consumers and carers, and designing person-centred processes for assessment and planning. The PCLI challenges mental health professionals to be accountable for outcomes, to avoid long stays and to quantify and manage risks associated with discharge. It has equipped and inspired mental health services to un-

pack consumers' capacities and preferences, assemble a suite of community-based, tailored supports, and reenergise rehabilitation psychiatry by demonstrating what is possible.

It appears that the majority of LHDs have now embedded aspects of the program within their ongoing operational and clinical governance processes, such as earlier commencement of discharge planning, engagement by inpatient units with community teams, and within at least one site, mandating community follow-up for at least two years. KI accounts indicate that practice change is indeed occurring, although it is incomplete and still requires extensive input from PCLI staff through ongoing monitoring and capacity building.

The collaborative underpinnings of the program has included the development of statewide networks and communities of practice between PCLI clinicians and peer workers, and through them, facilitated linkages with broader mental health and community service providers. The networks have been an important source of information about different models of care operating across the state, as well as an opportunity to workshop issues, problem-solve and learn from each other. Importantly, they have also provided an informal 'quality control' element for consumers transitioning across LHDs in terms of identifying suitable community service providers and supporting 'at risk' consumers who may be moving between LHDs.

## 3.6 Sustainability

---

### **Evaluation Question 6: Was the model sustainable?**

The PCLI has been underpinned by the key factors identified in the implementation science literature that are known to promote sustainable change (Damschroder et al 2009; Greenhalgh et al 2004; Stirman et al., 2016). It was embedded within policy frameworks that articulate contemporary aspirations for mental health service provision. Investments were applied to enhance capacity within health, and to leverage opportunities available within the community sector such as residential aged care and the NDIS. Leadership and governance arrangements have ensured that all stakeholders are cognisant of the program's strategic priority, including through KPIs and capacity building and culture change activities such as network meetings, dialogue days and development of communities of practice.

Sustainability of the PCLI is premised on the capacity of community aged and disability services to be able to support consumers in partnership with community mental health teams. This has been aided by the inclusion of clinical governance oversight processes and capacity building activities with staff within these partner services. However, KIs continue to raise concerns about the systemic limitations within these partners, particularly in terms of staff skills,

mix and continuity which is vital to support consumers with the level of complexity, comorbidity and risk of PCLI clients. KIs are not yet confident that these have been embedded sufficiently to continue if the PCLI staff were not present to provide guidance and oversight. While there are new models of care being developed to deliver 'wrap-around' services that include clear pathways between health services and 'home', these are not yet up and running. It is clear that there will be an ongoing need for the provision of clinical and behavioural support services within these services and, specifically, from highly skilled community mental health teams.

The ability of LHDs to adapt the targeting of consumers according to context and/or emerging challenges has been one of the program's strengths. The changing profile of consumers in terms of complexity, comorbidity and risk comes with additional challenges for community mental health, aged care and disability services. At this point there is still considerable value in the Ministry's having oversight of the strategic planning and resourcing of the PCLI, while continuing to foster strong executive support and clinical governance at LHD level.

The PCLI suite of assessment tools remains an area of particular concern. Although most KIs were generally in favour of assessment, they tended to describe the PCLI suite as far

larger than necessary and creating ‘overload’ when combined with the routine MH-OAT set of assessments and other locally used tools. Examination of the quantity and spread of missing data in the quantitative datasets has proven this to be the case, with the tools not being used consistently across sites and continuing gaps in baseline and follow-up measures. The challenges of introducing mental health outcomes tools and embedding them in routine care should not be underestimated, and this will take time. However, there are opportunities to improve uptake and ensure a greater proportion of PCLI consumers experience the potential benefits of comprehensive, structured assessment. Improving data completeness is also vital for demonstrating the program’s outcomes in terms of value for consumers and the system.

Overall, there is cause for optimism about sustainability. Active resistance by some inpatient staff members has declined and there is acceptance of multidisciplinary assessment and care planning. The program is aligned with the principles of value-based health care through an explicit focus on shared decision making with consumers and carers, workforce development within hospitals, and boosting resources and capacity in community service providers.

## 3.7 Value for money

---

### **Evaluation Question 7: Did the PCLI result in value for the money spent?**

The PCLI Stage One has resulted in a substantial reduction in the costs of care, with a total reduction of \$32.8M annually for 156 Stage One consumers who have transitioned to residential aged care or home care. Across the Stage One cohort the average cost of care incurred while living in the community

was \$143,459, amounting to a 59.4% reduction compared to the average cost during their index stay. Costs were lowest for consumers who transitioned to a generalist RACF and highest for consumers who transitioned to an SRACF with NDIS support. Nevertheless, transition to community living led to large reductions in average costs regardless of discharge destination and age, ranging between 37.0% and 72.5% savings compared with hospital-based care.

## 3.8 System efficiency

---

### **Evaluation Question 8: How has the PCLI improved efficiency in systems/ services/workforce?**

There is ample evidence—from KI interviews, program documents, evaluation observations and consumer and carer first-hand accounts—that the processes, structures and resources of the PCLI have addressed historical barriers to discharge from long-stay wards. The program has created well-documented and clear processes to guide transition planning, improving upon the existing procedures. There is now greater availability of skills and expertise, not just through the presence of senior clinicians in the PCLI positions but also through the capacity building they constantly undertake with inpatient and community mental health staff and external

providers. The unique bridging role of the PCLI clinician—sitting between inpatient and community, capacity building in both, and acting as a conduit for essential information—has helped break down ‘silos’ and improve efficiency within mental health services. Community mental health teams are better prepared to take on case management and monitoring of people with SPMI and complex needs at the point of discharge so that they have continuity of care. Aged care and disability providers have greater willingness and ability to work with these consumers, thus expanding the available options. Finally, a distinguishing feature of the PCLI is the strength and variety of networks it has established across NSW to build expertise and share knowledge around complex care mental health rehabilitation in community settings.

---

# Part 2

Consumer outcomes

Consumer and carer experiences

Provider and system change

Economic evaluation



# 4 Consumer outcomes

---

The consumer outcomes and economic evaluations make secondary use of the data from the HIE and PCLI databases, and the analysis of consumer outcomes adopts the definitions embedded in these sources. In June 2021, the Ministry PCLI team provided an extract of identified data from the PCLI database to InforMH, which matched PCLI consumers with their corresponding records in the HIE, the primary consumer-level data for the evaluation. A de-identified dataset was provided to the evaluation team. Consumer-specific data including information on health service use and scores on the routine MH-OAT tools were sourced from the HIE, whereas scores on the PCLI tools were sourced from the PCLI database. The **index stay** is defined as the hospital inpatient stay which ended in transition to the community. The discharge date from the index stay is assumed to be the date of transition.

Methods are described in Chapter 2. Briefly, the PCLI cohort was defined as individuals for whom entries existed in the PCLI database. This definition was adopted because it was assumed that the LHDs are best placed to identify consumers who have

experienced, or are at risk of experiencing, long hospital stays and to enter those individuals' records into the PCLI database. Because there is a lead time for data entry, a decision was made (in consultation with the Ministry PCLI team) to use data up to a 'cut-off date' of **31 December 2020**. The data extraction process was designed in collaboration with InforMH and the Ministry PCLI team.

In this chapter, we first describe the quality and completeness of the available data followed by a consumer profile including their personal and stay characteristics and baseline health status. Where sufficient data were available we investigated factors that predicted discharge from hospital and undertook analysis of changes in health outcomes from baseline to first follow-up assessment after transition. Finally, we describe consumer journeys after transition. In most cases results are presented separately for Stage One and Stage Two consumers. The material presented here is a summary and more information is available in Appendix 3.

## 4.1 Data quality, availability and completeness

---

The final de-identified analysis dataset included **1,004 PCLI consumers**, with information on their inpatient stays, emergency department presentations and non-admitted activity provided by hospitals as well as assessment data from the routinely collected MH-OAT tools (K10, LSP, HoNOS, HoNOS 65+ and RUG-ADL) sources from the HIE. Additional assessment scores (RAS-DS, LCQ, CAN-C, CANE, M-DAD and DemQOL) were sourced from the PCLI database. As stated above, extracts included data to 31 December 2020.

Assessments in PCLI were intended to occur at several time points: prior to discharge (Baseline Ax) and for a two-year follow-up period post-discharge: at 6 months (T1), 12 months (T2), 18 months (T3) and 24 months (T4). The time point T0 provided an optional opportunity to review the assessments prior to transition. Table 6 provides an overview over the assessments undertaken at each time point.

Over 90% of consumers had baseline (pre-discharge) data for the MH-OAT tools: the K10, LSP-16, and either the HoNOS or HoNOS 65+, consistent with other reports about this mandatory national data collection (Burgess et al., 2015). This proportion fell considerably at first follow-up, with between 36% and 60% having an assessment recorded after transition. It is important to note that the proportion of paired assessments was lower still, because not all of those who had a post-discharge score recorded for a tool also had a pre-discharge score for the same tool. (It was not possible to identify T2, T3 or T4 scores for the MH-OAT tools as these definitions do not exist in the HIE database. Instead, we distinguished between assessments at baseline (during the long stay) and follow-up (after discharge from hospital)).

**Table 6** Number of assessments by time point

Assessment tool	All consumers (N=1,004)		Transitioned consumers (N=674)			
	Baseline (Ax)	T0	Follow-up (T1)	T2	T3	T4
K10	915	-	367	-	-	-
LSP-16	917	-	457	-	-	-
HoNOS	890	-	496	-	-	-
HoNOS 65+	162	-	115	-	-	-
RUG-ADL	186	-	109	-	-	-
RAS-DS	315	36	56	27	18	15
LCQ	241	28	40	20	15	12
CAN-C	311	37	53	26	20	15
CANE	72	12	15	16	18	15
M-DAD	373	63	80	49	37	26
DemQOL	76	15	23	16	13	11

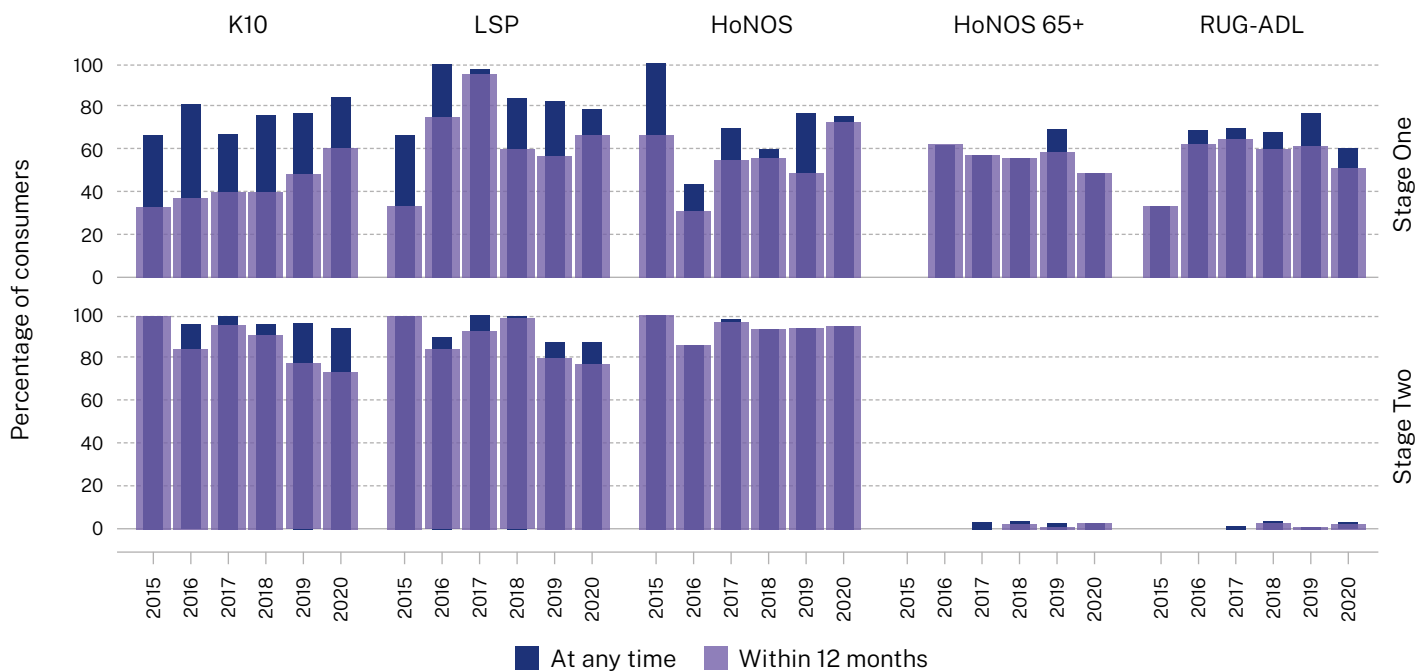
**Note:** Number of assessments was determined by 'total' score (where appropriate). Data extracted to 31/12/20.

For the PCLl assessment tools, data completeness remains a concern. The tools with the best coverage at baseline were those focused on needs assessment: combined, the CAN-C or CANE covered 38% of consumers. Scores for the person-centred, self-report tools – the RAS-DS and the LCQ – were available for around a third and a quarter of consumers, respectively. (It is acknowledged that collecting patient-reported data in mental health is a particular challenge; de Bienassis et al., 2021.) Follow-up data for the PCLl assessment tools were sparse. These quality and completeness issues mean that there are considerable limitations on the use of the PCLl database for routine reporting.

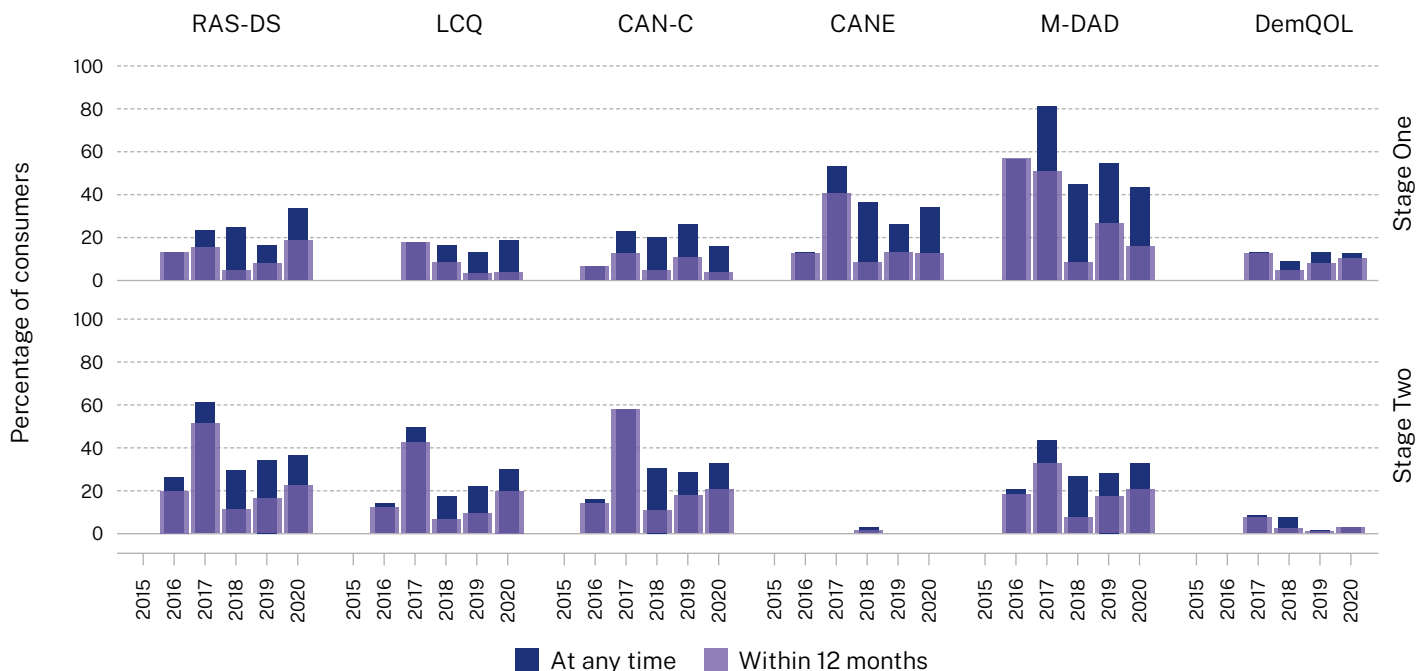
From the perspective of the evaluation, low data completeness – either because data have not been collected or not entered – places limitations on the validity and generalisability of the conclusions that can be drawn. If the data are not missing at random, there is a risk of bias. For example, if only one fifth of the cohort was assessed before and after transition, any findings would apply to that sub-group of the cohort. Whether the findings could be generalised to the whole cohort would depend on how the consumers were 'sampled' (that is, selected for follow-up assessment). The reasons why certain consumers are assessed and others are not are largely unknown and it is impossible to know whether a similar outcome would be observed if data were available for all consumers or whether those who received follow-up assessments were systematically different in some way (for example, more unwell), thus biasing the findings. This situation needs to be kept in mind when interpreting the consumer outcomes results.

Figure 5 and Figure 6 show the percentage of transitioned consumers who had a baseline assessment by year of transition. Green bars show assessments undertaken within 12 months before transition and blue bars include all assessments prior to transition. The 'mandatory' MH-OAT assessment tools are clearly used in routine practice, especially with Stage Two consumers, most of whom had been assessed with these tools within 12 months prior to discharge (Figure 5). Not unexpectedly, a much smaller proportion of consumers had scores for the PCLl-specific tools (Figure 6). Many of the baseline assessments occurred more than 12 months before transition. Stage Two consumers transitioned in 2017 were most likely to have recently been assessed with the PCLl toolkit; for Stage One no consistent trends were apparent. For Stage One consumers transitioned in 2020, around 18% had baseline assessments on RAS-DS, 15% on M-DAD, 12% on CANE and 9% on DemQOL within the previous year. Of the Stage Two consumers who transitioned in 2020, around 20–22% had baseline assessments on RAS-DS, LCQ, CAN-C and M-DAD within the previous year.

**Figure 5 Consumers with MH-OAT baseline assessment by year of transition**



**Figure 6 Consumers with PCLi baseline assessment by year of transition**



Analyses of health outcomes (that is, change in scores from baseline to first follow-up assessment after transition) can only include consumers with assessments at both time points (paired assessments). When this number is very low, the analysis will not produce reliable results. Table 7 shows the number of consumers with paired assessments, by assessment

tool. Where numbers are greyed out, this indicates that the number of consumers was too low for statistical testing or the proportion of consumers with paired assessments was too low to be representative. This included all the PCLi-specific tools. Even where testing is possible, caution is needed when interpreting results, especially if the underlying percentage of consumers is low.

**Table 7 Consumers with paired assessments (before and after transition)**

Assessment tool	Stage One (N=156)		Stage Two (518)	
	n	%	n	%
K10	50	32.1	308	59.5
LSP	80	51.3	350	67.6
HoNOS	41	26.3	427	82.4
HoNOS 65+	71	45.5	3	0.6
RUG-ADL	78	50.0	4	0.8
RAS-DS	7	4.5	41	7.9
LCQ	1	0.6	24	4.6
CAN-C	4	2.6	32	6.2
CANE	15	9.6	0	0.0
M-DAD	30	19.2	39	7.5
DemQOL	3	1.9	3	0.6

**Note:** Greyed out areas indicate insufficient data for outcomes analysis. Data extracted to 31/12/20.

## 4.2 Profile of the PCLI cohort at baseline

This section provides a description of the PCLI consumers at baseline, separately for Stage One and Stage Two. Unless stated otherwise, all consumers are included, even those who died prior to discharge and those who remained in hospital at the end of 2020.

Around 60% of Stage One consumers were male and more than 40% were aged between 65 and 74 years. Around one-third were aged under 65 years (Table 8). A substantial proportion of consumers in the Stage One initial cohort had principal diagnosis schizophrenia (46%) followed by schizoaffective disorder (14%). The proportion of consumers having schizophrenia (27%) was lower in the second-wave. The cohorts had quite different patterns of major diagnosis category,<sup>2</sup> with consumers in the initial cohort being more frequently grouped into the 'Mental Disease and Disorders' category (64%) than the second-wave cohort (24%). The 'Disease and Disorders of the Nervous System' category was more frequent for the second-wave than the initial cohort (14% vs 59%).

As would be expected, the initial cohort had much longer stays: 50% had spent four years or more in hospital (14% staying longer than 10 years) compared to only 3% of the second-wave cohort. The average length of stay for Stage One consumers was 3.9 years (SD 3.2), with 5.2 years (SD 3.6) for the initial cohort and 2.0 years (SD 1.1) for the second-wave cohort. Note that Table 8 shows ten Stage Two consumers recorded as second-wave in the PCLI database who have length of stays longer than seven years, although this is technically only possible for consumers in the initial cohort. This is most likely due to data entry errors.

Over two-thirds of Stage Two consumers in both cohorts were male and more than 50% were aged between 35 and 54 (Table 8). Principal diagnoses were similar in both cohorts, with the majority being diagnosed with schizophrenia (around 55%) followed by schizoaffective disorders (around 15%). The initial cohort of Stage Two had much longer stays: 50% had spent four years or more in hospital (with 19% staying longer than 10 years) whereas the vast majority (around 85%) of the second-wave consumers had stays of less than three years.

2. Major Diagnostic Categories are based on the principal diagnosis and are one building block of the Australian Refined Diagnosis Related Groups (AR-DRGs) which are used for classification and funding of hospital inpatient care (IHPA, 2020a).

**Table 8 Profile of consumers by stage and cohort**

Characteristic	Stage One (N=227)				Stage Two (N=777)			
	Initial cohort (n=132)		Second-wave cohort (n=95)		Initial cohort (n=228)		Second-wave cohort (n=549)	
	n	%	n	%	n	%	n	%
<b>Gender</b>								
Male	79	59.8	59	62.1	159	69.7	372	67.8
Female	53	40.2	36	37.9	69	30.3	177	32.2
<b>Age group</b>								
Younger than 25	0	0.0	0	0.0	6	2.6	38	6.9
25-34	0	0.0	2	2.1	35	15.4	113	20.6
35-44	3	2.3	1	1.1	57	25.0	155	28.2
45-54	9	6.8	7	7.4	71	31.1	138	25.1
55-64	34	25.8	21	22.1	54	23.7	98	17.9
65-74	57	43.2	43	45.3	4	1.8	7	1.3
75-84	25	18.9	17	17.9	1	0.4	0	0.0
85 and over	4	3.0	4	4.2	0	0.0	0	0.0
<b>Principal diagnosis</b>								
Schizophrenia	60	45.5	26	27.4	126	55.3	307	55.9
Schizoaffective disorders	18	13.6	15	15.8	35	15.4	79	14.4
Dementia in Alzheimer's disease	8	6.1	9	9.5	0	0.0	2	0.4
Vascular or unspecified dementia or dementia in other disease	6	4.5	11	11.6	0	0.0	0	0.0
Bipolar affective disorder	5	3.8	7	7.4	2	0.9	5	0.9
All other diagnoses	12	9.1	13	13.7	7	3.1	33	6.0
Missing <sup>1</sup>	23	17.4	14	14.7	58	25.4	123	22.4
<b>Major Diagnostic Category</b>								
Mental Diseases and Disorders	84	63.6	23	24.2	165	72.4	411	74.9
Diseases and Disorders of the Nervous System	18	13.6	56	58.9	0	0.0	7	1.3
All other MDCs	7	5.3	2	2.1	3	1.3	8	1.5
Missing <sup>1</sup>	23	17.4	14	14.7	60	26.3	123	22.4
<b>Total length of stay<sup>2</sup></b>								
Less than one year	27	20.5	31	32.6	22	9.6	153	27.9
1-2 years	17	12.9	42	44.2	32	14.0	211	38.4
2-3 years	11	8.3	17	17.9	34	14.9	104	18.9
3-4 years	11	8.3	2	2.1	26	11.4	41	7.5
4-5 years	9	6.8	1	1.1	15	6.6	20	3.6
5-6 years	9	6.8	1	1.1	12	5.3	9	1.6
6-7 years	14	10.6	1	1.1	13	5.7	1	0.2
7-8 years	2	1.5	0	0.0	6	2.6	0	0.0
8-9 years	3	2.3	0	0.0	12	5.3	3	0.5
9-10 years	10	7.6	0	0.0	12	5.3	1	0.2
10 or more years	19	14.4	0	0.0	44	19.3	6	1.1

1. Diagnosis coding and DRG classification only occurs after the inpatient episode has concluded. Therefore, there was no diagnostic or DRG information available for most current or recently concluded stays.

2. Length of stay is reported as it is recorded in the HIE. This does not take into account any previous stays. Length of stay for consumers who remained in hospital was calculated as at 31 December 2020.



## 4.2.1 Health status at baseline

From the comprehensive suite of assessment tools in use for the PCLI, 11 were selected for the evaluation based on relevance: five routine MH-OAT tools and six PCLI-specific tools (Table 9).

**Table 9 Overview of tools used in the consumer outcomes evaluation**

MH-OAT	Name of tool	What is measured	Direction of improvement	
K10	Kessler Psychological Distress Scale	Consumer-rated tool, measures global, non-specific distress based on questions about agitation, nervousness, fatigue and depression.	↓	
LSP-16	Life Skills Profile	Quality of life and general functioning in daily living (e.g., grooming, dressing).	↓	
HoNOS HoNOS 65+*	Health of the Nation Outcome Scales	Severity of mental health disorder, in terms of impact of mental illness symptoms on daily life.	↓	
RUG-ADL*	Resource Utilisation Groups – Activities of Daily Living	Functional independence in four basic domains of activities of daily living (ADL): bed mobility, toileting, transfer, and eating (known as ‘late loss’ ADL).	↓	
PCLI	Name of tool	What is measured	Use in PCLI**	Direction of improvement
RAS-DS	Recovery Assessment Scale – Domains and Stages	Personal recovery, including choice and control, satisfaction with social participation	Consumer-rated tool which helps identify what the person values and how they feel they are tracking with their recovery.	↑
LCQ	Living in the Community Questionnaire	Social inclusion and personal recovery, including choice and control, satisfaction with social participation, general wellbeing, quality of life, physical health	Consumer-rated tool which focuses on social inclusion and mental health recovery. Can be used to assess the extent to which a person is happy, hopeful, and participating in their community, and what they’d like to change.	↑
CAN-C CANE*	Camberwell Assessment of Need	Support needs and requirements for action	Ensures a broad range of needs are considered, along with help available from formal and informal sources. Useful to inform rehabilitation and care planning.	↓
M-DAD*	Modified Disability Assessment for Dementia	Independence in activities of daily living (ADL) and instrumental activities of daily living (IADL)	Used to screen for areas requiring specialised assessment. Highlights areas to discuss with consumers and potential care providers around strategies to optimise function.	↑
DemQOL*	Dementia Quality of Life	Quality of life for people with cognitive impairment	Used as an alternative to the LCQ for people planning to go to aged care facilities.	↑

**Note:** \* Tools for use with older adults. \*\* PCLI Planning, Assessment and Follow-Up Guide (NSW Health 2020a).

#### 4.2.1.1 Kessler Psychological Distress Scale (K10)

The K10 is a 10-item consumer self-rated questionnaire intended to yield a global measure of non-specific psychosocial distress based on questions about the level of nervousness, agitation, psychological fatigue and depression in the relevant rating period. The K10 scales were developed by Kessler and Mroczek during 1992-1994 at the Institute for Social Research, University of Michigan, and subsequently by Kessler at the Department of Health Care Policy, Harvard Medical School (Kessler et al., 2002).

Given the extensive use of the K10 in epidemiological studies, there is population reference material (norms). Scores under 20 indicate that the consumer is 'likely to be well', scores in the range 20-24 indicate the consumer is 'likely to have a mild disorder', scores in the range 25-29 indicate the consumer is 'likely to have a moderate disorder' and scores of 30 or more indicate the consumer is 'likely to have a severe disorder'. The K10 can be rated according to 'the last three days' or 'the last month'. The latter version has been used for the PCLI program

K10 baseline assessment data were available for 167 (74%) Stage One consumers and 748 (96%) Stage Two consumers. The majority of consumers were likely to be well; 56% in Stage One and 64% in Stage Two. There was a higher incidence of moderate to severe psychological distress among Stage One consumers (31%) compared to Stage Two (21%). Table 28 in Appendix 3 provides further details.

#### 4.2.1.2 Abbreviated Life Skills Profile (LSP-16)

The Life Skills Profile, also known as the LSP, was developed by an Australian clinical research group to assess a consumer's abilities with respect to basic life skills (Rosen et al., 1989). Its focus is on the consumer's general functioning and disability rather than their clinical symptoms; that is, how the person functions in terms of social relationships, ability to do day-to-day tasks and so forth. The original 39-item tool was reduced to 16 items as part of the Australian Mental Health Classification and Service Costs (MH-CASC) study. In the LSP-16, higher scores reflect higher levels of disability. The 16 items are scored from 0 (good functioning) to 3 (greater dysfunction) and can be reported across four broad domains:

- Withdrawal: 4 items, range 0–12
- Self-care: 5 items, range 0–15
- Compliance: 3 items, range 0–9
- Anti-social: 4 items, range 0–12

In this study, LSP-16 baseline assessment data were available for 197 (87%) Stage One and 720 (93%) Stage Two consumers. Across all subscales, Stage Two consumers had greater abilities and general functioning than Stage One. Using the standardised scores, the highest average score was reported for 'self-care' followed by 'withdrawal'. Consumers in both stages had relatively lower scores for the 'anti-social' and 'compliance' subscales. Table 29 in Appendix 3 provides further details.

#### 4.2.1.3 Health of the Nation Outcome Scales (HoNOS and HoNOS 65+)

The HoNOS was developed by the Royal College of Psychiatrists in the United Kingdom to be used by clinicians in their routine work to measure consumer outcomes (Wing et al., 1996). It was designed specifically for use with people with a mental illness and is best considered as a general measure of severity of mental health disorder.

The HoNOS 65+ is a variant of the general adult version of the HoNOS developed specifically for use with older people with a mental illness (Macdonald 1999; Shergill et al., 1999).

Both tools focus on health status and severity of symptoms and consist of 12 items covering the sorts of problems that may be experienced by people with a significant mental illness. Each item is rated on a five-point scale: 0 = no problem, 1 = minor problem requiring no formal action, 2 = mild problem, 3 = problem of moderate severity, 4 = severe to very severe problem. Ratings of 0 or 1 are not clinically significant. Ratings of 2, 3 or 4 are clinically significant, requiring active observation and intervention (Burgess et al., 2009).

In this study, complete HoNOS baseline assessment data were available for 154 (68%) Stage One consumers and 736 (95%) Stage Two consumers. Across both stages 'behaviour' had the least symptoms. For Stage Two consumers this is followed by the 'impairment' and 'symptom' subscales. 'Social' problems were most common for Stage Two consumers and at the same level as Stage One consumers. However, Stage One consumers still had slightly more problems according to the 'symptom' subscale and even more problems according to the 'impairment' subscale. Table 30 in Appendix 3 provides further details.

Complete HoNOS 65+ baseline assessment data were available for 135 (59%) Stage One consumers. Across the subscales, Stage One consumers assessed with HoNOS 65+ had more severe symptoms of mental health disorder compared to those who were assessed using HoNOS. However, the pattern across subscales was similar. Behavioural symptoms were the fewest, followed by 'symptom' and 'social' subscales. The most symptoms were in the 'impairment' subscale. Table 31 in Appendix 3 provides further details.

#### 4.2.1.4 Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)

This measure was developed by Fries and colleagues (1994) for the measurement of nursing dependency in nursing home facilities in the USA. The RUG-ADL measures ability with respect to what are called 'late loss' activities: those activities that are likely to be lost last in life such as eating and mobility. ('Early loss' activities such as dressing and grooming) are included in the LSP-16.) For this reason, this tool is generally only applicable to people aged 65 and over.

To complete the RUG-ADL, clinicians rate the consumer's need for assistance in four activities of daily living: bed mobility, toileting, transfer, and eating. The first three domains are rated 1, 3-5. A rating of 2 is not included. The domain 'eating' is rated 1-3. A total score is the sum of all four domains, ranging from 4 to 18. Higher scores indicate poorer functioning.

In this study, RUG-ADL baseline assessment data were available for 160 (70%) Stage One consumers. The vast majority (between 76% and 88%) of Stage One consumers were independent or required limited physical assistance. A small proportion required extensive or two-person assistance with bed mobility (13%), toileting (20%), transfer (15%) or eating (13%). The median RUG-ADL score for Stage One consumers was 4.5 (IQR 7). Only a small number (3%) of Stage Two consumers had these assessments because the tool is designed for those with issues of ageing. Table 32 in Appendix 3 provides further details.

#### 4.2.1.5 Recovery Assessment Scale – Domains and Stages (RAS-DS)

The Recovery Assessment Scale-Domains and Stages (RAS-DS) is a consumer-rated instrument which measures personal mental health recovery (Hancock et al., 2015). It has 38 items, these are statements rated on a four-point scale: ‘untrue’, ‘a bit true’, ‘mostly true’ and ‘completely true’. The items are divided into four recovery domains: Doing Things I Value (functional recovery); Looking Forward (personal recovery); Mastering My Illness (clinical recovery) and Connecting and Belonging (social recovery). Functional recovery refers to meaningful roles and occupations. Personal recovery refers to internal processes facilitated by empowering and inclusive environments through which consumers establish or re-establish a sense of hope, purpose and self-efficacy. Clinical recovery is generally seen as the successful management or reduction of symptoms. Social recovery incorporates social inclusion and the establishment of meaningful, support and satisfying social networks (Hancock et al., 2011).

For the purpose of the PCLI, the domains are reported according to three categories: scores lower than 25%, scores between 26 and 50%, scores between 51 and 75%, and scores greater than 75%. Higher scores are positive, indicating higher levels of recovery.

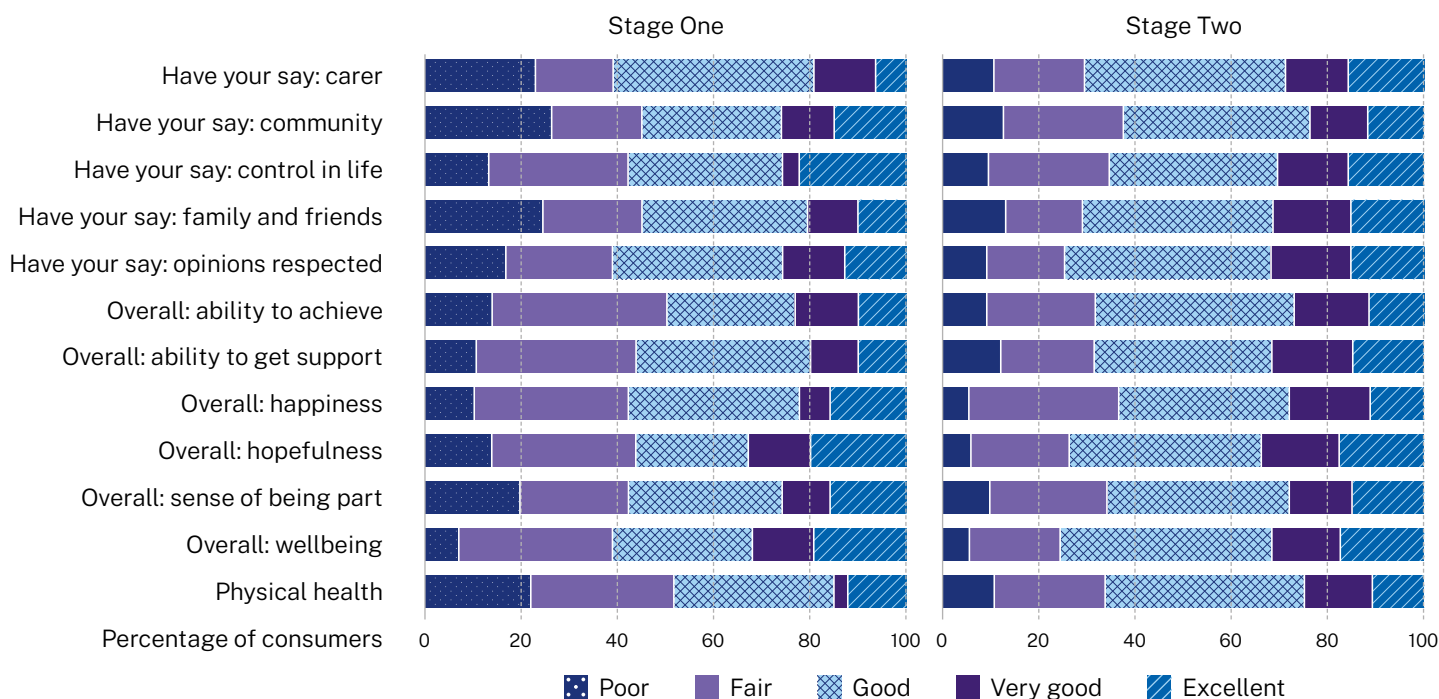
In this study, RAS-DS baseline assessment data were available for 49 (22%) Stage One and 274 (35%) Stage Two consumers. On average, Stage Two consumers had similar results across all four domains, all higher than Stage One. For Stage One consumers scores were highest for functional recovery and lowest for clinical recovery. Table 33 in Appendix 3 provides further details.

#### 4.2.1.6 Living in the Community Questionnaire (LCQ)

The Living in the Community Questionnaire (LCQ) was developed to monitor the extent to which adults with mental illness engage in meaningful vocational and community activity, have stable and affordable housing, and have a GP to look after their general medical needs (Coombs et al., 2016). It includes other aspects of social inclusion that can be important elements of a person’s recovery, such as having a say in important decisions or a sense of hopefulness for the future. The measure has 33 items focusing on social activities, education activities, voluntary work, time spent caring for others, employment and living situation and reported physical health. These are considered antecedents of, or contributing factors to, a sense of belonging to a community or a group. For this report only the items 21 to 26 and 28 to 33 were available. These are rated on a five-point scale; ‘poor’, ‘fair’, ‘good’, ‘very good’ and ‘excellent’.

LCQ baseline assessment data were available for 33 (15%) consumers in Stage One and 204 (26%) in Stage Two. Figure 7 presents the percentage of consumers reporting ‘poor’, ‘fair’, ‘good’, ‘very good’ and ‘excellent’ LCQ ratings. Overall, the majority of consumers in both stages reported ‘good’ to ‘excellent’ ratings in most of the LCQ items, with a substantial higher proportion in Stage Two (between 63% and 76%) than Stage One (between 49% and 61%). Table 34 in Appendix 3 provides further details.

**Figure 7 LCQ responses**



#### 4.2.1.7 Camberwell Assessment of Need (CAN-C) and Camberwell Assessment of Need for the Elderly (CANE)

The Camberwell Assessment of Need (CAN) was designed to measure clinical and social needs (Phelan et al., 1995). The CAN-C or clinical version was designed to be used by staff to plan consumer care. It has four sections for each of 22 domains and is completed from the 'staff' perspective and/or from the 'user' (consumer) perspective.

The Camberwell Assessment of Need for the Elderly (CANE) (Reynolds et al., 2000) was developed using a modified Delphi consensus process. It is based on the structured model of the CAN and uses the same algorithm for the identification of need. There are various versions of the CANE that can be rated by different respondents: consumer, staff, carer and researcher.

This report presents the findings from the tools' first section, which assesses need (no need, met need, unmet need or not known) for the domains. The purpose of this section of the tool is twofold: first, to assess whether there is a need in the domain, and whether effective help is already being given; second, to decide whether further questions about this domain are necessary to support care planning. Scores are determined using the follow algorithm:

- If a serious problem is present, regardless of cause, whether or not help is being given, then rate 2. This is an 'unmet need'.
- If there is no serious problem because of the help being given, then rate 1, 'met need'.
- Rate 0 when there is 'no need'.
- Rate 9 if the consumer does not want to participate, this means 'not known'.

The 22 domains are: accommodation, food, looking after the home, self-care, daytime activities, physical health, psychotic symptoms, information on condition and treatment, psychological distress, safety to self, safety to others, alcohol, drugs, company, intimate relationships, sexual expression, child care, basic education, telephone, transport, money and benefits.

In this study, CAN-C baseline assessment data were available for 44 (19%) consumers in Stage One and 275 (35%) in Stage Two. Over half (55%) of Stage Two consumers self-reported that they had identified needs compared to 43% in Stage One. Of those, 79% had unmet need in Stage One and 59% in Stage Two. From the staff perspective, all Stage One consumers assessed with the CAN-C had identified needs and all had unmet needs; 95% of Stage Two consumers assessed with the CAN-C had identified needs, of whom 78% (n=204) had unmet needs. Table 35 in Appendix 3 provides further details.

CANE baseline assessment data were available for 77 (34%) Stage One consumers (and, as would be expected, less than 1% of Stage Two consumers). Only 14% of Stage One consumers self-reported that they had identified needs, and 64% of those consumers had unmet needs. According to carers, only 6% of consumers had needs, and 80% of those consumers had unmet

needs. A substantially higher number of consumers with needs was reported by staff (77%), and the vast majority of those consumers (88%) had unmet needs. Table 36 in Appendix 3 provides further details.

#### 4.2.1.8 Modified Disability Assessment for Dementia (M-DAD)

The Disability Assessment for Dementia (DAD) (Gélinas & Gauthier, 1994) is a caregiver-based interview that uses a 46-item questionnaire to evaluate instrumental and basic activities of daily living (ADL) in people with cognitive impairments. For basic ADL, 19 items are evaluated within the subdomains of hygiene, dressing, undressing, continence, and eating. For instrumental ADL, 26 items are evaluated within the subdomains of meal preparation, telephoning, going on an outing, finance and correspondence, medication, and leisure and housework.

A modified version of the DAD was used for PCLI. This version has 40 items across 10 domains: hygiene (7); dressing (5); continence (2); eating (3); meal preparation (3); telephoning (4); going on an outing (5); finance and correspondence (4); medications (2); and leisure and housework (5). Responses are coded 0 = never / almost never, 1 = sometimes, 2 = always. For the PCLI, scores are reported as a simple count of individual items where the consumer is always capable of undertaking that basic or instrumental activity of daily living. Thus, higher scores indicate better functioning.

The following score ranges are possible:

- Basic ADL: 17 items, range 0–17
- Instrumental ADL: 18 items, range 0–23

Additional domains for reporting include:

- Initiation: 13 items, range 0–13
- Planning and organisation: 11 items, range 0–11
- Effective performance: 16 items, range 0–16

In this study, M-DAD baseline assessments were undertaken for 124 (55%) Stage One consumers and 267 (34%) Stage Two consumers. Results are reported as percentage of items consumers are always capable of undertaking. Across all domains, the Stage Two cohort had on average better results than the Stage One cohort, as would be expected given that the latter (by definition) have significant issues of ageing. The pattern across domains was very similar. The highest average was reported in the 'basic ADL' domain and the lowest in 'instrumental ADL'. The averages for 'initiation', 'planning' and 'effective performance' were all quite similar. Table 37 in Appendix 3 provides further details.

#### 4.2.1.9 Dementia Quality of Life (DemQOL)

The Dementia Quality of Life (DemQOL) is a condition-specific instrument that aims to capture health-related quality of life in older individuals with cognitive decline and dementia (Smith et al., 2005). There are consumer-reported and proxy versions. For the PCLl the domains are reported as ‘feeling’, ‘memory’, ‘everyday’ and ‘overall’. The ‘feeling’ domain asks questions about experiencing worry, anxiety, sadness or irritability. The ‘memory’ domain asks questions about forgetting people or having muddled thoughts. The ‘everyday’ domain is about having enough company, getting affection and making yourself understood.

In this study, complete DemQOL baseline assessment data was available for 22 (10%) Stage One consumers. Overall, the domain with the best results for Stage One consumers was ‘memory’ followed by ‘everyday life’ and ‘feelings’. The lowest results were recorded for ‘overall quality of life’. Given that this instrument is designed for older individuals, only small number (3%) of Stage Two consumers had this assessment. Table 38 in Appendix 3 provides further details. There is some caution expressed in the literature about the reliability of the DemQOL domains given the multidimensional nature of dementia (Chua et al., 2016). This, together with the small number of assessments, means the findings should be interpreted with caution.

### 4.3 Transitions to community living

Overall, two out of three consumers (n=674, 67%) were transitioned to the community by the end of December 2020. This comprised 156 (69%) Stage One and 518 (67%) Stage Two consumers (Table 10). In Stage One, the proportion of consumers transitioned to the community was noticeably higher in the second-wave cohort than in the initial cohort (75% vs 64% in Stage One). As would be expected, around half of the transitions in the initial cohort were early in the program (2016 and 2017), whereas most transitions in the second-wave cohort occurred later, in 2019 and 2020.

Almost one-fifth (19%) of Stage One consumers and around one-third of Stage Two consumers remained in hospital at 31 December 2020. Thirty-five (3%) consumers had died in hospital, most of whom were people with significant issues of ageing (28 in Stage One, 7 in Stage Two). For those 104 (29%) consumers of the initial cohort who remained in hospital at the end of 2020 their stay in hospital has continued for another five-and-a-half years or 2,011 days since the commencement of PCLl on 1 July 2015.

**Table 10 Transition status by stage and cohort**

Transition status	Stage One (N=227)				Stage Two (N=777)			
	Initial cohort (n=132)		Second-wave cohort (n=95)		Initial cohort (n=228)		Second-wave cohort (n=549)	
	n	%	n	%	n	%	n	%
Discharged to community								
in 2015 <sup>1</sup>	3	2.3	-	-	6	2.6	1	0.2
in 2016	16	12.1	-	-	36	15.8	14	2.6
in 2017	25	18.9	15	15.8	37	16.2	34	6.2
in 2018	11	8.3	14	14.7	26	11.4	56	10.2
in 2019	17	12.9	22	23.2	19	8.3	102	18.6
in 2020	13	9.8	20	21.1	19	8.3	168	30.6
Total transitions	85	64.4	71	74.7	143	62.7	375	68.3
Remaining in hospital	25	18.5	18	18.9	79	34.6	173	31.5
Died in hospital	22	16.3	6	6.3	6	2.6	1	0.2

1. This was a six-month period (1 July to 31 December 2015) only

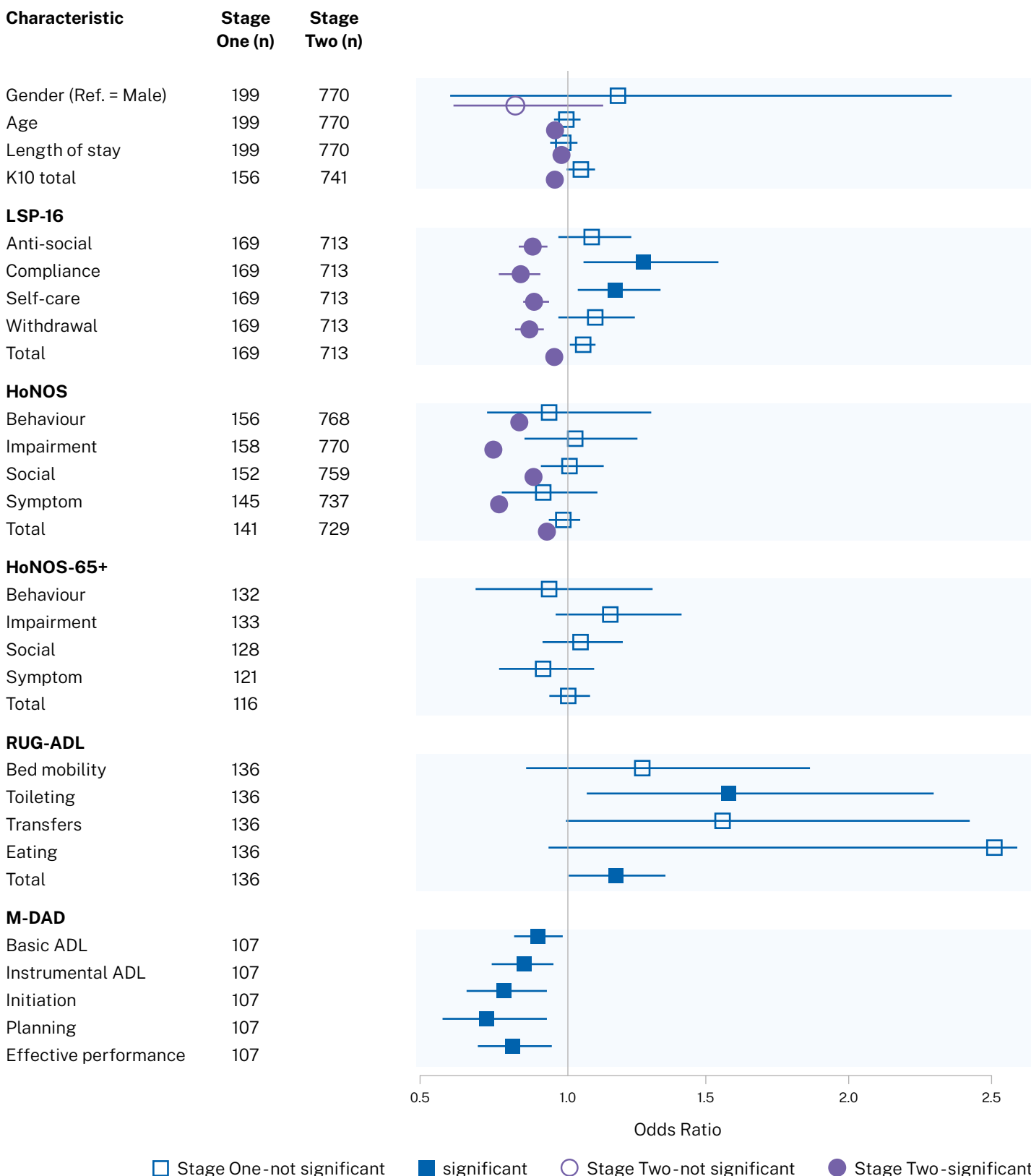
### 4.3.1 Factors predicting transition

For all consumers discharged from hospital (except those whose discharge status was due to death), we undertook statistical analysis to identify characteristics of the consumer, their hospital stay or their health outcomes that were associated with likelihood of transition to the community. The results are presented in Table 11 and Table 12.

Figure 8 contains a visualisation of those results and presents the odds ratio and 95% confidence interval (CI) for the prediction of discharge from hospital based on available data, separately for Stage One and Stage Two consumers. An odds ratio greater than one means higher likelihood of discharge. Stage One results are shown in blue and Stage Two results are red. Significant results have a filled square or circle.

Gender was not found to be significantly associated with discharge from hospital for either group of consumers.

**Figure 8 Predictors of discharge from hospital**



### 4.3.1.1 Predictors of Stage One transitions

Stage One consumers with poorer general functioning and higher disability measured by the LSP-16 domains of compliance and self-care had a higher likelihood of

discharge. One-unit increases in the compliance and self-care domains (indicating increased functional impairment) were associated with 26% and 16% greater likelihood of discharge, respectively.

**Table 11 Factors predicting discharge from hospital**

Characteristic	Stage One (N=199) <sup>1</sup>				Stage Two (N=770) <sup>2</sup>			
	n	OR	95% CI		n	OR	95% CI	
<b>Sex (Ref. = Male)</b>	199	1.17	0.58	2.35	770	0.81	0.59	1.12
<b>Age</b>	199	0.99	0.96	1.03	770	0.95 **	0.94	0.96
<b>Length of stay<sup>3</sup></b>	199	0.98	0.94	1.03	770	0.97 *	0.95	0.99
<b>HoNOS</b>								
Behaviour	156	0.93	0.71	1.29	768	0.82 **	0.74	0.89
Impairment	158	1.02	0.84	1.24	770	0.73 **	0.67	0.80
Social	152	1.00	0.90	1.12	759	0.87 **	0.83	0.90
Symptom	145	0.91	0.76	1.10	737	0.75 **	0.70	0.80
Total	141	0.98	0.93	1.04	729	0.92 **	0.92	0.94
<b>LSP-16</b>								
Anti-social	169	1.08	0.96	1.22	713	0.87 **	0.82	0.92
Compliance	169	1.26 *	1.05	1.53	713	0.83 **	0.75	0.90
Self-care	169	1.16 *	1.03	1.32	713	0.88 **	0.84	0.93
Withdrawal	169	1.09	0.96	1.23	713	0.86 **	0.81	0.91
Total	169	1.05	1.00	1.09	713	0.95 **	0.93	0.96
<b>K10 total</b>	156	1.04	0.99	1.09	741	0.96 **	0.94	0.98

1. 28 consumers in Stage One and

2. 7 consumers in Stage Two were excluded from the analysis because they had died in hospital during their index stay.

3. Length of stay is reported in six-month increments and as it is recorded in the HIE. This does not take into account any previous stays. Length of stay for consumers who remained in hospital was calculated as at 31 December 2020.

**Note:** \* indicates significant at  $p < 0.05$  and \*\* significant at  $p < 0.001$ . These p-values refer to the log odds of being discharged in the univariate logistic regression.

**Table 12 Additional factors predicting discharge from hospital for Stage One**

Characteristic	Stage One (N=199) <sup>1</sup>			
	n	OR	95% CI	
<b>M-DAD</b>				
Basic ADL	107	0.89 *	0.81	0.98
Instrumental ADL	107	0.84 *	0.73	0.95
Initiation	107	0.77 *	0.64	0.92
Planning	107	0.71 *	0.55	0.92
Effective performance	107	0.80 *	0.68	0.94
<b>HoNOS-65+</b>				
Behaviour	132	0.93	0.67	1.30
Impairment	133	1.15	0.95	1.40
Social	128	1.04	0.91	1.19
Symptom	121	0.91	0.75	1.09
Total	116	1.00	0.93	1.07
<b>RUG-ADL</b>				
Bed mobility (Ref. = Independent / supervision)	136			
Limited assistance or one or two person	-	1.26	0.85	1.85
Toileting (Ref. = Independent / supervision)	136			
Limited assistance or one or two person	-	1.56 *	1.06	2.29
Transfers (Ref. = Independent / supervision)	136			
Limited assistance or one or two person	-	1.54	0.99	2.42
Eating (Ref. = Independent / supervision)	136			
Limited or extensive assistance	-	2.49	0.95	6.58
Total (Ref. = score 4)	136			
Score > 4	-	1.16 *	1.00	1.34

1. 28 consumers were excluded because they had died in hospital during their index stay.

**Note:** \* indicates significant at  $p < 0.05$  and \*\* significant at  $p < 0.001$ ; p-values refer to log odds of discharge in the univariate logistic regression.

For the RUG-ADL, we compared the lowest possible score (4 = 'independent or supervision only') with all other scores (possible range 5-18). For the total RUG-ADL score, reduced capacity in 'late loss' activities of daily living was significantly associated with 16% increased likelihood of discharge. Additionally, a one unit increase on the toileting domain was associated with 56% increased likelihood of discharge.

All domains of the M-DAD were significantly associated with the likelihood of discharge, indicating that higher capacity in instrumental and basic activities of daily living in people with cognitive impairments was associated with reduced likelihood of discharge. One unit increase in the basic ADL, instrumental ADL, initiation, planning and effective performance domains were associated with 11%, 16%, 23%, 29% and 20% decreased likelihood of discharge respectively.

Together, these findings suggest that Stage One consumers whose issues of ageing were associated with quite severe functional impairments were most likely to transition to community living. Although this might seem counterintuitive, it makes sense given the nature of the cohort. People experiencing greater disability and requiring greater assistance with activities of daily living would seem more suited to life in an aged care facility – the destination for almost all Stage One consumers – than those who were still relatively mobile and capable of self-care.

No other scores or consumer characteristics were significantly associated with discharge from hospital. However, it should be noted that statistical significance of an observed association depends in part on the sample size and the Stage One cohort is relatively small.



### 4.3.1.2 Predictors of Stage Two transitions

For Stage Two consumers, increasing age and length of stay had a significantly negative effect on the likelihood of discharge. Each additional year of age was associated with 5% decreased odds of discharge from hospital and each additional six-month period in hospital was associated with 3% decreased likelihood of discharge.

All HoNOS subscales and total HoNOS scores were significantly associated with the likelihood of discharge. Those with more severe mental health disorder were less likely to be transitioned to community living. A one-unit increase on the behavioural, impairment, social or symptom subscales (indicating more severe disorder) was associated with 18%, 27%, 13% and 25% decreased likelihood of discharge respectively. Overall, a one-unit increase in the total HoNOS score was associated with 8% reduced likelihood of discharge.

All domains and total LSP-16 scores were significantly associated with the likelihood of discharge. Those with higher disability were less likely to be transitioned to community living. A one-unit increase on the anti-social, compliance, self-care or withdrawal domains (indicating lower quality of life and general functioning in daily life) was associated with 13%, 17%, 12% and 14% decreased likelihood of discharge respectively. Overall, a one-unit increase in the total LSP-16 score was associated with 5% reduced likelihood of discharge.

Stage Two consumers experiencing psychological distress (K10) were significantly less likely to be transitioned to community living. A one unit increase in total K10 score was associated with 4% decreased odds of discharge from hospital.

Together, these findings indicate that Stage Two consumers experiencing greater severity of mental health disorder and/or greater psychological distress were less likely to leave hospital. Poorer general functioning in daily life also appeared to be a barrier to transition. These findings would be expected, given that the usual destinations for Stage Two consumers are SIL group homes, HASI/HASI+, private homes or public housing. These community living options offer a range of disability supports but no 24/7 clinical support as is available in hospital (although they are linked with community mental health services for regular follow-up). It appears that PCLI teams and treating teams are ensuring that people are as clinically well as possible, and equipped for daily living, before arranging their discharges from hospital.

Age and length of stay are significant predictors of discharge – the older the person, and the longer they have been in hospital, the less likely they are to transition to community living. However, this effect may be an artefact of how these variables are measured. In the current study these values were determined on the discharge date (or at 31 December 2020 for consumers who remained in hospital). With the passing of time, as the PCLI began more than five and a half years ago, the difference in age and length of stay between consumers who remain in hospital and those who have transitioned naturally increases.

## 4.4 Health outcomes following transition from hospital

The analyses in this section include 674 (67%) consumers (156 Stage One and 518 Stage Two) discharged from hospital by 31 December 2020, excluding those who died during their stay. For tools with sufficient paired data (see Table 7) we compared scores before and after transition, using the last baseline assessments and the first follow-up assessments. Five assessments tool had enough paired assessments to warrant statistical testing: K10, LSP-16, HoNOS, HoNOS 65+ (only Stage One) and RUG-ADL (only Stage One).

Where appropriate, subscale scores were standardised to represent the individual's actual score as a **percentage of the highest possible score** (i.e. range 0 to 100). This makes tools or subscales with different scoring systems directly comparable. Differences were then calculated as 'follow-up score minus baseline score'. For all the tools used in the analysis of health outcomes, a reduction in score over time indicates improvement (Table 9). In other words, if consumers improve on average following transition, follow-up scores will be lower than baseline and the difference between the mean scores will be negative (Table 11 and Table 12).

### 4.4.1 Stage One health outcomes

For Stage One consumers, the LSP-16 results for all subscales (except 'withdrawal') and the total score show significant improvements in general functioning following transition, with the biggest improvements in 'antisocial' followed by 'compliance' and 'self-care'. The HoNOS 65+ 'impairment' scores increased significantly between baseline and follow-up, indicating deterioration in cognition and physical health. The RUG-ADL results for all domains (except 'toileting') and the total score show significant deterioration in 'late loss' activities of daily living: bed mobility, toileting, transfers and eating. The HoNOS 65+ 'impairment' domain and RUG-ADL both pertain to cognitive and physical health factors and functioning. With the limited data available it impossible to differentiate between the effects of ageing (between assessments) and changes in service provision. Changes in K10 and HoNOS were not significant.

**Table 13 Health outcomes after transition for Stage One**

Outcome tools	Stage One (N=156)			
	Pairs n	Baseline mean (SD)	Follow-up mean (SD)	Mean difference
<b>HoNOS 65+<sup>1</sup></b>				
Behaviour	84	10.8 (10.2)	9.5 (8.5)	-1.2
Impairment	84	47.6 (28.4)	55.8 (28.9)	8.2*
Symptom	79	23.9 (15.9)	25.7 (16.9)	1.8
Social	76	32.0 (19.7)	29.5 (16.6)	-2.5
Total	71	26.4 (13.6)	28.0 (12.2)	1.6
<b>K10</b>	50	20.8 (9.0)	17.8 (8.2)	-2.9
<b>LSP-16</b>				
Withdrawal	80	47.3 (26.2)	47.8 (24.2)	0.5
Self-care	80	53.7 (23.5)	47.9 (24.4)	-5.7 *
Compliance	80	33.6 (28.8)	26.5 (22.3)	-7.1 *
Antisocial	80	32.5 (27.7)	22.9 (21.8)	-9.6 **
Total	80	43.0 (22.4)	37.6 (18.7)	-5.4 *
<b>HoNOS<sup>2</sup></b>				
Behaviour	47	8.9 (11.8)	9.8 (12.0)	0.9
Impairment	48	34.4 (21.2)	35.7 (22.9)	1.3
Symptom	44	25.0 (13.8)	28.2 (19.7)	3.2
Social	45	28.9 (23.0)	26.1 (16.6)	-2.8
Total	41	23.5 (13.5)	24.8 (12.0)	1.3
	More dependent n (%)	No change n (%)	Less dependent n (%)	Mean difference
<b>RUG-ADL</b>				
Bed mobility	14 (17.9)	61 (78.2)	3 (3.9)	0.32 *
Toileting	14 (17.9)	58 (74.4)	6 (7.7)	0.24
Transfers	9 (11.5)	67 (85.9)	2 (2.6)	0.23 *
Eating	13 (16.7)	60 (76.9)	5 (6.4)	0.14 *
Total	25 (32.1)	43 (55.1)	10 (12.8)	0.94 *

**Note:** \* indicates significant at  $p < 0.05$  and \*\* significant at  $p < 0.001$ . These p-values refer to the paired t-tests or Wilcoxon Signed Rank tests (non-parametric equivalent) used to examine differences between the baseline and the follow-up assessment.

1. Subscale scores of the HoNOS65+ have been standardised to represent a percentage of maximum possible score (i.e. range 0 to 100) to enable direct comparisons. For all these tools, lower scores indicate less severe problems.

#### 4.4.2 Stage Two health outcomes

For Stage Two consumers, the LSP-16 results for all subscales (except 'antisocial') and the total score show significant decline in general functioning following transition, with the largest deterioration in 'withdrawal' and 'compliance' followed by 'self-care'. The HoNOS 'impairment' scores increased significantly, indicating deterioration in cognition and physical

health over time. Changes of all other HoNOS subscales, HoNOS total and K10 were not significant.

**Table 14 Health outcomes after transition for Stage Two**

Outcome tools	Stage Two (N=518)			
	Pairs n	Baseline mean (SD)	Follow-up mean (SD)	Diff. mean <sup>1</sup>
<b>K10</b>	308	16.2 (7.7)	16.1 (7.6)	-0.1
<b>LSP-16</b>				
Withdrawal	350	30.4 (21.5)	35.9 (22.6)	5.4 **
Self-care	350	34.7 (19.7)	36.7 (18.9)	2.0 *
Compliance	350	19.0 (19.0)	24.0 (21.6)	5.0 **
Antisocial	350	17.6 (19.4)	17.6 (19.9)	0.0
Total	350	26.4 (15.7)	29.3 (16.2)	2.9 **
<b>HoNOS<sup>2</sup></b>				
Behaviour	458	8.7 (12.2)	8.5 (12.1)	-0.2
Impairment	468	18.2 (19.4)	23.4 (18.7)	5.0 *
Symptom	457	19.2 (18.3)	20.7 (19.0)	1.5
Social	439	22.3 (22.5)	22.0 (19.2)	-0.3
Total	427	17.4 (15.2)	18.4 (13.5)	1.1

**Note:** \* indicates significant at  $p < 0.05$  and \*\* significant at  $p < 0.001$ . These p-values refer to the paired t-tests or Wilcoxon Signed Rank tests (non-parametric equivalent) used to examine differences between the baseline and the follow-up assessment.

## 4.5 Consumer journeys after transition

Again, the analyses in this section include 674 consumers (156 Stage One and 518 Stage Two) discharged from hospital by 31 December 2020, excluding those who died during their stay. On average, Stage One consumers have had around two years and 3 months, or 845 days, since transitioning, while Stage Two consumers have had 701 days in the community.

### 4.5.1 Presentations to hospital emergency departments

During their time in the community, 11 consumers (7%) of Stage One and 39 consumers (8%) of Stage Two had at least one ED presentation (Table 15). Two Stage One consumers accounted for almost half of the ED presentations in that group (16/33) and these frequent visits tended to be triaged as emergencies. Almost all (31/33) Stage One presentations to ED did not have a mental health diagnosis recorded as the primary diagnosis at the time. For Stage Two, nine consumers were frequent presenters to ED (range 8-37 visits), accounting for more than three quarters of all ED presentations (156/201).

Of these, the three most frequent presenters had 83 ED visits between them. However, unlike in Stage One, triage categories were distributed similarly across frequent and non-frequent presenters, with 76% of Stage Two ED presentations classified as urgent or semi-urgent. This suggests that most consumers are well supported in the community whereas a small number frequently require emergency treatment.

**Table 15 Emergency department presentations after discharge from hospital**

Characteristic	Stage One (N=156)		Stage Two (N=518)	
	n	%	n	%
<b>Persons</b>	11	7.1	39	7.5
<b>Presentations</b>				
Primary mental health diagnosis	2	6.1	76	37.8
Other primary diagnosis	31	93.9	125	62.2
Total	33	100.0	201	100.0
<b>Triage</b>				
Resuscitation	1	3.0	0	0.0
Emergency	12	36.4	20	10.0
Urgent	13	39.4	82	40.8
Semi-urgent	7	21.2	71	35.3
Non-urgent	0	0.0	28	13.9

#### 4.5.2 Mental health related readmissions

A readmission was defined as ‘mental health related’ if it included one or more days in a specialist mental health ward. On average 94% of days in such readmissions were spent in specialist mental health wards, suggesting this is an accurate definition of whether a consumer required mental health care.

Most readmissions (892/960, 92.9%) for Stage One were not mental health related. One-fifth of consumers (n=33, 21.1%) in Stage One had a mental health related readmission, with an average length of stay of 80 days (SD 138).

For Stage Two, more than three-quarters of readmissions (695/910, 76.4%) were mental health related. By definition this group is younger (Table 8) and less likely to have physical problems associated with ageing than Stage One consumers, so we would expect a higher proportion of hospital admissions to be related to mental health. Just over one-third (n=180, 34.8%) had mental health related readmissions with an average length of stay of 48 days (SD 126).

**Table 16 Hospital readmissions after discharge from hospital**

Characteristic	Stage One (N=156)		Stage Two (N=518)	
	n	%	n	%
<b>Persons</b>	69	44.2	218	42.1
<b>Readmissions</b>				
Mental health related	68	7.1	695	76.4
Non mental health related	892	92.9	215	23.6
Total	960	100.0	910	100.0

Most mental health related readmissions resulted in short-term stays, including 513 stays continuing for less than four weeks (32 Stage One, 481 Stage Two). There were, however, 21 consumers (3 Stage One, 18 Stage Two) who went on to have another hospital stay longer than 365 days, of whom eight remained in hospital on 31 December 2020. On that date, a further 10 consumers (3 Stage One, 7 Stage Two) were in hospital having had stays of between 180 and 365 days and therefore ‘at risk’ of another long, mental health related stay.

Altogether, on 31 December 2020, 4% (n=7) of transitioned Stage One consumers and 9% (n=45) of transitioned Stage Two consumers were current admitted patients, and the majority of those stays were mental health related.

### 4.5.3 Community mental health service use

Most consumers in Stage One (n=140, 90%) and Stage Two (n=497, 96%) have had at least one mental health community team contact, with total number of contacts 5,707 and 46,224, respectively. On average, Stage One consumers received a visit from the community mental health team every 23 days, whereas the corresponding figure in Stage Two was every eight days. A small number of consumers (16 (10%) of Stage One, 21 (4%) of Stage Two) did not receive any community mental health follow-up. The reasons for the lack of follow-up cannot be ascertained from the administrative data but should be explored for quality assurance purposes.

There is no marker in the HIE dataset for destination (e.g., generalist aged care, MH-RAC partner, SIL provider) so it is not possible to look at differences in the frequency of community mental health visits depending on accommodation type. Number of follow-up visits will also depend on period of time elapsed since transition and may be affected by factors such as readmission to hospital (during which time no community follow-up is required).

### 4.5.4 Consumer profile in MH-RAC network services

Sixty-three (40%) of the 156 Stage One consumers who transitioned to aged care transitioned to MH-RAC network services, that is, facilities with which NSW Health has a partnership agreement. Two types of MH-RAC services exist: MHACPI units (n=3) and SRACFs (n=3). Table 17 provides an overview of Stage One consumers who have transitioned to these services based on available data from MH-RAC routine reporting for 58 of the 63 consumers.

The average length of stay of Stage One consumers in MHACPI units was one year and seven months (583 days, SD 401 days), ranging from short stays to longer than three years. The MHACPI model is designed to provide transitional support, and 21 consumers have been discharged into mainstream aged care (as of 31 December 2020). In SRACFs the average length of stay since discharge was one year and eight months (608 days, SD 380 days) with no transitions to mainstream aged care.

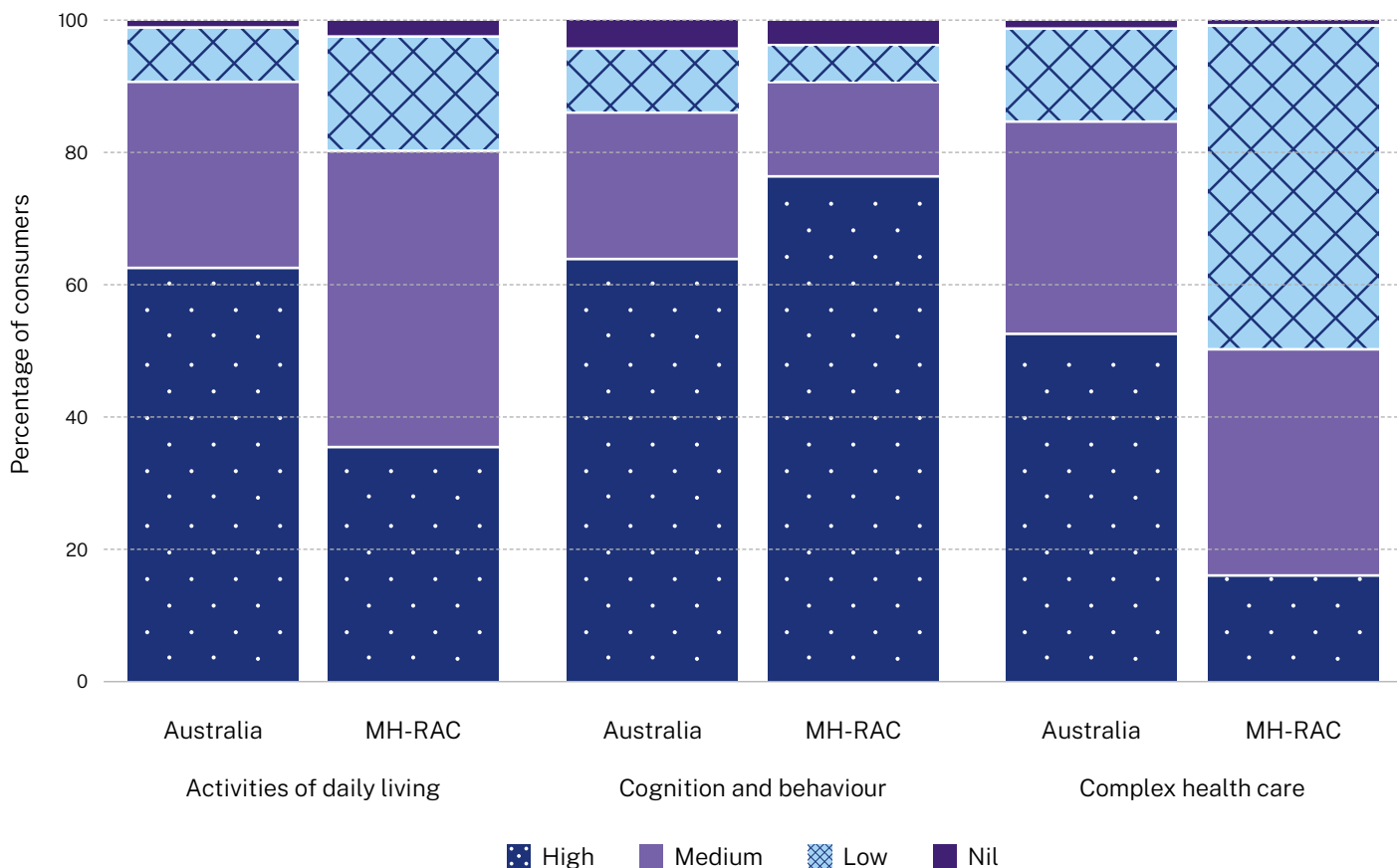
**Table 17 Profile of consumers in MH-RAC**

Characteristic	MHACPI (N=48)		Specialist RACF (N=10)	
	n	%	n	%
<b>Gender</b>				
Male	29	60.4%	4	40.0%
Female	19	39.6%	6	60.0%
<b>Age group</b>				
Younger than 65	7	14.6%	4	40.0%
65-74	19	39.6%	4	40.0%
75-84	16	33.3%	2	20.0%
85 and older	6	12.5%	0	0.0%
<b>Primary mental health diagnosis</b>				
Schizophrenia	17	35.4%	10	100.0%
Dementia (includes all types)	21	43.8%	0	0.0%
Depression	4	8.3%	0	0.0%
All other diagnoses	6	12.5%	0	0.0%
<b>Secondary mental health diagnosis</b>				
Depression	12	25.0%	2	20.0%
Psychosis	6	12.5%	4	40.0%
Dementia (includes all types)	8	16.7%	0	0.0%
All other diagnoses	22	45.8%	4	40.0%
<b>Location</b>				
Within referring LHD	39	81.3%	6	60.0%
Outside referring LHD	7	14.6%	0	0.0%
Information missing	2	4.2%	4	40.0%
<b>Discharge status</b>				
Not discharged	27	56.3%	10	100.0%
Death	1	2.1%	0	0.0%
Discharged to hospital (mental health unit)	3	6.3%	0	0.0%
Discharged to specialist RACF	5	10.4%	0	0.0%
Discharged to generalist RACF	12	25.0%	0	0.0%

For the 58 Stage One consumers who were in MH-RAC facilities and had available data, the Aged Care Funding Instrument (ACFI) score contains additional information about the domains of activities of daily living, behaviour and complex health care (Australian Government Department of Health, 2017). The majority of Stage One consumers living in these facilities require high (36%) or medium (45%) assistance in activities of daily living. In the behaviour domain, 77% of Stage One consumers have high needs and an additional 14% have medium needs. Around 50% of Stage One consumers have low needs for complex health care.

Figure 9 shows the distribution of ACFI scores for Stage One consumers in MH-RACs compared to the national average in 2019-20 (AIHW, 2021). As a group, Stage One consumers have lower care needs relating to activities of daily living and complex health care, but higher care needs relating to cognition and behavioural issues, compared with national averages.

**Figure 9 Comparison of ACFI scores**



It has been shown that the current ACFI mechanism insufficiently captures the care needs of residents (Eagar et al., 2019). Therefore, classification and funding of residential aged care is currently transitioning to a new system, the Australian National Aged Care Classification (AN-ACC).<sup>3</sup> Unfortunately, it is not known which AN-ACC class Stage

One consumers will be categorised to. For the vast majority it can be assumed that they are not bedbound and are either independently mobile or mobile with assistance. Given the structure of the AN-ACC classification, this would most likely result in classes with relatively low funding levels compared to typical aged care residents.

3. <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/residential-aged-care-funding-reform> last accessed 12/08/2021

# 5 Consumer and carer experiences

Numerous studies documenting the outcomes of deinstitutionalisation have demonstrated that people who have had long stays in hospital can achieve improved quality of life in the community (e.g., Hobbs et al., 2002; Leff & Glover, 1999; Priebe et al., 2002). There are concerns, however, that people with SPMI and complex needs may have missed out on these benefits (Irmiter et al., 2007; Novella et al., 2010). Because of their exceptionally high needs, this group is at risk of unsatisfactory outcomes including social isolation, poverty, poor physical health and substance misuse (Davis et al., 2012). It is therefore essential for any evaluation of a community transition program to include the first-hand experiences of those directly affected, in this case the PCLI consumers and their family carers.

This chapter addresses the anticipated outcomes at the 3-5 year mark, according to the PCLI program logic (Figure 4), for consumers and family carers. For consumers, these outcomes should include greater engagement in transition planning, more choice and control, improved well-being and quality of life, and more opportunities for social participation. For carers, the anticipated outcomes include satisfaction with the quality, security and safety of the care provided in the community.

The outcomes presented here are based on three sources of data. The most important source is the first-hand accounts from 37 interviews with consumers and carers between July 2018 and May 2021. The Stage One consumers had been transitioned to aged care facilities (mostly MH-RAC network partners) and the Stage Two consumers to group homes or, in a few cases, to public housing. The earlier interviews focused mainly on Stage One consumers and carers and the later were mainly Stage Two, although most years there was a mixture of both groups.

The relationship between housing choices and quality of life for people with SPMI is well established (Brackertz et al., 2019). Important factors in realising the benefits of community living are affordability, quality (that is, new and well-maintained buildings) and location in neighbourhoods with high amenity and low levels of crime and physical deterioration. Homes which meet consumers' needs for autonomy and meaningful social connection can reduce symptoms of mental illness, health service use, and costs of care (Brackertz et al., 2019). To ensure that all important domains of satisfaction were captured, the interviews included questions based on the Easy-Read version of the Adult Social Care Outcomes Toolkit (ASCOT; Turnpenny et al., 2015) which measures aspects of an individual's quality of life that can be affected by social care and social housing.<sup>4</sup> (The tool itself was not used or scored.)

Two earlier evaluation reports contained findings from some of these interviews. Vignettes based on consumer and carer accounts of pre-transition experiences are reproduced<sup>5</sup> here to provide context for the findings.

All transcripts were pooled and re-analysed for this final report, and a summary of the preliminary findings was sent to a group of PCLI peer workers and the consumer and carer representatives on the PCLI Steering Committee. They were invited to participate in an online Knowledge Exchange Forum, where findings were presented and a structured discussion was facilitated by members of the evaluation team. The forum was recorded and transcribed, and their lived experience reflections on the data are reported below.

Finally, key informants' accounts of consumer and carer engagement are also reported. They provide insights into the challenges of transition planning and the efforts that providers are making to ensure consumers and carers are involved in planning the transition process.

4. <https://www.pssru.ac.uk/ascot/>

5. Most of these originally appeared in Evaluation Report 4 (Williams et al., 2019)



## 5.1 Vignettes: pre-transition histories

---

All the consumers interviewed by the evaluation team had experienced long stays in hospital. One had been ‘in and out’ of hospital for over 50 years, several for over 30 years, and some others had stays of approximately 10 years. A few could not actually remember how long they had been hospitalised. Many of the older consumers had experienced numerous previous admissions and transitions, including being detained in mental health institutions that have since closed as a result of deinstitutionalisation.

Diagnoses of schizophrenia or related disorders were most prevalent, followed by bi-polar disorder or severe depression. Most consumers also had co-morbidities such as acquired brain injury, intellectual disability, diabetes, or heart disease. A history of trauma was common: consumers had experienced homelessness, drug abuse, suicide attempts, relationship breakdown, or divorce. They had witnessed or initiated violence, lost custody of children, or been estranged or separated from their families of origin.

Examples of consumer histories are below, with names and details altered to protect identity.

- Adam tends to play down his illness and its impacts, even though he was homeless for a few years. His schizophrenia was managed in the community, with occasional hospital stays of a few months. A few years ago, his illicit drug use precipitated a medical emergency, which left him with brain injury and cognitive impairment.
- Brian’s marriage broke down after he developed serious mental health issues and was no longer able to work. He attempted suicide when his ex-wife said she would prevent him from seeing his children.
- Chris was diagnosed with schizophrenia and hospitalised in his early teens. After absconding repeatedly, he was placed in a locked ward for his own safety. The illness and its treatment interrupted the normal processes of puberty leading to severe impacts on his functioning, and he requires an exceptionally high level of support.
- Dean’s family came to Australia as refugees who had been caught up in a civil war. Dean started experiencing psychosis in his teens. He frequently ran away from home, got into trouble with the police, and ended up in hospital for long periods.
- Elizabeth’s children were removed by authorities as she was unable to care for them due to her severe mental illness. She struggles with English as a second language and wishes she could return to her home country.
- Frank was a victim of violent crime several times in the area where he used to live. He says his old school friends are ‘all on drugs’. A couple of years ago Frank was arrested and taken to the emergency department, where he was physically restrained, after he became aggressive towards police.
- Gail has spent about 35 years in hospital – more than half her life. She had a ‘breakdown’ in her mid-20s. This led to a series of admissions including a stay in a psychiatric hospital which then closed during the 1980s. After a short, ‘failed’ move to the community, she moved to a long stay unit and remained there into her 60s.
- Helen lived well in the community for many years with mental illness and an intellectual disability. She stopped taking medication, her relationship broke down, and she had a health crisis and could not return to independent living. Helen can be ‘disruptive’ and now needs a secure aged care environment.

## 5.2 First-hand accounts by consumers and carers

This section describes how consumers and carers experienced the transition process. Their views of the current accommodation (in SRACF, MHACPI unit, SIL group home or other public housing) are presented. Consumers' and carers' current health and wellbeing are then described, and the section concludes with their social participation, post-transition.

### 5.2.1 Experiences of the transition process

#### 5.2.1.1 Feelings about transition to community

When the prospect of leaving hospital to live in the community was first raised emotions were mixed. Consumers were more likely than carers to be excited about transition, but there were also some worries. Many Stage One consumers, who were unwell in hospital, didn't clearly remember the transition process and they couldn't recall how they were feeling.

*I was very happy. I have already stayed here for one night and I just checked it out. I just –but I was very excited to actually be out of hospital. (Consumer, Stage Two)*

*[I had some concerns about] getting out of hospital –I was in there for a long time. I was just a little bit uncomfortable. (Consumer, Stage Two)*

Carers reported high levels of anxiety, especially if they had had previous experience of 'failed' discharges from hospital followed by traumatic readmissions when the person again became acutely unwell. Two carers explained how this history influenced their thinking initially, when the idea of transition was first raised.

*She went and lived in community living, which just never worked for her, the support wasn't there, she was sharing a flat, she wasn't coping, it just wasn't working, and that happened a couple of times for her, and so then when she eventually got to [hospital], I just felt that that was more secure and she was better cared for, and as time went on that wasn't always the case, but when they were then starting to talk about her going out back into living in different types of community facilities that the government were looking at bringing back in, I just went, no, it's not going to happen. (Carer, Stage One)*

*So she finished up at the [hospital] and they tried to move her out to a group home. ... And the –she was just –didn't fit in there at all, so –but unfortunately ... as soon as she moved out ... she was instantly homeless, because they discharged her. (Carer, Stage One)*

Later, both of these carers said they were very glad that they had taken the chance and allowed the transitions to go ahead. Like most of the other carers, they wanted their loved ones to be safe and also to live the best life they could.

#### 5.2.1.2 Support and information

Staff acknowledgement and understanding of consumers' and carers' concerns helped alleviate anxiety. PCLI staff and staff in the community helped address concerns by providing information, reassurance and time to get used to the idea of moving out of hospital. At one site, a carer liaison officer provided individualised support and encouragement to people whose relatives were living in an older people's long-stay mental health unit. For consumers, PCLI clinicians and peer workers (and in some cases, family members) played important roles in encouraging them to think about the future and to feel more positive about the transition.

*[PCLI staff] took my thoughts seriously and they didn't discard me as a family member. They actually care about what I feel and what I think and my son, how –what he needs. So that's what changed my mind. They made the transition really easy. (Carer, Stage Two)*

*She loves that when people take a special interest in her, like the PCLI staff do; she feels very special when they talk to her about things. And they tend to get things out of her that she hasn't talked about for a long time because they have a way of getting the information out. (Carer, Stage One)*

*I had Mum with me, so it was a good support. She was just helpful and positive about what I could do with the place. (Consumer, Stage Two)*

Most consumers were offered the opportunity to visit the community accommodation provider before making a decision regarding transition. These visits were often the main source of information about the option(s) available. Photographs and even videos were sometimes used to help consumers understand what was on offer.

If they were interested and willing to be involved, carers were also involved in site visits to aged care providers or group homes. Seeing the 'home' that was being offered was, for many carers, the turning point in the decision making process. Some would have preferred more information about the transition and to have been more involved in decisions relating to transition. A few would have liked more information about the person's mental and other health conditions, prognosis and what treatment and interventions were being actioned or recommended and why they were being transitioned where they were. Information about access to NDIS support was one area that carers felt was lacking. For example, one carer thought that the staff should have communicated more about the implications of transition to aged care, which resulted in the loss of the person's opportunities for NDIS-funded community access support.

*I needed to know a lot more than what was going on. I was just told what was happening and as I said, I didn't know much about dementia. I didn't know how quick it progressed or just what to expect next and that. And I just felt lost. Completely lost. ... Probably if someone had come to see me and told me what was going on, why they were sending him here, how his behaviour was. ... But just someone to let me know exactly what he was doing and why*

*he was going to be sent here and there. It would have been a good idea, but [instead] I had to sort of fumble through and find out as I went along. (Carer, Stage One)*

*Because she moved to aged care after the age of 65 and see, if she had moved at 64 years and 11 months, she would have continued [NDIS]. So they should have known that and they didn't. That was very disappointing. (Carer, Stage One)*

### 5.2.1.3 First impressions

The first impressions when viewing community accommodation option(s) for both consumers and carers were mostly positive. Characteristics that consumers and carers liked in the aged care facilities and group homes were cleanliness, modern décor, natural light, and a welcoming atmosphere. They also talked about good neighbourhoods and security. Safety was very important to carers and most carers liked staffing options that included 24 hour and/or clinical support. Sometimes proximity was the main factor that carers considered, particularly for Stage One carers who were often older and found it difficult to travel long distances for visits. Having the consumer living closer was one of the enablers for carers to support the transition process.

*The first time I saw it, I thought it was fine. It was a lovely day, like today. It was breezy; the windows were open ... my first impressions were positive. (Carer, Stage One)*

*So, the idea of her being able to move, not to a group home, but to a semi-secure place or even a secure place ... they had security... I was very pleased to hear it. (Carer, Stage One)*

*And they just rang me one day and said, 'We're bringing him up to [aged care provider], there's a vacancy.' And I thought oh, thank heavens. So, I'm only 10 minutes. ... I'd be closer. I could spend more time with him. I think that was about all I thought of at the time. (Carer, Stage One)*

### 5.2.1.4 Choice of accommodation

In general, consumers and carers said they had limited choices about where the person would go when they left hospital. Some thought they had no choice or at least they were not offered a choice, and only a few recalled looking at more than one option for accommodation providers. Some said the choice was between the place that was on offer or staying in hospital, while a few others thought if they decided against the first option they would be offered others.

The issue of choice of accommodation appeared to be more of a concern for carers than consumers. This was particularly the case for Stage One carers, some of whom were unsure whether the person had the capacity to understand what was being proposed. Indeed, some felt their person did not understand that they were moving until after they had moved and, when interviewed, a few Stage One consumers did not appear to recall moving. Some carers thought that the information given to consumers and their opportunities to participate in the transition process might not have been appropriate to the consumers' capacity or level of understanding.

*I don't know that she'd take it in ... you can't ask someone who has been in [hospital] for 10 years what your goals are. (Carer, Stage One)*

*No, there was no choice at all. It was only [aged care facility] and, I mean, we could have said no. But no, there was no choices at all offered. (Carer, Stage One)*

In contrast, many of the Stage Two consumers were excited or happy to be moving out of hospital and willingly took the first option that was offered.

*No, I had the choice. I had the choice if I could get out of hospital and see what it is like in the community. Yeah, just to see how it is, and I had that support then ... As soon as I walked through the door I thought, if you've got the opportunity to take it, you might as well take it. Yeah. (Consumer, Stage Two)*

*I think I would've had the option of choosing another one but I wanted to take up this house. (Consumer, Stage Two)*

### 5.2.1.5 Nature of transitions

One of the main concerns for carers was the possibility that the person would not cope in their new home and then have an acute admission and lose their place in the community, becoming effectively homeless. For this reason, some carers were very reluctant to see the person discharged from their hospital 'bed'. Longer periods of transitions, staged transitions and keeping beds open, alleviated a lot of anxiety, particularly for carers.

*I can remember feeling very concerned, because [at first] they said once she leaves, that's it she can't come back. But I'm just trying to remember how that conversation went, because I said, "Well what if something does go wrong and this doesn't work, then what's going to happen?" And, I think, there was a period of a month or something where [name] had an opportunity to go back, and then the conversation relaxed more as time went on and it was, like, if this really doesn't work for [name] she can come back. (Carer, Stage One)*

*I would say [we heard about the transition] probably about six to twelve months before she moved. So there was plenty of warning given, which was good. It gave us a lot of time to think about it. (Carer, Stage One)*

Some transitions had a longer lead time to give consumers and their carers time to process the idea of moving out of hospital and get to know the place. Some had to wait until placement sites were ready or vacant. Most people were transitioned into the community in a staged manner which both consumers and carers preferred. Gradual transitions, with opportunities for visits and overnight stays, helped people get used to the new place and ensure that they were making the correct choice for them.

*The fact that she could transition for periods of hours and half-days and then days and then eventually a sleepover, I think was perfect. It means that it wasn't a jolt change for her. (Carer, Stage One)*

*I spent one night here - I think I spent two nights. .... Went two, two, five, five, seven, seven, seven, seven. (Consumer, Stage Two)*

*He's been going there a few times before they actually let him stay there. So there was quite a gradual, gentle transition. It wasn't just like; "here you go" and you moved out. I think it was slow, over a few times. They said; "let's try it once, and stays overnight and see how he goes". So there's a lot of care. (Carer, Stage Two)*

Rehabilitation programs within hospital settings that supported a journey to independence helped facilitate successful transitions as consumers had already been accessing the community and also had some skills for independent living.

*I spent 11 months down there, at [the hospital]. But I worked my way through, stayed clean, did a men's health group, peer support group, drug and alcohol counselling. I had carers come and see me and take me out in the community. I went from [unit a] to [unit b] to [unit c]. And [unit c] is more independent. You buy your own shopping; you only cook for yourself. (Consumer, Stage Two)*

## 5.2.2 A home in the community

### 5.2.2.1 Private spaces

People liked having a room of their own, where they could have their own belongings, and make their own decisions about how they could arrange this space and what they could do there. Although an aged care facility is very different to a house or unit, carers and consumers felt the environment was still far preferable to a hospital setting where people often had common bathroom facilities and where personal possessions including clothes and even false teeth might be shared.

*We've tried to make her room more comfortable for her by providing some furniture ... a desk that she could sit at and colour in, and a box for dolls and toys, and things that she collected along the way. (Carer, Stage One)*

*Somebody has given her lots of stuffed toys. So one of the cupboards is just full with all these stuffed toys. So there's not much room to put anything else there. But anyway, if that makes her happy, good. (Carer, Stage One)*

*I think the best thing was having his own room. He likes to go into his room and have a lay down and get away from things if it's too rowdy for him in the main common areas and that. .... It was different at [the hospital]. ... it was the dormitory type thing, where he couldn't go to his room and lay down. Here, he's got his own room. ... he likes it here much better. (Carer, Stage One)*

*... in places like [hospital], there's always a pool of clothes, because people come and go and never take anything away. So she was often in something that I've never seen before and the ward staff keep things clean and keep them dressed, but I don't think they particularly care whose it is, unless it's specifically marked. (Carer, Stage One)*

Some Stage Two consumers transitioned into accommodation on their own, but most went into group homes with 24/7 supports available. This level of support was appreciated, as was the privacy and comfort that came with having one's own room, facilities and furniture.

*I'm living by myself so it's the first time I've lived by myself ... I've got a bit of clutter but it's neat and tidy; it's all stacked ... Yes, as clean as I like it to be, yes. (Consumer, Stage Two)*

*Yes, it's good. I get the easterly sun in the morning and the sun in the afternoon. It's a bit bright, but I've got a comfortable lounge, dining room table; I sit in the kitchen most of the time. Bed is comfortable; I've got a sofa lounge as well for visitors set out tidily. (Consumer, Stage Two)*

*[It was] the first time ever that when I went in there he didn't say he wants to come home. He didn't say that. He's always been saying that in the hospital, but he never said that. It's like his own - he has his own room ... (Carer, Stage Two)*

### 5.2.2.2 Feeling safe, welcome and connected

Carers, in particular, saw safety as an important element of choosing the right home. At first some carers were concerned that a place in the community might be less safe than hospital, where nursing care was available. However, once the person was settled in the community, most carers were less worried and some even felt the community placement was safer as there were fewer people on site who were acutely unwell.

*And when I visit, it's a very good atmosphere in the house. It's a really safe and good environment. (Carer, Stage Two)*

*If you wanted to do a risk management, I'd say there's probably a higher risk in a mental health ward, because people are there because they're mentally in a bad state, so - but she never had any issues over at the [hospital] massively there. But I'd say that this would have to be better. (Carer, Stage One)*

Consumers and carers talked about a family atmosphere where they felt welcome and connected in the accommodation options in the community. Compared with hospital, the people who lived in or supported their home in the community felt more like friends and family.

*Everyone's friendly. And to the extent that - it took me by surprise, but everyone's the same. So I think it's just the way they run the place. And it took me by surprise. ... Not saying the hospital was bad, but it's that - there's, you know, yeah, the one on one contact that families and close friends have, it's - it just makes it a really homey feel. (Carer, Stage One)*

*We all trust each other. I could leave my smokes out there all day and go somewhere and come back and there wouldn't be one taken. I'll leave my wallet out there with \$100 in it or-not that there's ever that. But we don't steal from each other. I don't even lock my door. I just close it. So that's a really good thing. (Consumer, Stage Two)*

Carers found that community facilities were much more accommodating and welcoming for visitors. They found the staff were more likely to know them and that there were nice spaces where they could visit with their loved ones.

*We can sit out in the garden there and talk. ... And during COVID, we've got to go to her room. So I bought her a little table and chairs, and we sit outside on her little balcony area and that's quite pleasant. Yeah. So I take down things to do with her there on the balcony. (Carer, Stage One)*

### 5.2.2.3 Dignity, choice and freedom

Most consumers and carers reported that the staff were kind and caring and treated them with dignity and respect. They received the encouragement and support they needed, as some struggled with low motivation or other 'negative' symptoms, without feeling harassed or ordered about. Consumers valued the knowledge that support staff were able to share and the conversations they had with staff and others.

*Even if I just go to the reception, it's a different-not that hospital was bad by the way. They were-I thought they were extraordinary, but it's a different-clinical observation is different to this kind of one on one. (Carer, Stage One)*

*I need a bit of a nudge every now and again. [Support worker] was going-I think she said three times to me-it wasn't hassling me... I said yeah, because I sometimes get a bit lethargic and leave my washing in the dryer. (Consumer, Stage Two)*

*The staff are well suited to the care of such vulnerable people and are to be commended. They are kind, encouraging, supportive, understanding and accepting of [consumer's] peculiarities. (Carer, Stage Two)*

Most consumers and some carers spoke about an increase in choice and control which many described as 'freedom'. There were differences in what constituted freedom depending on where they were, and their cognitive ability or their age. Even people who lived in more controlled environments such as aged care facilities spoke about an increase in choice and control compared to hospital. Just to be able to go to your room when you felt like it, for example, instead of being told to go to your room at certain times was seen as a positive for consumers and carers.

*I've got freedom, can do whatever I want whenever I want, have a drink if I need one, food, and go out places, unlike the hospital. (Consumer, Stage Two)*

*I think it's better here. The only reason is there's more freedom outside than it is in hospital, especially when you just went there and you're in the system, they restrict you, lots of stops, you know? Like I said before, [when I was in hospital] if I go out I'd have to sign, coming in I'd have to sign... but here you just go out and then come in whenever you want. (Consumer, Stage Two)*

Some consumers spoke about some of the challenges of being more independent and able to make their own choices. This could create a level of anxiety because they were not used to having responsibility and weren't quite sure how to do it. They could see it would take some time to learn. Nevertheless, they also appreciated the freedom to be human; for example, be a bit messy sometimes, eat something less than good for you, have a lie in rather than exercising on a day when you're feeling a bit lazy. Choice and control also had some implications for physical health which are discussed in the next section.

*No, it's just, maybe it is a bit too comfortable, I have to keep myself a bit more busy, so I can probably bring that comfort down. (Consumer, Stage Two)*

Many people reflected on differences between hospital and living in the community. Some said that while the hospital staff were great and they did the best they could, it was not a home. Although the care in hospital was appreciated, it could not compare with the more flexible and personalised support in the community.

### 5.2.2.4 When it doesn't feel like home

There were a couple of examples where being in the community didn't feel like home, where people felt unsafe or isolated. Some things that consumers and carers described that made the PCLI placement feel less like home included: when the place was not clean or comfortable or when the person did not feel safe or connected to the community. For example, social isolation was a problem for one consumer who was used to living in a busy inner-city location, with lots of incidental contact with passers-by on the footpath, but was now living alone in a suburban location with poor transport links and no street life.

*[He] has consistently told me of his feelings of isolation and loneliness, which I have made known to staff and management ... Sadly, [he] went as far as saying to me a couple of weeks ago 'that it was better in hospital because there were always people around'. (Carer, Stage Two)*

Some consumers saw the PCLI placement as temporary accommodation rather than a permanent home, with some having aspirations to live fully in the community with or without support and others aspiring to return to a previous home. This didn't necessarily mean that they didn't see their current accommodation as home for now.

*Some of them want to stay here forever. But I don't want to stay forever, to be honest. ... Save up a lot of money, hopefully... Probably put it towards a house maybe. (Consumer, Stage Two)*

## 5.2.3 Health and wellbeing

### 5.2.3.1 Being happy in the community

There were many reports of positive impacts on consumers' well-being following transition. People were less depressed, more active, more engaged, less agitated and happier in the community than they had been in hospital. Well-being was fostered through feelings of belonging, social connections, feelings of safety, and increased independence and confidence.

*I find I'm functioning a lot more, because I gave up on life, I was lying in bed 24/7 in hospital because I was so depressed. But I get up at 5 o'clock every morning and even when I get up at 5 o'clock and then I may lay down for an hour at lunch and then I'm up again. (Consumer, Stage Two)*

*I think his mood is definitely much better overall and he feels good. ... I think the outbursts are less. They are, I think, less severe, less threatening to himself or anything like that. He's – I think he's definitely in a better mood. (Carer, Stage Two)*

*I was thinking of self-control too, I sort of, I don't know, it feels like I can control my anger, I used to have, a while back, because it's always been the anger. At the moment it feels like, it feels like I can get on with it. ... Well I think, for starters it'd be the medication that would be helping me out. And I don't know, it's like – because I need that space, if I haven't got space, it's just not working, but if you've got the space there and you think it's helping you out. (Consumer, Stage Two)*

*Best thing I ever done. I'm happy. ... I like to run my own life, before I die. (Consumer, Stage One)*

Consumers and carers said stabilisation of medications and increased effectiveness of other treatments along with support of community mental health teams and staff in the community settings have improved their mental health. Some consumers also spoke about an increased motivation to improve their mental health since they moved to the community.

*I'm compliant with all my medications and things. This place has really saved me. (Consumer, Stage Two)*

*I had a problem with medication there for a week where I wasn't taking it properly. But I told the workers here and now I just show them my medication. (Consumer, Stage Two)*

*We just finished a relapse plan for if I was to go backwards, what signs would it be? I've got [name], who's my case officer. I see the psychologist once every two weeks. I see the Clozapine clinic once a month. And they're fantastic. It's really positive. (Consumer, Stage Two)*

Consumers reported that having assertive support to encourage them to engage in activity helped to get them up and active and lessened depression. Carers also spoke about the importance of having enjoyable activities to occupy the consumers each day.

*I had motivational problems where I didn't want to get out of bed. This was all before I moved out [of hospital], but I had poor sleeping patterns and – yes, I just was glad to have something to do and my fear was not to fall back into those patterns. (Consumer, Stage Two)*

*[Being active, doing exercise] clears out the whole system. Yeah. Makes you feel nice, calm and relaxed. (Consumer, Stage Two)*

*We have the NDIS. She's visiting my place once a fortnight. She's going to start swimming, hydrotherapy thing, every alternate fortnight that she comes to my place. She goes to a place called [disability support provider]. I think she goes two days a week now and they're trying to increase it to three. She really likes that. So she does a bit of line dancing. She does crafts. She's made friends there and she is extremely happy with it. She likes that. (Carer, Stage One)*

For the younger consumers it appeared to be especially important to have something to aim for and look forward to, to create a sense of purpose. Now that they are settled in the community and have good support and improved mental health, some consumers are working towards training, volunteering or paid work. Some are also working towards living more independently.

*I stopped in there with one of my carers to ask what days [I could volunteer]. ... So I'm going to try and see about doing that on a Friday. (Consumer, Stage Two)*

*Well once I get a car and stuff, we'll be able to drive to the beach and stuff. ... It would mean so much hey. Because I can go down visit ... when I want and stuff, and taxi some of the boys around to different places. (Consumer, Stage Two)*

*I am just waiting to stay relaxed for another – maybe rest of this year and then I will be just fine. I think I will just – maybe just move out somewhere like maybe around the area, and maybe get a part time job. (Consumer, Stage Two)*

Another very important contributor to improved mental health and well-being was professional psychosocial support services. Some consumers might need help to make decisions that ensure their mental health does not decline. One person said she would like more counselling. She was not sure whether this was available to her and had not asked. She suggested the service could let people know what support was available, as that would make her feel more in control and able to request help when she needed it. Other consumers felt they had benefited from mental health programs.

*Just having people to talk to really helped as well. (Consumer, Stage Two)*

*Yeah, say, "I got letter in my mailbox, what is this for?" and they said, "Okay, this is for this, this is for that." So, if I have an appointment, they take me there and they refer me to programs, like, for example, NDIS. (Consumer, Stage Two)*

### 5.2.3.2 Changes in physical health

Consumers and carers spoke about support in the community to check on and address physical health conditions, some of which may have not been monitored or looked after so well in hospital. There were many examples of support for preventative health, like weight loss, diabetes control and smoking cessation. A lot of people were being encouraged to do regular exercise and eat healthy food, and there were examples of people successfully making healthier choices and improving their physical health since transition. For example, one Stage One consumer had been encouraged to reduce smoking and eliminate alcohol because of adverse interactions with prescription medications.

*I got my eyes checked. [Name] rang up and got me an optometrist appointment. So I'm going to get glasses. Because I used to wear them 12 years ago. (Consumer, Stage Two)*

*I walk all around the oval. (Consumer, Stage Two)*

*Sugar has some problems, like diabetes and other things like that, you know, so I said, "Okay, that's a good idea." I drink my tea without it. (Consumer, Stage Two)*

*[My support worker] took me to the store and showed me the sections him and his wife and family shop from, as a vegan, and what to get. How to make stir fry sauces from, say, curry paste with coconut milk instead of just buying them off the shelf. (Consumer, Stage Two)*

Some consumers and carers reported declined physical health since transition. For Stage One consumers, these changes were mostly attributed to the natural process of ageing.

*I'm getting old now, that's the trouble. (Consumer, Stage One)*

*She's just been started on [medication] because her ankles are carrying a lot of fluid. That's been ongoing now for a few weeks, and to me it doesn't appear to have made that much difference. But that's a part of ageing, isn't it? (Carer, Stage One)*

At some aged care facilities there were increased opportunities for physical exercise which had helped improve the health of some older people:

*Not a huge improvement, but I think – I'm hoping that the ability to get out and walk and will bring back some – even more mobility for her. (Carer, Stage One)*

For Stage Two consumers, decline in physical health was most often attributed to increased choice – and the freedom to make poor choices. People are able to eat more junk food, cakes and drink more soft drink than they could in hospital. At least one person indicated that they smoked more now as they could do so more freely. Some had put on significantly more weight – although, interestingly, they often quoted exactly how much weight, suggesting that someone was helping them to monitor the situation.

*When I first came here, I was 97 kilos. I'm 140 now. I've put on about 30 kilos. ... I just eat junk. I've got to stop doing it. (Consumer, Stage Two)*

*I've put on a bit of beef. I've got to stop eating rubbish and drinking chocolate drinks every day and that. I'm 130 kilos. I think I was 118 when I got here. (Consumer, Stage Two)*

*I smoke more [now]. [In hospital] you have to go for a walk bloody all the way to the end of the hospital. It would take you half an hour just to walk there and back. You've got five minutes. You are better off just sitting down and having a book to read in hospital, you'd go crazy. (Consumer, Stage Two)*

Consumers were well aware that there was some negative impact in making their own decisions. Having more freedom of choice sometimes meant that they might do things that might not be the healthiest choice. They did not lack knowledge of healthy behaviours or good intentions, just motivation and follow-through; in that respect, their problems were not particularly remarkable or specific to people with SPMI. They also had insight that they were more likely to stick to decisions when they felt those decisions were their own.

*I buy vegetables but I just don't get motivated to sit there and chop it all up. ... I want to start cooking more stir fries. ... I'm going to start working on riding to the station to get a bit of exercise plus a bit more independence. (Consumer, Stage Two)*

*I used to buy a can of soft drink... but I look at myself, I say, no, maybe it's the soft drink or the Coke, that's making my tummy go out, it was flat, you know. And I don't like it when it's going out like that. So, I said, okay, maybe it could be the Coke because I hear on the news, you know, Coke is no good for you, people keep taking drinks, it has sugar in it... so that has an impact – a negative impact, the side-effects on your system, but I said, okay, well, I'm going to stop taking this ... so that doesn't give me problems. So, now, I don't drink Coke. (Consumer, Stage Two)*

*I'd like to do more bike riding. I've got a pushbike and I've got bike tracks all the way around me. ... I guess more exercise and that – rides to healthier eating, of appearance, but I want to feel good. I don't want to be a bit – laying a bit around; I'd rather be healthy. (Consumer, Stage Two)*

*I'm still smoking a fair bit and I've got to cut down on that but I enjoy my cigarettes at the moment. (Consumer, Stage Two)*

There appears to be a tension for support workers in encouraging consumers to improve their health whilst also supporting choice and independence. There were examples of where the staff in the community had strongly pushed consumers to make healthier choices, and other examples where perhaps the community staff were more flexible or less concerned about physical health outcomes than hospital staff had been.

*Because [my support staff] tell me that I have to go on a diet, and to look at my [health]. I get upset because sometimes we go to buy a cake, I cannot buy. I want a cake to be at home for me in case I feel like having a slice and have a coffee or tea. ... They buy things, they ration it out; he says, eat that much. I get really angry because I like to eat a lot. But they are real strict, the ones that tell me to lose weight. (Consumer, Stage Two)*

*Lately they've been coming down heavy on me with the exercise and stuff, pushing me into exercising and dieting. And I appreciate it, yeah. (Consumer, Stage Two)*

*Like I say, "Oh, miss can I have a couple of lollies, it says I can have lollies on my dietician sheet." The doctor – the nurses [at the hospital] say, no you can have them once a week or something and hold that out as long as possible. And the nurses here will say, "Okay," more like a mother type. (Consumer, Stage Two)*

### 5.2.3.3 Impacts of ageing

In the Stage One cohort, in particular, there are significant impacts of ageing (including early ageing) on consumers' health. While there has been natural physical and cognitive decline in older people who have transitioned, some carers believed that ageing processes had been accelerated by institutionalisation. Once the person was settled into their new home in an aged care facility, it seemed to some carers that the physical needs overtook the psychological needs in terms of priority and impact on function.

However, some functional declines proved to be reversible after transition from hospital. For example, one consumer was described as 'catatonic' when she was in hospital and her family carer believed the transition 'woke her up':

*I personally think it was just because she was so isolated and then all of a sudden in here she was forced to communicate, sit at a table, eat with people. The nurses here have been great as well. (Carer, Stage One)*

For others, increases in functioning after transition appeared to be short term with continued declines related to ageing.

*[Name] really was institutionalised at [an early age] and her health deteriorated over the years ... being in a government hospital and not having the, I guess, the staff to be able to put time and effort into [consumer's name] and focus more on [consumer]. ... I think, it was just easier for the [hospital] staff to go, oh, we'll just get her a wheelchair, we'll just put a nappy on her, so it's always to accommodate, and she got away with it and, look, I think it's all too hard and too late now. ... The aged care service did get her out of nappies though for a while, I'm not sure if she's back into them, but I know they did put a bigger effort into trying to work with her on all of that [than the hospital]. (Carer, Stage One)*

There was also an example where a person was required to use a mobility aid to prevent falls when walking outside the aged care facility with support staff. Although the person preferred not to use the walker (and had gained some confidence in walking without it, while in hospital), it was necessary to comply with safety guidelines. There had been attempts to engage the person in physiotherapy to improve mobility and balance, but they were not cooperative.

### 5.2.3.4 Carer health and wellbeing

Transitions had an overall positive effect on carers' health and well-being in the longer term, although when they were first discussed there were short-term negative impacts in terms of worry and anxiety. However, once their person was transitioned and seen as safe and happy, carers mostly felt more positive and more hopeful than they did when the person was in hospital. Carers liked being able to visit consumers whenever they could and felt welcome and comfortable to do so. They also liked being able to access all the areas their loved ones accessed which they often could not do in hospital. Many carers reported that the relationship with their loved one had improved since their transition into the community.

*Yes, I'm less stressed or worried about [name] now ... I don't have sleepless nights over it anymore. (Carer, Stage One)*

*You do get to see what's going on which is – [at the hospital] we were always ushered to the visitor room so we were closed off. ... We were closed off. Whereas at least at [the aged care home] we do get to see what's going on around the place, which is good I think. (Carer, Stage One)*

Carers reported that it helped if they were involved and kept up to date. Most appreciated the efforts of community providers to keep them informed, although for some this was too 'intense' and demanding.

*And I found it good, because I could come here. The staff were wonderful to me. ... I had to go and talk to [staff] about a couple of behaviour problems he was having. And she explained it all to me and they're very good. You know, they sort of take care of me as well as [name] and that's what I appreciate. (Carer, Stage One)*

*The centre was pushing me this week too. ... And then this woman contacted me and this is an example of staff that don't know what they're doing. She contacted me and she said, "We've got to fill out this advanced care directive for [consumer name]." And I said, "Look, I know I've got to do it." ... I said, "Just give me a bit of time." But it was like as if it's got to be done now. You know what they're like; their bosses said these all have to be filled out, it's got to be done now. So she sent it to me straightaway. So I sent it off to her, but I just thought there's no understanding though, from my point of view with these things. (Carer, Stage One)*

Some carers have their own health issues, sometimes related to ageing. Following transition it appeared to be easier for carers to take time out for their own health needs without worrying too much about leaving the person in the care of others for a short period. Nevertheless, fear about what would happen when they were too old or infirm to visit was a recurring concern for carers.

*I had to go into hospital just recently. ... I was out of commission for about a fortnight before I could come back over. And they kept saying, "Look, he's well looked after, we'll look after him, don't worry." And they did. They were good to him. They kept him busy and, yeah. (Carer, Stage One)*



*But my biggest worry is, as I age, I'm not going to be able to drive. And when I'm in my late 70s, 80s, and she's in her 80s, I'm not going to be able to see her because I won't be able to get there. (Carer, Stage One)*

There were some other stressors for carers, particularly around finances and guardianship. Some carers of Stage One consumers were struggling to understand aged care funding and its implications for their own financial situations. Another source of stress was the knowledge that, for people living in MHACPI units, there may be future transitions. Some were dreading the move from MHACPI to mainstream aged care, whereas others wanted this to happen sooner rather than later so they could get everything finally settled.

Carers also struggled with ongoing grief and loss. This was especially the case for carers (usually parents) of younger consumers, but it was also apparent that the oldest carers were still mourning the life that the person (usually a sibling) could have had. It was a source of comfort, however, to know that the person was now safe, happy and well cared for.

*I certainly hope that he can stay there and be looked after by these really great people. That would be my favourite outcome that he's always there. ... The chance that he will be healthy again is very, very slim. He's spent more than half his life in treatment, in care. He is not at all fit to lead a normal life. ... I cry every time I see him.... But at the same time I feel at peace that he's now in a really caring environment. (Carer, Stage Two)*

Most carers did not appear to have robust support mechanisms in place for themselves. Some carers spoke about some support provided by services but this was mostly on an informal basis and usually directly related to meeting the needs of the consumer.

## 5.2.4 Social participation and meaningful occupation

Transition into the community in a safe and supported way had allowed people to begin to rebuild social connections. Being settled and healthy has helped consumers to be more able to make social connections and to re-engage in activities.

*I think [consumer] is more communicative [now]. Up until she came here, if you wanted to talk to her –not that she'd say much, but you had to be prepared to chase her around, because she used to sit down and then she's off. ... And you had two more words and she's off. So, I'd say she's [now] – she'll sit down and be cheeky and talk and just have more normal conversations. (Carer, Stage One)*

*I could never get [consumer name] engaged with anything in [the hospital], whereas with here at [community facility], it's fantastic, she's got so much interaction with other people, and so now, I think, [consumer name] is much happier and she's not living a boring life. (Carer, Stage One)*

### 5.2.4.1 Social connections with staff and other residents/housemates

Consumers and carers reported that engagement with the staff of aged care facilities, group homes and disability support providers was a vital source of social connection as well as support for the person's well-being and cognitive health. There were looser boundaries in relationships with staff in the community than there had been with staff in hospital. These relationships often served as steppingstones to extending social connections to peers, for example by helping people to practice social interaction.

*One stand out positive has been observing [consumer name]'s improved conversation. Having only the staff and myself to relate to 24/7 over these past four months has given [consumer name] a concentrated opportunity to practise relating in a 'well' and appropriate manner. I feel this is giving [consumer name] confidence in relating to the average person. (Carer, Stage Two)*

*He's creative, you know –used to be. And, yeah, he's –I don't know if they have people come in, but people who work there are very –one guy is actually an artist –he likes to do things artistically with him. The other guy takes him to play basketball and they do things already. (Carer, Stage Two)*

There were many examples of opportunities to make social connections within the houses and facilities, often facilitated by the staff through group activities. Similar histories or experiences of adversity and discrimination and shared interests have helped consumers to connect with each other, along with traditional ways of socialising such as sharing a meal.

*We have a cook up on the weekend. I get vegetables and they get whatever they have. But if I cook something like garlic bread or something, I offer it to the fellows and they do the same back. (Consumer, Stage Two)*

*And me and [my housemate], we like have deep and meaningful and confide in each other. So that makes me feel safe. (Consumer, Stage Two)*

*The guy I live with has a studio, we can use it together. It's good, it has a mic and board, I've done some singing. (Consumer, Stage Two)*

However, some consumers are naturally less inclined to be sociable and therefore more reliant on paid staff for their daily interactions with other people.

*So in terms of connecting with other people, she connects well with all the helpers. She connects well with the PCLI team members that come and visit her. But as for other people in the centre, no, I don't think she does connect. (Carer, Stage One)*

*His [consumer's] only 'friends' and 'social' contacts over the past nine years have been paid staff and fellow patients or residents in care. (Carer, Stage Two)*

#### 5.2.4.2 Participation in the community

For some people, access to community access funding through the NDIS was particularly important to enable community participation. The range of activities appeared to be limited, however; mostly people went to the shops, for a coffee, or to a park or beach for exercise and relaxation. A few had more formal community connections such as singing in a choir, attending church, playing sport, or attending self-help groups. Support (from staff or carers), safe neighbourhoods, and local facilities and infrastructure (e.g. public transport) helped consumers to access local communities. Some were able to access the community reasonably independently but most required assistance of some kind, even if this was just transport.

*She goes out for coffee and chocolate with the various carers. (Carer, Stage One)*

*I usually go for a drive or go for a walk. They take us out for coffee as well. ... Go bowling. We usually get a lot of takeaway as well. (Consumer, Stage Two)*

*I like to go out by myself as well, not always with the support workers. Like, the support's there, so maybe if I want to—just to get into the community, because I'm an independent person. (Consumer, Stage Two)*

*He's a very good singer. His voice, without rehearsing, is really—he sings in [first language] a lot, but he's still able to sing in English songs that I never was aware that he—he's very spontaneous to click and come up with a song. (Carer, Stage One)*

Some consumers are engaging in training or paid work or working towards this. For example, one consumer has completed qualifications and is now employed as a peer support worker. Others have done work experience placements or volunteering.

*[I have been working] now, probably about four months. I'm loving it.... Well these days I go to people's houses, transport people, and take people out shopping, and things like that. ... I can share my experiences, what works for me and what doesn't. And then I get real enjoyment out of it, I like seeing people improve and stuff. (Consumer, Stage Two)*

*I do garden and lawn care. Yes, that's with a [local charity].... Yes I do [enjoy it], very much. People there are good people and helpful, encouraging. (Consumer, Stage Two)*

*I mean I've done some great things. I did a capacity building project for four weeks, for 2.5 hours a day, to work on how better to—the communication between worker and client. That went really well and I've been asked to be a part of the lived experience advisory group that meet once every two or three months and talk about what could be done better. (Consumer, Stage Two)*

#### 5.2.4.3 Connections with family and friends

There were examples of stronger connections with family following transition, including at least one case of reconnecting with children who had been removed for protection years earlier. With the support of staff, one carer had been able to spend time with a sibling who had been estranged from the family, and said it had been 'wonderful for us' to 'regain lost ground'. The person now looked forward to visits from family. Another consumer was better able to have visits from his young children now that he was living in a house rather than in hospital.

*I've got my son now and he adores me so I talk to him all the time. (Consumer, Stage Two)*

Sadly, however, some consumers have limited or no contact with or support from family or friends. For some, especially those in Stage One, family and friends may have died. Consumers and carers gave examples of how relationships with family and friends can break down for people who have long-term mental illness and also long periods of hospitalisation.

*You lose a lot of people when you're mentally ill, I've lost a lot of friends and all of that from my breakdown (Consumer, Stage Two)*

*Sadly, [consumer name] sabotaged his numerous friendships and acquaintances in the years prior to his lengthy hospital stay and rarely had a visitor during those nine years. (Carer, Stage Two)*

*I miss my family a lot. ... All passed away. My wife was a good woman, she was. Seventy five when she died. She had a brain tumour. (Consumer, Stage One)*

*I have got a few friends coming here, but they've sort of stopped coming. You know what it's like; they come here for a while then they forget you. (Consumer, Stage Two)*

In some cases, there was a conscious decision to limit connections with family or old friends due to negative experiences in the past or because those boundaries helped them maintain their mental health and stay away from unhealthy lifestyles, such as involvement with drug and alcohol culture.

*[Lots of my old friends] are all on drugs. I've been clean about four years now. They're all on ice now and heroin. I never touch that shit anymore. ... I didn't want to get too involved in that stuff, so I just left. (Consumer, Stage Two)*

*Christmas, Easter, Mother's Day, Father's Day, or maybe public holiday or something like that, I might go and have some dinner or something with my family. Only for about maybe two hours, two and a half hours, and then I can ring my support worker to come pick me up, and they bring me back home. (Consumer, Stage Two)*

#### 5.2.4.4 Individual differences and preferences

It is sometimes difficult to judge whether consumers have insufficient access to opportunities for social participation or whether their lack of participation is due to individual differences and preferences. Some consumers would prefer to observe others or passively participate in social events; for example, one said they liked to ‘clap along’ to music or dancing, and another liked to just sit near others and knit or read. Time alone can be a strategy to preserve and nurture well-being for some individuals. These consumers emphasised that they liked being alone, and were not lonely. For others, connection with animals provides a sense of social participation.

*And she’s in the corner of that room, whereas she’s not out in the lounge and there’s a TV in it, which she doesn’t watch. And she just sits and I don’t know, she must just watch the passing parade all day I think. ... She’s happy to just do that, sit and watch the world go by. She tells us she’s happy, she tells the staff she’s happy. She tells the PCLI team she’s happy. So it hasn’t been a bad move, at least it’s something different for her outside of hospital. Yeah. But you would like her to have a more meaningful life, but that’s us, isn’t it, putting our values on her, I think, rather than just accepting what is. (Carer, Stage One)*

*There were chickens here the other week, hatching on a table out here under a hot lamp and that was just very exciting. (Carer, Stage One)*

#### 5.2.4.5 Challenges: COVID-19

There has been some quite significant challenges with supporting social connections during the pandemic and associated lockdowns and restrictions. Although most of the data collection occurred before the pandemic began, there are a few examples of where the people talked about the effect of COVID. In addition, many of the activities that people were doing to connect in their community cannot be done during times of lockdown. Carers of Stage One consumers were locked out of some aged care facilities for some months in 2020 and are now locked out again due to the current public health orders.

*But, I mean, I haven’t seen her for a long time now because they’ve been shut down again. They’ve been in lockdown for so long, I can’t go and see her anymore. So this [staff member], she’s full of life and full of beans and she does Facetime [to link the consumer and carer], which is great. (Carer, Stage One)*

*Well I’m locked in now because of COVID but before that I’ve been cooking and going fishing. I caught an eel, octopus, flathead and breams. I still do my art and I have a few pieces hanging in my room. (Consumer, Stage Two)*

## 5.3 Lived experience reflections

Preliminary findings were presented and discussed at the Knowledge Exchange Forum involving two peer workers and two PCLI Steering Committee members with lived experience (LE participants) as mental health consumers or carers. The major points of discussion are outlined below.

### 5.3.1 Level of consumer participation in decision making at the transition stage

LE participants suggested that more focus was needed at the transition stage to support consumers to make informed choices. They indicated that staff should ensure that consumers and carers understand the consequences of different options and that they know that they have the choice to say no. Choice should be facilitated by strategies to ensure all information provided is appropriate for the level of understanding of consumers and carers.

*... it’s critical to have consumer participation in their own plan, so that they don’t just feel like they’re being shifted on to the next place, and I think that that’s very, very behind where we need to be. (LE participant)*

### 5.3.2 Tensions between choice and duty of care

LE participants indicated that freedom to make choices was an important feature of living more independently for consumers but that it was also important that consumers received the support they required. They noted the consequences of getting the balance wrong.

*Well I think a lot of consumers fall through the gap in that space where they seem to have more capacity and then the solution is to go back to more of an independent, even with the support of the PCLI, but to go back to independent living and then, I guess, ultimately re-present and have another episode of distress, which is quite – I don’t think that’s resolved in the space I’m working at, I don’t think it’s nearly resolved. Because there’s a conflict of tension between wanting people to have independence and autonomy versus the support that they might need, at least in the short-term. (LE participant)*

Tension between recovery concepts of choice and control versus duty of care and risk concerns have been documented elsewhere (Perkins & Repper, 2014). Autonomy and self-determination are critical elements of recovery (Commonwealth of Australia, 2013; Copeland, 2003) but psychosocial support is sometimes required to support recovery especially with people with complex needs (Corrigan

& Phelan, 2004). The decline in physical health since transition, for example, is of concern. It is well documented that people with serious mental illness have a much higher prevalence of serious and chronic illness and mortality rates 20-30 years earlier than the population on average (Wheeler et al., 2018). Therefore it is especially important that support workers do not overlook or understate these risks. Strategies that support the provision of individualised, flexible care that incorporates safety measures help balance these tensions (Slemon et al., 2017). LE participants suggested that key is for staff get to know people so they are able to understand the difference between a poor choice and a dangerous one.

*There's lots of people that don't like doing their housework ... and sometimes when people – consumers are becoming disorganised in the house, sometimes it's an early warning sign that they may be deteriorating, or it could be just simply that they're just like everyone else. (LE participant)*

### 5.3.3 Accommodation issues

LE participants raised concerns about the availability of appropriate accommodation options. While there are guidelines within the PCLI framework, it appears, that in practice, these might not always apply due to a lack of availability or sometimes due to the consumers' preference. LE participants indicated that strategies to facilitate PCLI support in some social housing and private accommodation options were problematic. LE participants also stressed the importance of the provision of bespoke accommodation and support options for PCLI participants with complex needs (i.e., the anticipated Stage Two SLS services).

*I don't know how you solve that though as people are gonna go into public housing models, and if that's their choice ... I've been a little bit frustrated, because when you have a consumer that is very definitely wanting to go into a particular model, there's less jurisdiction around those standards. We can do what we can but it's like, social workers from the [MH] team liaising with Public Housing and it's just – you can only get on so far. (LE participant)*

*I am so hopeful because this PCLI initiative is very mindful of having appropriate accommodation for people. And that is something that the Ministry has spoken about in terms of their planning when it comes to having long-term vision for this program, and I'm very hopeful. I'm very hopeful that there'll be more options for people when it comes to living in a more supportive environment. (LE participant)*

### 5.3.4 Hospital reform

While acknowledging that good recovery is occurring in the community, LE participants raised concerns that highlighting the success of transition into the community might take the focus away from building capacity and accountability within hospitals to work with people in recovery oriented ways with a rehabilitation focus.

*I think there is a slight danger with those comparisons ... I think it abdicates hospitals from actually becoming what they need to be, and then you don't have that continuity of recovery which is very important. Because it's not like, oh now you're in the community you can recover now because you couldn't before, which is sort of where we're at now. (LE participant)*

One of the dangers of success of specialised programs like PCLI is that responsibility can be abdicated to a particular program and a few people (Newman & Emerson 1991). A dichotomist narrative of community living versus hospitalisation might also demoralise and alienate hospital staff towards further reform. Hospitals can draw on good practice already happening in some hospital models while also learning from community partners to increase rehabilitation opportunities in hospital settings.

## 5.4 Key informants' perceptions of consumer and carer experiences

Consumer and carer engagement is integral to the PCLI transition processes. In this section, we look back over five years of evaluation data to identify the ways in which key informants have described efforts to engage with PCLI consumers and their families, and the factors that have helped or hindered engagement. Themes and sub-themes across time are presented in tabular form in order to summarise the large quantity of data available. The chapter concludes with a summary of key informants' perspectives on the benefits of the transitions to community achieved during the PCLI implementation to date.

### 5.4.1 Consumer engagement

During the course of the evaluation, five overarching themes were apparent in key informants' accounts of their efforts to engage with people who had experienced, or were at risk of experiencing, long hospital stays (Table 18). Within those overarching themes, distinctive sub-themes emerged over time, reflecting the stage of development of the program, but there was also a considerable degree of consistency in the way these issues were discussed.

**Table 18 Consumer engagement: themes and change over time**

Overarching themes	Sub-themes over time				
	2017	2018	2019	2020	2021
<b>Committing to new processes</b>	Demonstrate that clinical care is possible outside hospital ‘with the right supports’		Transitions are highly tailored to individual consumers, detailed and personalised	Peer workers add value to transition processes and can advocate for consumers	Access to peer workers is essential; whole PCLI team advocates for consumers
<b>Taking it slowly and carefully</b>		Avoid pressure to discharge quickly, so that all supports are in place first	Ensure initial experiences are safe and positive with support from a trusted person	Transitions can take six months or more to complete, labour intensive for staff	
<b>Acknowledging emotions</b>	‘This is a very delicate, gentle process that has people’s emotions very much tied in it.’	Consumers may find transition processes ‘intense or confusing’	Consumers may fear that ‘everything will unravel’ similar to previous experiences of discharge to community		Developing empathy – consumers’ experiences are ‘real for them’, should not be dismissed as breakthrough symptoms
<b>Managing expectations</b>	How realistic is it for long-stay consumers to have a ‘vision’ of community living and what they might like?	Some consumers have fixed ideas about how or where they want to live, which may not be feasible given their support needs	Pre-match providers of accommodation with consumer support needs for a curated list of choices		Sometimes complex things happen to take decision making out of people’s hands, but they can still have their voices heard, which promotes a sense of autonomy
<b>Empowering the consumer</b>	Allow some involvement in decisions even within restrictive hospital environment; this is essential to prepare for self-care		Need for formal mechanisms to determine how and when consumers are brought into planning process		Build on existing support networks and consumer preferences; include the consumer voice in any decision making

#### 5.4.1.1 Consumer engagement in 2017

During the earliest interviews, in late 2017, KIs emphasised that the PCLI constituted a challenge to the idea of ‘custodial’ care and a *commitment to new processes* that would enable least-restrictive care. However, there was also recognition that the prospect of transition could trigger strong *emotions*. Consumers, along with carers and some inpatient staff, could be very anxious about the prospect of moving out of hospital and these emotions should be handled gently and carefully. A history of bad experiences of trying to survive in the community with little support could lead to understandable

reluctance to leave hospital, where at least the environment was clean and safe. Consequently, people needed information and reassurance about their continued access to clinical care in the community; they wanted to know what would happen if they became unwell, so they could get help quickly.

The PCLI and inpatient teams collected information about –and from –the consumers, such as the length of time since they last lived in the community, how engaged they were with their families or other potential sources of support, and whether they could realistically envision a life outside of hospital. It was recognised that the sustainability of transitions would rely, to

some extent, on *empowerment* of people while they were still in hospital to start making some of their own decisions. This would mean adopting a model of care and a mindset that did not promote institutionalisation:

*If you don't include the person in their care in the hospital, they're never going to feel that they've got any decision making capacity in the community. You can't just kick them out of the hospital and then go, right, you're on your own. Even with people wrapped around you, suddenly you're involved in your own care. You've got to start involving those people in their own care, here in the hospital setting. (Program manager, 2017)*

#### 5.4.1.2 Consumer engagement in 2018

By the second round of data collection, attention had moved towards the themes of *managing expectations* and taking transitions *slowly and carefully*, as enthusiasm for community living started to take hold in long-stay wards. KIs began to talk about trying to slow down transitions (initiated by inpatient staff) to ensure all supports were in place. Some expressed concerns that the initial round of assessments may have raised hopes prematurely or set up unrealistic expectations for the options currently available in the community. While some consumers were reluctant to leave hospital, others had specific, ambitious goals. Nevertheless, inpatient and PCLI staff were working to create individualised packages of support in aged care and disability care settings that would meet consumers' assessed needs and expressed wishes (see case example).

#### **Illustrative case example: Engaging a consumer in transition planning (2018):**

*So he was a big challenge, and [PCLI clinician] did a lot of work with him and he was like, nope, nope, nope, not going, not going, not going – quite normal. One day he asked if there were coat hangers. I said, 'He's going.' He has thoughts in his head about whether there will be somewhere for him to hang his clothes. He's super scared, he's super nervous and this is all he's ever known. And he – we had lots of contingency plans in place and we involved the public guardian and we spoke to him about it as well at length and we're like, 'This is what we need to do.' So he was fully engaged in the process. Anyway, he ended up – we had all kinds of things ready in the background because we thought this could be really difficult. Well, this guy once he gets there, [sees that] he's going to love it. The first day he got there, went over to the library, borrowed himself some books, told [PCLI clinician] they need to go out the next day to buy some different bedding because he didn't like what we'd given him.*

In relation to *empowerment*, the issue of consumers' capacity for decision making was raised. For example, one key informant noted there was a delicate balance between providing choice for the consumer while also dealing with guardianship, which assumed that people did not have capacity to make informed decisions about accommodation and support: 'it's a very grey area'.

#### 5.4.1.3 Consumer engagement in 2019

These themes appeared again in the 2019 data collection, with subtle changes that reflected the development of the program. In discussing their *commitment to new processes*, KIs highlighted the tailored process of designing transitions around the capacities and wishes of individuals, as well as their support needs. This was complicated by factors such as intellectual disability, acquired brain injury, English as a second language, trauma histories, behavioural issues and serious physical illness. A further challenge was failure to develop, or loss of, necessary life skills for daily living, due to early onset of mental illness or institutionalisation. Consequently, care planning for transition remained a labour intensive and painstaking process.

The task of *managing expectations* had become more prominent in KI accounts. Several implementation sites handled this by creating 'curated' lists of accommodation options based on the match between consumer needs and provider capacity. By showing consumers (and families) only the places that were best suited and available, they could avoid creating unnecessary stress and disappointment. Attention to *emotions* remained high, with PCLI staff and inpatient staff working with individuals to overcome their institutionalisation and fear of change. One way to ease anxiety was to ensure that early experiences of the new home were all positive and the person felt well supported by a trusted staff member or family member, while staged, gradual transitions allowed time to adjust. *Empowerment* again surfaced as a theme, this time in relation to the need for embedding recovery orientation into practice by ensuring that clinicians habitually involved consumers in decision making around their care planning.

#### 5.4.1.4 Consumer engagement in 2020/21

Later interviews emphasised the value that peer workers' lived experience added to consumer and carer engagement. Over time, the combination of these new resources (i.e., the peer workers' skills and expertise) and growing acceptance of the PCLI processes among inpatient teams placed PCLI teams in an improved position to advocate for consumers in case reviews and MDT meetings. One key informant stated that the willingness of clinicians on the team – not just peer workers – to speak up on behalf of consumers was unusual and valuable:

*Even though sometimes we as individuals don't necessarily get our way with things, or have the outcome in life about some of the things that we want, it is important that we are heard. (Peer worker, 2021)*

The theme of *taking it slowly* continued in KI accounts; for instance, one said that transitions to aged care facilities could take six months or more and were 'detailed and labour intensive'; they could not be rushed. Conscious efforts continued around *empowerment*, but consumer involvement in planning and decision making still varied even within hospitals (e.g., across units and among different staff groups). However, some KIs were confident that the consumer voice was being considered in all decision making, either through the PCLI team or through inpatient staff – particularly allied health practitioners – having ongoing conversations with individuals. One key informant suggested that the PCLI helped to counter

the NDIS focus on deficits by drawing attention to strengths and the things people like, want and enjoy. The processes also fostered empathy by putting into perspective the impacts of symptoms on people's life goals, prompting consideration of how to incorporate supports around these experiences, because 'for them it's real'.

## 5.4.2 Carer engagement

One of the earliest themes in key informants' accounts of carer engagement was the strong, mostly negative emotions that arose when the idea of transition to community living was raised: fear, anxiety, hostility and anger. We have labelled this *fear of change*. It was mirrored by a theme relating to *trust in the health system*. At first, some key informants encountered suspicion that the PCLI was a cost-cutting exercise aimed at ward closures. Trust in the system was initially very low. Many carers could remember previous mental health care system initiatives aimed at deinstitutionalisation and were wary about what the PCLI would mean for consumers and their families. The third theme was *family dynamics*, which captured discussions around the diversity of carers and family situations, including situations in which consumers had lost touch with or become alienated from families or had no living relatives.

### 5.4.2.1 Overcoming fear of change

Useful insights into working with the families of people with complex mental illness were provided at a PCLI Dialogue Day in 2017 by an invited presenter, Dr Carmelle Peisah, president of Capacity Australia. Dr Peisah outlined research on family impacts of serious mental illness and why carers might resist the move out of hospital. A diagnosis of psychiatric illness can dominate a family and it may seem as if things have always been, and always will be, this way, leading to a loss of 'chronicity', which stifles hope:

*... new possibilities and progress are not considered ... events stand still and individual action is paralysed. (Agnetti & Young, 1993, cited in Dialogue Day 5 report, NSW Health 2017).*

Dr Peisah advocated a tailored approach, recognising that changes may be upsetting and the consumer's transition to the community will require a period of adjustment for their family.

Key informants subsequently talked about the efforts made to work gently with carers to open their minds to the possibilities of community living for their person. In many cases this took time and persistence. Any sense of hurry or pressure could create misunderstandings, damage *trust*, and reinforce *fear of change*. One of the major worries for carers was a perceived lack of clinical expertise available in the community compared with hospital, particularly for the Stage One cohort who were moving into aged care facilities. One key informant noted that families had largely been shielded from the realities of life in a long-stay ward, to avoid distressing them. Consequently it was hard to envisage that an aged care environment could be preferable, providing more privacy, choice and freedom. Carers were routinely invited to tour and inspect potential facilities and in many cases changed their minds once they saw what was on offer. For some families, the proposed move

triggered previous traumas. Engaging carers was difficult at sites that housed old, long-stay wards which had a culture of containment. It was easier at sites where carers had never been led to believe that hospital was a long-term solution.

### 5.4.2.2 Building trust

Trust was built gradually, assisted by the availability of PCLI clinicians to support treating teams and carers in identifying and evaluating options, and by hospital policies which allowed trial periods in the community (staged transitions) with the possibility of return to hospital if things did not work out. Reassurances of access to clinical care were crucial to overcoming carers' fears that the person would not cope and the transition would 'fail', potentially leaving the person homeless and unsupported. However, by 2019, key informants were reporting that they had observed a change in mindset among families and *increased trust* in staff and the system. In later interviews the theme of *fear of change* was notably less prominent.

### 5.4.2.3 Understanding family dynamics

In relation to *family dynamics*, PCLI teams realised early in the program that it was best to work with carers individually rather than in groups. One key informant told the evaluation team that there had been 'really difficult meetings' with large groups where carers were 'quite angry and distraught'. Both the PCLI teams and the inpatient teams had roles in working closely with families, undertaking collaborative planning with consumers, and problem solving around specific issues (e.g., providing travel training so that a carer could regularly visit his partner at her new home). Relationships between consumers and carers had to be taken into account; at times there were conflicts of interest that had to be worked through to balance the needs of both parties. In the most recent interviews, one key informant talked about utilising family and friends where possible to facilitate and sustain the transition. By building an understanding of family dynamics, the PCLI teams can work with consumers to identify who they would like to be part of their network of supports and then try to build on that foundation, perhaps by capacity building with carers where required.

## 5.4.3 Perceived benefits for consumers and carers

The evaluation has drawn on a variety of sources to document KIs' views of the benefits to consumers and carers arising from transitions to community. Before first-hand accounts were available, the evaluation presented case studies based on reports from PCLI Dialogue Days. A vital source of information has been the observations of PCLI staff at the implementation sites, recounted during interviews, at meetings, or in LHD reports. Program documents such as LHD reports to the PCLI Steering Committee, internal LHD activities that documented and promoted the benefits for individual consumers, the 'Postcards from Home' initiative by the HNE LHD (and now adopted by several other LHDs) and a film produced by the Ministry PCLI team have also been important sources of evidence for the evaluation. In addition, the evaluation team members have visited all the MH-RAC facilities multiple

times, plus several mainstream aged care facilities housing Stage One consumers, as well as numerous group homes and other types of supported accommodation where Stage Two consumers are now residing.

#### 5.4.3.1 Stage One: 'rementia' and recovery of functioning

*Evaluation Report 4* and *Evaluation Report 5* included the accounts of aged care facility managers who had seen the life-changing effects for Stage One consumers of moving out of hospital and into the MH-RAC facilities or mainstream aged care homes. Their accounts included descriptions of increased physical mobility, improved communication and social interaction. At a 2019 meeting of the MH-RAC network, a PCLI clinician reported on what he described as 'rementia': recovery of functional capacity due to greater opportunities for social interaction and an enriched environment. Examples of functional gains described by various stakeholders have included consumers who have picked up musical instruments, burst into song, danced with aged care staff, used extended vocabulary in conversation, or folded their own clothes and put them away with care.

*Well, neither of them was mobile when they came to us. [First consumer name] had a forearm support frame and could manage a few steps with someone, and [second consumer name] was in a wheelchair, and they're both up and mobile now. (Aged care provider, 2019)*

*When he first got here one of our residents, [consumer name], we were told had no interests except for watching football. [Consumer name] has travelled to Queensland twice ... He went by bus, tour bus ... had a cruise, had a nice time ... (Aged care provider, 2019)*

Aged care providers acknowledged that people who arrived through the PCLI were generally more mobile and less physically dependent than the average aged care resident and therefore more in need of activities and social engagement. However, it appeared that the aged care funding system worked against recovery and rehabilitation goals by providing disincentives for providers to accept people with behavioural (rather than physical) issues or to invest time and effort in working with these people to improve their behaviours and social functioning.

Several aged care providers felt that MH-RAC partners would benefit from a small amount of additional funding to provide leisure and lifestyle activities that would promote mental health recovery. According to one provider, with 'just a little more money' a wish-list of activities would be within reach, such as extra outings, therapy animals, 'inventive and innovative' approaches using technology, and activities at weekends as well as during the week. These views were consistent with those expressed by Stage One consumers and especially carers who noted that a greater focus on active rehabilitation and meaningful occupation could be beneficial.

The evaluation team was told numerous stories about Stage One consumers who were found to have much greater capacity than previously suspected while they were in hospital. One consumer who had been incontinent regained control of these functions; another's diagnosis of advanced dementia was

reviewed and her medication regime revised, within the secure environment of a MHACPI unit, leading ultimately to great improvements for this individual. Aged care providers believed the improvements they had witnessed were due to greater personal freedom, which can include the ability to go for a walk, to go to the pub for a beer, or (very commonly) to smoke, which is not allowed in public hospitals. Freedom can also mean declining to take part in activities. One consumer, who had received travel training to prepare for a weekly trip to the cinema, decided he'd rather stay home instead. Another liked to indulge in the occasional day in bed, just because she could. This was a treat, because in hospital, she had no access to her room during the day.

#### 5.4.3.2 Stage Two: freedom, hope and social interaction

For the younger cohort of Stage Two consumers, reported benefits of community living have included a less restrictive and more personalised, home-like environment, the opportunity to go on regular outings, and greater interaction with family and friends.

*And the patient we were discussing who had a really successful transition – I looked after him in [hospital] five years ago and he was receiving muscular sedation on a regular basis because he had a social disability and didn't tolerate being in a closed environment and not going anywhere. But his environment is now – he's got his own room, a really nice group home, regular activities. He's got his own little touches, a little fish tank and things, and I saw him after five years and I would've thought that he would've deteriorated but he actually looked younger and much happier. (PCLI clinician, 2019)*

*So since this consumer has moved into a group home, she's got regular visits from her sister and her little niece, which is so heart-warming because they feel comfortable going to visit her over there, which was not possible [here]. (PCLI clinician, 2019)*

In mid-2021, on behalf of the evaluation team, one KI contacted some consumers - with whom they had previously worked in their transitions to community - to check on their progress. Both were very pleased to hear from the PCLI staff member and happy to share their stories (which have been included in the consumer accounts above):

*I could hear his smile through the phone. It was amazing to hear him be so animated and excited about all the things he's been doing. He started laughing, 'Yeah I know, I can do it all myself now'. He seemed really proud of himself and how far he had come. (PCLI program manager, talking about Stage Two consumer)*

Like the Stage One consumers, the younger Stage Two consumers have a strong need for meaningful occupation; that is, activities that challenge them sufficiently to build a sense of competence and that provide opportunities for social connection and useful contribution to the community. For many, this type of stimulation is available through NDIS-funded activities; however, a continuing focus on mental health rehabilitation remains important following transition and should be a key aspect of the Stage Two SLS models.



### 5.4.3.3 Summary of benefits observed by KIs

Previous evaluation reports have included sections on key informants' perceptions of how consumers and carers have experienced transitions to community and we refer the reader to those reports for details. Overall, there is plentiful qualitative evidence of observed benefits for consumers including:

- improved quality of life (e.g., freedom to go out shopping, to the beach, or for coffee; picking up old hobbies again such as sports, art or music; exercising choice and control in everyday life; comfortable living arrangements);
- improvements in function (e.g., older people regaining continence or mobility or demonstrating better cognitive function and capacity for communication once in aged care environments; greater attention to dress and grooming; younger people taking responsibility for cleaning and cooking meals in group homes);
- greater social participation (e.g., willingness and ability to care for others; spontaneous speech from people who had previously been uncommunicative; more frequent visits from relatives; renewed contact with children for those who had been estranged or removed);
- better mental health (e.g., not requiring PRN medication as often, or at all; greater optimism and energy; a sense of being heard and being able to speak up about what they want and need; insight and commitment to continue treatment regimes; hope and planning for the future, including plans for study or work);
- better physical health (e.g., gaining greater self-regulation of tobacco use; making efforts to exercise or lose weight).

*She is working on her goals of getting out and healthy eating. She does regular laps of the park across the road from the house. (PCLI program manager, talking about Stage Two consumer)*

Benefits for carers have also been reported by KIs, particularly increased family engagement and improved relationships. Carers had pleasant spaces where they could visit, and it was easier to spend time together with the consumer in a relaxed and informal way, either at the consumer's home, the family home, or on shared outings. For most, initial anxiety about the transition had given way to relief and gratitude that a better life was possible for their person.

To conclude this section, a case example is presented: a KI recounts how PCLI clinicians and a community care provider worked together to improve a consumer's quality of life.

### Illustrative case example: Improving a consumer's quality of life (2021)

*He's got very poor memory and he's had a lot of ECT and so every day he just thinks that he's had a terrible day. Even if they've taken him to a great activity and he's loved it, if you speak to him, he was just like, 'No, it's a terrible day.'*

*And he can only attribute feeling low to needing admissions because that's what would happen when he would like have a decline, he'd have this manic episode and then decline and become very depressed. And so his understanding of going to hospital is being depressed and then his biggest fear is dying in hospital because he spent so much time in hospital.*

*We worked with the provider around what we could record that could be quite reflective for him, so that he can actually see that he has had good moments and there are good things happening in his life. To remind him, because of the poor memory.*

*They started strategies around having a calendar where they write events on it and they get him to cross it off, to count down [the days], to keep him motivated and excited about things. And they've been working on reflective journals and diaries to have at the end of the day.*

*So that when he was kind of going, 'I've had a bad day,' they'd be able to say, 'Hey, but at lunchtime we did this and I saw that you were smiling, and is your mood really only one out of 10?' And then he'd say, 'No, it's actually a little bit higher.'*

# 6 Provider and system change

This chapter addresses the anticipated outcomes at the 3-5 year mark, according to the PCLI program logic (Figure 4), at the level of providers, partners, mental health services and the system. It provides evidence on the extent to which they have been achieved and where possible identifies enablers of, and barriers to, implementation.

The providers referred to in the program logic and this chapter include those directly involved in implementing the PCLI (i.e., program managers, executive leads, PCLI clinicians and peer workers) and those whose workplaces have been the target of practice and culture change under the PCLI (i.e., treating teams in long-stay units, case managers within community mental

health teams, and to an increasing extent, clinicians within acute mental health units). Partners include community-based providers of residential aged care, supported accommodation, and disability support services.

This chapter brings together data from a range of sources including longitudinal key informant (KI) interviews, two surveys of inpatient staff (2018 and 2020), notes from observations made by evaluation team members who have participated in many PCLI meetings, quantitative datasets and program documents. Where relevant, we have included findings from previous evaluation reports to illustrate change over time as the program has unfolded.

## 6.1 Availability of expertise and skills

### 6.1.1 Staffing enhancements

For innovations to succeed, there must be adequate human, organisational and financial resources for implementation (Fixsen et al., 2005). There is no doubt that the enhancement funding provided under the PCLI has been fundamental to achieving both transitions to community and deeper changes in practice within inpatient mental health units and disability and aged care partner services. This has enabled the recruitment of program managers, clinicians and peer workers who have the expertise and confidence to drive the changes required. In the main, PCLI staff are highly skilled and motivated, working in an organisational context that is supportive and structured to meet the needs of the local service environment. They are the most visible and active ‘champions’ of the PCLI at LHD level and have been instrumental in engaging other inpatient and community mental health staff. Stage One clinicians in particular have been able to build on the foundations of earlier OPMH enhancements which saw managers take on strategic leadership roles within LHDs, effectively providing the foundation for the aged care partnership development activities.

The decision to provide sufficient funding for positions at senior levels within each LHD was crucial to success. KIs spoke of the challenges of promoting recovery-oriented services within a system that is ‘paternalistic’, a ‘medical model’ and dominated by ‘powerful psychiatrists’ and where long-time staff had a sense of ‘hopelessness’ about patients that ‘nobody would ever (expect) ... to be discharged’. As such, program managers and clinicians have required exceptional

skills in stakeholder engagement, influencing and negotiation in order to implement PCLI processes, establish new ways of working and build capacity within health services as well as cross-sector partners. Sophisticated interpersonal and communication skills and expertise in trauma-informed practice have also been important when working with consumers and their families as they address the fears, anxieties and uncertainties associated with transition.

*(A)dvanced clinical skills in working with families ... not just standard communicating ... You're actually having some really difficult conversations with families, and that requires a skill and expertise and a recognition of what's gone before and some of the ....traumatic experiences to where they are now (PCLI program manager, 2018)*

The program's success has been underpinned by the personal commitment of the PCLI teams to delivering recovery-oriented mental health services. KIs frequently referred to how the program aligned with their personal values, described variously as ‘passionate’, ‘excited’, ‘invested’ and ‘engaged’ and ‘wanting to succeed so that... we don't have this situation again’. These attributes were clearly important in sustaining clinicians as they faced the challenges inherent in changing practice. There was a deep sense of satisfaction in enabling consumers ‘to be the masters of their own journey’ and in seeing long-term staff change in their attitudes and ways of working. Interviewees also noted the personal benefits they had received, in terms of professional expertise, confidence and understanding of the broader policy context.

## 6.1.2 Training

It was recognised early in the program that embedding the PCLI processes and ethos was not something the PCLI-funded staff could do alone but would require active participation by many other nurses, allied health professionals and medical staff. Program managers and executive leads actively challenged the language around ‘PCLI processes’ being associated with certain staff members, emphasising that these were ‘good practice’, and therefore elements of core business: ‘we’re all in the business of getting people out of hospital by whichever route’.

One of the first tasks for implementation sites was raising awareness of the program, what it aimed to achieve, and how others could get involved. At the six primary implementation sites, this occurred during 2016. Responses to the first staff survey in late 2018 showed that this messaging was reasonably effective, with 58% of respondents agreeing or strongly agreeing that *‘The rationale and objectives of the PCLI were clearly communicated to me at an early stage of the program’*. A training needs analysis in June 2016 identified that around 1000 staff members across the primary implementation sites required training in the PCLI tools and assessment processes (Thompson et al., 2018). With coordination by the Ministry PCLI team, training modules were developed and delivered in 2016 and the first quarter of 2017. According to key informants in late 2017, the training was valued but it was too early to detect any impacts on practice; some suggested that recovery training, in particular, would need to be undertaken multiple times before the ‘lightbulb moment’ occurred, motivating change. There were concerns that any gains from this ‘huge burst’ of training could be lost quickly due to staff turnover.

Survey findings validated the views of key informants that a one-off program of formal training could not suffice to increase the availability of skills for transition planning. In Round 1, 35% of respondents agreed or strongly agreed with the statement, *‘Training programs were adequate to prepare me for the practice changes required by the PCLI’*; by Round 2 this had decreased slightly, to 33%. However, 48% of the respondents to Round 2 agreed or strongly agreed that, *‘The PCLI has increased the skills and capabilities of the mental health workforce’*, up from 44% in Round 1. A substantial proportion of respondents in both rounds (49% and 44% respectively) endorsed the statement that, *‘I understand how to implement PCLI activities’*. This suggests that other workforce development strategies were having an impact.

## 6.1.3 Coaching and mentoring

Throughout the program, workforce development has taken place using a variety of strategies, most of which do not involve formal training. The predominant approach is continuous, informal coaching and mentoring of staff by the PCLI clinicians and program managers. Although time consuming, it is effective, as demonstrated by key informant reports that inpatient treating teams are increasingly taking a greater role in conducting assessments, dealing with NDIS procedures, and evaluating the suitability of community supports for individual consumers. This approach requires ‘a lot of working with, a lot of working alongside’ other staff: asking questions, making

suggestions, starting conversations. It requires not only high-level clinical knowledge and experience, but also soft skills in communication, advocacy, and facilitating adult learning. PCLI clinicians and program managers are modelling recovery-oriented language and actions in their everyday interactions with other mental health care providers in the expectation that eventually others will see the benefits of this style of practice until ‘it just becomes a cultural thing’. Key informants have observed ‘a change in mindset’ but still a reliance on the PCLI clinicians; the next step is empowering staff so that they routinely look for signs of complexity and start planning transitions early, to avoid long stays.

Staff in acute units and community mental health teams are also receiving mentoring, particularly from PCLI staff at LHDs which do not have long-stay units. For instance, one key informant described how they had invited a community mental health case manager to attend weekly transition meetings, first getting them comfortable with the process, then asking if they’d like to chair the next meeting, and effectively building their skills over time to take over the support of the person in the community. Another had been advocating within an acute unit for individuals who would benefit from a longer stay, to allow more time for assessment, rehabilitation and structured planning to obtain the supports they needed for sustainable transitions. Yet another spoke about arranging meetings between all the relevant stakeholders but not necessarily leading the discussions, just being available to answer questions, provide suggestions, and model recovery orientation:

*‘I’ve been saying, if you want to put strategies in for these consumers, you really need their buy-in, you need them to be a part of it. And then [the staff say], ‘Yeah, I remember, I need to do that, I’ll go and do that.’ Still early stages. I’m hoping that after a while, that will become their thought processes. (PCLI clinician, 2021)’*

## 6.1.4 Consultation and empowerment

A consultation role is increasingly mentioned in KI accounts, as other clinicians gain skills and knowledge for transition planning but perhaps lack the confidence to ‘drive it themselves’. One KI described it as bringing ideas and resources to the table so that staff can ‘complete their core business to the best of their ability’. For example, PCLI clinicians and program managers have led the way in coaching staff around how to navigate NDIS procedures and maximise funding for the benefit of consumers; staff call on the clinicians when something goes wrong or when a particular report is needed or a service model assessment completed. The PCLI roles are sufficiently flexible to allow this kind of *ad hoc* input to inpatient and community mental health teams and also to providers external to health who are supporting PCLI consumers in their community living. They build capacity by ‘not handholding the whole way’ but demonstrating how things are done and then providing prompts or advice as needed.

The PCLI clinicians are now being approached for advice and input, asked to participate in complex case reviews, or to accept referrals for consumers who are not yet long-stay but need a higher level of attention and follow-up than usually available. This is a positive change, indicating a level of respect for their expertise and valuing of the contribution from the PCLI.

*In the beginning I had to invite myself into spaces but now myself and [other PCLI staff] are invited into spaces, which is a pleasant change ... now even consultants ask for us to join in ... (PCLI clinician, 2021)*

The PCLI clinicians have sought to build capacity in other ways, such as empowering peer workers, developing leadership behaviours in individual clinicians (local champions or leads) who have shown strong interest in the PCLI, and designing resources and/or specific training to meet local needs. For instance, one LHD has recognised that clinicians can be nervous about managing specific risks and comorbidities such as drug and alcohol addiction, intellectual disability, or chronic disease, and there are plans to provide education around these areas so that staff are empowered to make appropriate referrals and connect consumers to the right services on

transition. Another has worked with nursing staff to develop their expertise with particular tools, so that they can play a more prominent role in care planning discussions. To counter the issue of high staff turnover which rapidly diminishes the returns from mass training efforts, another LHD has devised a tailored training program for each unit, upskilling one or two staff members at a time on each of the non-discipline-specific assessment tools. This has led to a large improvement in completion rates for these tools.

These efforts are ongoing, and will need to continue in order to achieve the goal of making transition planning ‘everyone’s business’. It is not just about skills and expertise but about changing the way staff think, instilling into the culture certain guiding principles:

*It seems to me the PCLI principles probably are wraparound principles that should apply initially to anybody who comes in to mental health care ... So that those general levels of high assessment of social needs, psychological need, mental health need should always be considered more in-depth. And then see who can graduate out of need ... But that means that we have to educate the system to think that way. (PCLI clinician, 2021)*

## 6.2 Collaboration within health services

The health system is historically compartmentalised according to professional specialties and service types, and divisions exist even within inpatient services (long-stay, rehabilitation, subacute and acute) and community services (OPMH, adult assertive outreach teams and so on). In effect, this creates ‘silos’ each with their own discrete management and treatment teams and modes. For example, one KI noted that different units at the same hospital had different referral procedures, creating obstacles to implementation of the PCLI.

Compartmentalisation has advantages and disadvantages for change efforts. It is sometimes assumed that organisational culture is monolithic, conservative and stable, but collections of sub-cultures can exist within health care organisations (Carlström & Ekman, 2012). The diversity of sub-cultures can be a strength, improving communication, collaboration and coordination of activities within units (Carlström & Ekman, 2012). However, contemporary, recovery-oriented practice requires a collaborative approach across stakeholders and sectors to ensure the services and supports provided are tailored to the needs of the individual consumer.

The collaborative intent of the PCLI has been modelled by and driven from the Ministry through clear accountabilities such as key performance indicators tied to funding to LHDs. In the main, this has resulted in strong leadership at the local level and support for program staff to challenge entrenched practices and assumptions regarding consumers’ capacity, including among senior personnel such as psychiatrists. As one KI commented, ‘it’s essential to have good engagement with (the psychiatrists) ... and that they have a good relationship with the GP as well, who is primarily responsible for providing those medications, scripts, any changes in

medications, et cetera’ (PCLI program manager, 2020). Collaboration has been modelled by engagement of executive leads and PCLI personnel in numerous governance and program development processes (e.g., steering committees, working parties) at State level.

A recurring theme throughout the evaluation has been the bridging role of PCLI clinicians and teams, facilitated by positioning the clinicians within service structures in ways that best fit local circumstances. PCLI clinicians are predominantly located within or alongside their respective client-based units: Stage One teams have generally been attached to OPMH services with in-reach to inpatient units; Stage Two is more varied, with clinicians attached to inpatient units, sitting within assertive outreach or adult community mental health teams, or with specialist sections of LHDs that serve vulnerable persons (e.g., intellectual disability, drug and alcohol) or deal with partnerships and transitions.

Regardless of where they are physically located, each one has the objective of ‘straddling’ the inpatient and community health services within and across LHDs, and linking health with the community services sector such as housing, disability and aged care services. In this way, the PCLI clinicians facilitate continuity of care. They communicate essential information and build capacity across the system and across sectors. They also ‘bridge’ old ways and new ways of working. KIs emphasised the value and uniqueness of this role.

*They work across the inpatient and community which is different compared to how everyone else's workload is assigned ... that [clinician] is seeing both sides of the coin, so they can say, 'Well actually I have seen this patient in the community [doing] really well.' Or, 'We should prevent [this person] leaving hospital.' And they can also advocate very strongly when someone does need an admission to say, 'This cannot be managed, they have previously met this threshold and the person does need the admission.' So the person's admission is not delayed which can often lead to a longer stay. (PCLI program manager, 2018)*

*You're in between all of them, and I think that's been unique as well because that's where people have openly said things to me about what they feel might be happening or what they're struggling with. So I think the position actually gives you like that you don't have a bias to one area or another (PCLI clinician, 2021)*

As a result of PCLI input, community mental health teams are better prepared to take on consumers at the point of discharge from hospital to make sure they have continuity of care and come back to a well-supported position in the community. The PCLI clinicians engage early with the community case managers and encourage them to be part of transition planning. They also undertake capacity building activities with the community teams, as described above.

### 6.2.1.1 Collaboration across NSW

Collaboration has also been enhanced across districts through state-wide networks established through the PCLI. These networks are nurtured through regular gatherings such as the weekly collaboration teleconferences for program managers

and executive leads, the Practice Network meetings for PCLI clinicians and the MH-RAC Network meetings involving aged care providers, Stage One/OPMH clinicians, OPMH service managers, PCLI program managers, and Ministry PCLI team members. Prior to COVID-19, these meetings were face-to-face and occurred twice or three times a year, providing opportunities for sharing information, learning from each other and from guest presenters, and (for the MH-RAC Network) benchmarking best practice. The strength and variety of these networks and the links they have built are a notable achievement and a distinguishing feature of the PCLI that sets it apart from similar initiatives.

As well as building shared purpose and implementation fidelity among the participating sites, the PCLI state-wide networks assist individual consumers, particularly those who are transitioned across LHD borders. For instance, in one LHD that refers people to rehabilitation units in other districts, the PCLI clinician remains the primary contact between the LHDs and is part of the person's transition planning and supports when they return. The relationships developed across LHDs mean that PCLI staff can advocate strongly for the appropriate level of follow-up community mental health care when consumers move out of hospital to other districts.

*The relationships across districts have been improved by PCLI, I think because we're able to say, this client's moving out of district, we need them to be linked with the most assertive community team that you've got access to in the district and we understand that you're under the pump but this one, this is an individual who really needs that level of care, rather than just going through intake (PCLI clinician, 2021)*

## 6.3 Community support

Successful transitions hinge upon well-planned discharges from hospital. The evaluation team has consistently noted the individualised nature of transition planning and the great care taken to understand consumers' needs and ensure they have the most appropriate supports available to them, whether that is in aged care, a Supported Independent Living (SIL) group home funded by an NDIS package, a HASI Plus home, or a private residence. In one of the earliest interviews a KI noted that deinstitutionalisation was not new, 'but maybe we are doing it in a way that is much more thorough than has been done before' (PCLI program manager, 2017). More recently, KIs have emphasised how careful transition planning is the key to the PCLI processes:

*...taking into consideration all their needs and attempting to meet each need so they will be supported in the community once they are discharged. (PCLI program manager, 2021)*

The goal is to avoid further long-stay mental health care admissions, and also to avoid a cycle of very frequent admissions; both these situations reveal an underlying lack of appropriate community supports. Because of the severity of

their mental illness, it is generally accepted by KIs that PCLI consumers will need treatment –including inpatient admissions –from time to time. This is verified by the findings in Section 4.4 which show that 21% of Stage One and 35% of Stage Two consumers have required mental-health-related readmissions. However, the finding in the same section that less than 10% of consumers have presented to ED demonstrates that most of these readmissions are planned rather than precipitated by emergencies, suggesting that community management of mental illness is generally working well. The following sections describe factors that have contributed to success. (See also Chapter 8 for discussion of challenges remaining).

### 6.3.1 'Getting to Know You' processes

The 'Getting to Know You' processes, including the use of the PCLI suite of assessment tools and the accompanying guides, have contributed to this success. One KI said these tools forced staff to check their assumptions about long-stay consumers and whether the reasons they could not leave hospital years ago still hold; another described the tools

as “absolutely gold” with consumers who are very complex and not well understood; another said every consumer was entitled to have ‘good clinical formulation’. Various benefits of assessment were highlighted, many of which revolved around starting a conversation and developing understanding of what the person wants out of the transition and what recovery will look like for them.

*And I’m not confident anyone actually asked them what they wanted. I’m not confident that anyone asked them whether they felt listened to, whether they wanted to see a GP, whether the fact that they didn’t have a job was actually important to them, whether they felt like they had friends with shared interests. (PCLI program manager, 2020)*

*So trying to see the person as a whole again, their whole life story rather than just seeing it as one admission at a time. (PCLI clinician, 2021)*

One KI described the tools as ‘grounding care’ in knowledge of the person (PCLI clinician, 2021). Another said the assessment process was ‘a prompt to sit down with consumers and get an understanding of what they want, what they value, what recovery means to them’ which then informs selection of possible pathways to explore and helps overcome ‘clinical nihilism’ in the treating team—although this KI also believed this could be achieved ‘just by having the PCLI clinician in the room saying, “This person doesn’t have to live in hospital”’ (PCLI clinician, 2021). Another said the key was ensuring processes were ‘slowed down to have a very careful and planned discharge that would be sustainable’; the fact that very few consumers later returned to hospital had ‘reinforced for [staff] that the capacity of people to function effectively in the community is much greater than we imagined’ (PCLI program manager, 2021).

The *Planning, Assessment and Follow-Up Guide* (NSW Health, 2020a) and the *Journey to Home Guide* (NSW Health, 2020b) are well-regarded by KIs. The former is a means to educate and inform clinicians about the PCLI processes, including consumer and carer engagement, to ensure that people undergo the consumer ‘journey’ as it was designed. The latter is being used by several LHDs to engage groups of consumers in discussions to prepare for transition to community. Facilitated by staff, group sessions focus on key elements in the *Journey to Home Guide* such as what supports consumers might want and what they might need to know for the transition. One KI said they appreciated that the document was written with lived experience input from peer workers.

Various local resources have been created to supplement these guides and maximise the usefulness of the tools in care planning, such as assessment summary templates, guidelines and flowcharts for processes, separate spreadsheets for units to use in tracking assessments for individual consumers, and guides or templates for NDIS assessment reporting. In addition, there are a variety of approaches to creating directories of community providers who are screened and critically assessed on a range of criteria that indicate suitability for accommodating and caring for PCLI consumers.

## 6.3.2 Matching people with the right supports

KIs were able to identify characteristics that they sought in community providers that marked them as potentially suitable as supports for PCLI consumers.

In aged care, a *willingness to accept mental health input* was crucial, indicating that the provider comprehended the complexity of these consumers and their needs. Ideally the provider was also keen to *invest in upskilling* their aged care workforce. A capacity to deal with ‘behaviours’ was another criterion mentioned by KIs; a *secure environment* and the *match with other residents* were key elements that indicated suitability. One KI described a case of mismatch between the person and the facility which ultimately resulted in the person’s return to hospital—and their later (more satisfactory) transition to another facility. This KI concluded that the problem resulted from the placement of this relatively mobile and occasionally aggressive person among frail, very elderly people many of whom were in wheelchairs, combined with the staff’s inability to deal with the person’s ‘severe’ behaviours (e.g., hitting others).

Several KIs felt that locked dementia units were not suitable for people with a primary diagnosis of mental illness, again because the PCLI consumers tended to be ‘young old’ and more physically capable. For someone emerging from hospital, transition was ‘the beginning of a new life’, so a different approach to aged care provision was needed compared with what is currently provided to the older, more frail and less mobile population currently living in aged care homes. Indeed, one KI felt that being co-located with residents with dementia ‘could be quite challenging for consumers and for some quite confronting and potentially traumatising’ (PCLI program manager, 2018).

Other important criteria for suitable aged care providers included the *organisational culture* (‘openness and willingness’ were favoured); evidence of ongoing engagement with mental health services, especially OPMH and psychiatrists visiting regularly; the design and staffing of the facility; a geographical location convenient to the person’s family; and most importantly, a history of a productive and trusting relationship with local mental health services.

Despite having been in hospital for many years, even decades, many Stage One people have been able to go out into mainstream residential aged care environments:

*These consumers have been able to step away from hospital, and in fact pretty much sustainably step away from state-based mental health systems to more generalist systems which has been really, really quite pleasing to see, and those changes have been sustainable. (PCLI program manager, 2020)*

In the burgeoning and relatively unregulated NDIS disability space, KIs said that PCLI staff and treating teams had a difficult task to critically assess the capacity of providers. They spoke about the challenges of enabling consumer choice and control whilst being realistic about the consumers’ ability to make informed and appropriate choices. As one KI put it, it was unfair to expect a person who had been institutionalised for 20 years, who has not even had a choice about when to have

a cup of tea, to make such an important decision unassisted. Therefore, the job for the person's support team was to gather 'facts as opposed to marketing spin', to interrogate claims and ask for details and evidence of capacity, and to assemble summaries of strengths and deficits to inform decision making by the consumer, their family, or the public guardian. Although new services were constantly becoming available, there was a tendency to feel that established services represented a lower risk based on their accumulated experiences:

*So I think the teams were actually also really looking into detail as to what a service, and I'm talking about NDIS providers generally, what a provider says they can offer from a complexity standpoint because we often get them coming and saying, "We can definitely do complexity. That's our speciality." But then when you look at the risks for the individuals, how would they demonstrate they can? We learn from experience with past transitions. That does help. (PCLI program manager, 2021)*

At some LHDs staff are taking part in forums with groups of providers who meet to look at de-identified consumer profiles and try to match them with vacancies. The PCLI role provides clinicians with sufficient flexibility and independence to be able to build links with providers in this way and then take information to those who will make the decisions. KIs said these links were helpful and had enabled them to find accommodation that is nicer, better staffed and cheaper for consumers than older options such as boarding houses. By developing expertise around what options were achievable for individuals, they could contribute to more robust and sustainable pathways out of hospital.

### 6.3.3 Monitoring and follow-up assessments

The extent to which PCLI staff continue to be involved with consumers following transition appears to depend on the needs of the person, the capacity of the providers, and local factors such as workloads and expectations of the PCLI role. For example, at one LHD the PCLI clinicians have quite an active role following transition, checking that the fit between the person and their accommodation service is working, and 'really ticking off that the care [the provider] was saying they could provide [was being provided as expected], because obviously we don't want things to fall apart the person have to come back if it was just that they weren't matched to the right service' (PCLI program manager, 2021).

Another factor which influences monitoring and follow-up is the capacity of the community mental health services at each LHD. One LHD mandated the two-year follow-up assessments after the PCLI team found that they had 'lost track' of a few consumers after community mental health teams discharged them or were not providing the intense case management they needed. With support from the LHD executive, and a concentrated effort to train community mental health clinicians in using the assessment tools, they were able to embed the follow-up assessments into routine practice for the PCLI consumers. However, other LHDs are not able to follow suit due to a lack of resources in their community mental health services. One KI explained that they could advocate strongly for continued care on the basis that a person had experienced a long admission and there was a need to ensure

they were settled, but had to be realistic about the ability of the services to carry out assessments or keep cases open because of the heavy caseloads already carried by community clinicians.

From time to time, people will require admission to hospital for physical or mental health care. Many of the PCLI consumers have chronic health conditions which require ongoing care (for example, dialysis for kidney failure). During acute exacerbations of the illness they may present to emergency departments and be admitted to acute care. When these events occur, it is important that treating clinicians are aware of the person's history as a long-stay (or potential long-stay) consumer with SPMI and complex needs as this will affect discharge planning. Some LHDs have set up various ways of making sure this information is passed on, such as flagging the person in the electronic medical record (EMR) as a PCLI consumer.

PCLI teams have also been involved in setting up systems to avoid unnecessary admissions to acute units. For example, at one LHD, there have been negotiated changes to clinical governance arrangements which previously required consumers to spend time in a local acute unit following discharge from a long-stay ward in another LHD. Now, instead of this intermediate step, consumers can be discharged directly to the community team in the originating LHD. This avoids the detrimental mental health impacts of sitting in an acute ward without rehabilitation activities available, which: 'is more than an inconvenience ... it is a real step back for a person'. Another key informant spoke about the potential role of the PCLI as a safety net for consumers whose family or NDIS supports in the community break down, potentially resulting in 'social' admissions to hospital which can set back their recovery.

Special arrangements have also been made around maintenance electro-convulsive therapy (ECT) which some consumers require on an ongoing basis. Clinical governance requirements previously meant that people were retained as inpatients, but one LHD, with executive and medical leadership, has developed strong processes and structures to support discharge with readmission for ECT maintenance. This was trialled with one Stage One consumer and subsequently it was found that the person was doing so well, living in the community, that they no longer required ECT. According to the program manager at that site, the person has not experienced any relapses or readmissions – an excellent outcome for that individual.

### 6.3.4 Capacity building with disability providers

The advent of the NDIS has created opportunities for Stage Two consumers to return to the community, live in domestic-scale dwellings and be supported access to activities, services and resources available within their local area. These features were not available within the hospital environment. However, as explained in Section 8.3, specialised service developments are required for those whose exceptionally high clinical needs cannot be met through NDIS models.

A recurring theme among KIs has been the challenges regarding workforce in the disability support sector, which is generally low paid, low skilled, highly casualised and has a high turnover, and the absence of clinical governance arrangements. In one LHD a consumer was readmitted to hospital soon after transitioning under an NDIS package as there had been 'assumptions about what people are doing and what their roles are compared to what they actually do'. Consequently, the PCLI role is often conceptualised as a 'broker' or 'bridge' between health and community sectors, building linkages and facilitating improvements in care through capacity building activities.

Feedback from a number of KIs has highlighted the importance of ensuring providers, particularly within the disability sector, are clear about their respective roles in regard to supporting clients with mental illness, including responsibility for case management and who should be called if advice is required. PCLI staff also put in place various plans, procedures and systems designed to ensure best practice in the care of the consumer. They develop relationships with providers so that communication can happen quickly if necessary to enable efficient mental health service responses. They also work with NDIS-funded behaviour support practitioners to ensure that behaviour support plans, reports and guidelines accurately reflect the person and their needs.

KIs had differing views on the best timing for capacity building efforts. One emphasised that the earliest period when the person is transferred from hospital to home was 'the crucial period' when providers, families and community mental health clinicians required the most support. During this time frequent meetings might be needed, easing back once the person had settled in well. Another KI talked about making monthly visits to a provider which housed multiple complex consumers, 'just to discuss issues ... anything that's come up'. This ongoing contact was appreciated by the provider and they felt it made things run more smoothly. Another KI spoke about opportunistic encounters with staff during home visits to consumers in SIL group homes. As well as checking in with the person, the clinician will talk to staff about the person, whether they have noticed anything of concern, and provide some ideas and resources on how to navigate or manage those issues.

Provider forums which originally focused only on matching consumers with vacancies are now shifting towards capacity building. Along with representatives from disability service providers, NDIS coordinators of supports attend some of these meetings. Facilitated by PCLI staff, these meetings are opportunities for working together on systemic issues, brainstorming around particular problems that consumers are

experiencing, and making direct contact with mental health services if needed. They also put providers in touch with services outside health that they might be able to access for the benefit of consumers, and with training supports.

There was broad agreement on the kinds of topics that providers want to learn more about. Primarily, these needs focus around recognising and managing mental health crises, and distinguishing between serious symptoms of mental illness and other problems, such as a person's frustration with functional impairments. At the Murrumbidgee LHD, the headquarters of the rural roll-out of the PCLI, there are plans to trial a training package for crisis management that was developed in South Australia. The developer has agreed to add more mental health content to the training, and other LHDs are interested in participating, so this may become a NSW-wide trial. Providers also need help with managing medications, and general moral support and supervision. One KI suggested that providers would also benefit from first-hand experience of the hospital setting to gain a different perspective on the consumers and where they have come from. This exposure and knowledge would help them to understand:

*... what a person has been through and what their trajectory through clinical care has been like. (PCLI clinician, 2021)*

### 6.3.5 Functional partnerships across mental health and aged care

In the past, the lack of suitable accommodation and support services for consumers with complex SPMI posed a major barrier to transitions. Through the PCLI, new opportunities have been presented that build on the qualities and attributes available in aged care providers. The partnerships established with aged care homes have been designed to enable Stage One consumers the opportunity to transition to and live in a supported accommodation service that aims to deliver person-centred care within a home-like environment. For those under 65 at the time of transition to aged care, community access supports may be available through the NDIS.

The PCLI has enabled these options to be available for consumers through the additional funding for accommodation design features, additional staffing levels, capacity building within partner services, and ongoing clinical oversight and support. That said, the partnerships have not always proceeded smoothly and there have been challenges in implementation fidelity, particularly in relation to the MHACPI model. While provider partners, in the main, continue to be committed to the program, there have been several examples of disconnect between the operational priorities of those undertaking day-to-day care delivery and the aspirations of the broader organisational management. The workforce and governance challenges experienced by the aged care sector are long-standing and well documented; therefore active, ongoing cultivation of the partnership arrangements will be required.

As reported earlier in the evaluation (*Evaluation Report 4*, Williams et al., 2019), aged care partners recognise the importance of consistency in staffing for PCLI clients but also wish to have a broader group of staff who are skilled in mental health, to give staff a break occasionally and ensure coverage at times of staff turnover or leave. This approach has



additional benefits of supporting other residents within the facilities who may not have been through the PCLI processes but nevertheless have histories of mental illness. The MH-RAC work was described as intense and unpredictable, and required specific skills and personal qualities:

*So we don't recruit [staff members] for MHACPI specifically, we want to make it so that everybody's equally skilled so we can utilise their resources, because MHACPI is intense; that's what I'm finding, it's intense ... Staff have to be psychologically present and mentally present and that on its own takes a fair bit more out of them than the physical work. (Aged care provider, 2019).*

The capacity of an aged care service to provide person-centred care is very much dependent on the facility leadership (Masso & McCarthy, 2009) that sets the organisational standards and culture, which in turn is reflected in the nature of the staff working in that service. In the main, leadership within aged care services appears to have a clear understanding of the importance of having staff with the right attributes, attitude, and experience, to deliver care to these clients.

Capacity building is one component of the ongoing relationships between PCLI Stage One teams and the MH-RAC partners. It has required enormous investment by the teams and this input is ongoing due to constant staffing and structural changes in the organisations that provide the MHACPI facilities. Formal training for aged care staff has been provided as needed, focusing on skills such as basic assessment of psychiatric symptoms, recovery-oriented practice and trauma-informed care. A large part of the capacity building is modelling by the Stage One team of 'qualities and values that we'd like to see consumers benefit from' (PCLI program manager, 2020) such as being collaborative and open in professional relationships, and respectful and empowering with consumers. Although time consuming, KIs generally saw this as a worthwhile investment which paid dividends in terms of better communication and preventing the escalation of small problems which could lead to readmissions.

PCLI Stage One teams have also established systems, plans and procedures to support the MH-RAC partners; for example, designing a process to follow if someone has to go to the ED, or developing a behaviour support plan that aged care staff can follow. There are monthly Clinical Advisory Committee meetings where potential problems can be discussed, and the PCLI clinicians also visit consumers in the MHACPI units regularly, checking with the manager beforehand whether there are any specific issues that need attention. The OPMH services and Stage One teams have worked to embed clinical oversight processes and implement pathways between inpatient and community mental health around the needs of individual consumers.

In turn, the aged care providers involved in the MH-RAC partnerships have said they appreciate the building of networks with community mental health services and the development of appropriate referral pathways. They feel better equipped to navigate the mental health system on behalf of their residents.

Previous evaluation reports have identified eight factors associated with successful partnerships between the PCLI and MH-RAC facilities:

- A shared commitment to overall program goals;
- Person-centred philosophy of care/support;
- Program infrastructure with appropriate staffing capacity;
- Agreed processes for oversight and ongoing support;
- Trust between individuals and organisations;
- Sustained and effective leadership in LHDs and aged care facilities;
- Willingness to learn from experience;
- Fidelity to the MHACPI model.

In *PCLI Evaluation Report 5* we reported extensively on the development and maintenance of the MH-RAC partnerships, and the reader is directed to that report for further information.

## 6.4 Culture of recovery

Recovery orientation is a pattern of behaviours by clinicians in their delivery of care, including:

- Promoting hope and self-determination;
- Facilitating collaboration in care planning and incorporating consumers' goals;
- Focusing on consumers' abilities and skills in daily living;
- Considering alternative treatments; and
- Involving families and carers (Waldemar et al., 2016).

The Australian recovery framework acknowledges that recovery may be a struggle for many people (Australian Health Ministers' Advisory Council, 2013). This is the case for the PCLI consumers, who are characterised by severe and persistent mental illness (SPMI), most commonly treatment-resistant schizophrenia (Killaspy, 2019). The PCLI is designed for people who also have a range of other complex needs such as cognitive impairment, developmental disorders or intellectual disability, substance use, or physical health problems, which together severely impair their daily functioning.

Personal recovery is distinct from clinical recovery and therefore can still be experienced even in the ongoing presence of symptoms of severe mental illness (Slade et al., 2008). Consistent with this definition, perhaps the most apt description of recovery we encountered during the course of the evaluation was from an experienced clinician who objected to the word itself – but not to the concept. To this KI, recovery was not about absence of illness but the presence of valued activities, social connections, quality of life, choice and control over some important things, and a glimmer of hope for the future.

*Recovery is about giving patients agency, it is treating them as people, it is stopping us from being completely paternalistic, it is saying that these people actually do function, this is – recovery to me, is the idea that a person has the ability to make choices in their life. (Inpatient staff member, 2019)*

### 6.4.1 The challenge of culture change

The introduction of the PCLI challenged the prevailing culture in mental health long-stay wards, which KIs described as 'custodial', 'over-protective' and 'paternalistic'. Previous studies have demonstrated that mental health care providers may be familiar with the concept of recovery yet struggle to translate it into practice (Waldemar et al., 2016). This finding applied also to the providers in this study. Although there was awareness of the principles of recovery orientation and person-centred care, particularly among staff members who had more recently graduated, there were serious obstacles to incorporating these principles into care delivery. The dominant belief was that certain people would stay in hospital for life, because no other services could provide the care they needed. The belief was not just shared among frontline staff but was

entrenched in clinical governance and policy. Influenced by the legacy of the attempted Richmond reforms of the 1980s, no one wanted to be responsible for discharging people out to face disadvantage and poor outcomes. Family and carers were generally happy for people to stay in hospital where they were 'safe' and 'looked after' as many consumers had experienced multiple 'failed' attempts at community living over the years, resulting in considerable stress and trauma for themselves and their families.

In this context, it was not surprising that the PCLI program managers faced resistance to the principles and processes they were introducing. Inpatient staff in the older people's mental health units were concerned that the older consumers would not survive the transition to aged care, that aged care services were not equipped or staffed to meet their needs, and that it was cruel to move people on from a place that had been their 'home' for so long, where the staff had become 'their family'. In the adult services, staff expressed concerns about potential risks to vulnerable consumers and risks posed to others. For some, no amount of evidence (or discussion of professional boundaries) could shift their attitudes, and program managers were aware of a few who actively worked against implementation. Some staff left their jobs rather than adapt to the new way of working.

It is important to understand that the collective assumptions, values and behaviours that make up 'organisational culture' endure over time because they work; that is, they are an effective response to conditions in the workplace and are maintained because they produce desired results (Carroll & Quijada, 2004). Resistance to change is not just a negative characteristic of individual staff but can actually be reinforced through organisational structures and systems (Carlstrom & Ekman, 2012). In the case of recovery orientation, organisational climates and 'change fatigue' can block acceptance of new ways of working (Gee et al., 2016). Other barriers to recovery-oriented practice identified in the literature are the physical limitations of the facilities, contradictory procedures, and a lack of resources (Waldemar et al., 2016).

Observations of the primary implementation sites early in the evaluation confirmed that the context was not conducive to recovery orientated practice. For example, at some sites staff were working in older facilities with dormitory-style sleeping arrangements, communal shower facilities and poor line of sight for observation. Similarly, the requirements of compulsory treatment orders have to take precedence over consumer choice in some cases. Further, staff who had been working at the same facility for many years had had relatively little exposure to the contemporary definition of recovery and were therefore more likely to see it in more medical terms as reduction in symptoms or stabilisation of illness (Waldemar et al., 2016). The lack of realistic options for support outside hospital made staff reluctant to talk about transitions to community because it was upsetting:

*I was aware that I didn't talk about home with people because you didn't know where they were going to go. So it was a very distressing conversation for you as a clinician, even more so for the person. (PCLI clinician, 2018)*

## 6.4.2 Progress towards a recovery culture

Despite these enormous challenges, the PCLI has contributed to fundamental change in culture at the participating sites. This is evident from key informant accounts, observations during site visits, and from the responses to the inpatient staff surveys which are summarised here (see Appendix 2 for full results). In the Round 2 survey, 88% of respondents agreed or strongly agreed with the statement, 'People with complex mental illness can and should be supported to live in the community'. For most items pertaining to recovery-oriented practice change, a majority of respondents indicated that the PCLI had contributed positively:

- 'Staff encourage and support consumers to develop and enhance links in the community' (63%)
- 'Care is more person-centred' (59%)
- 'Service provision is driven by hope and optimism for the consumer's future' (57%)
- 'Recovery-oriented approaches to care have been embedded' (49%)

The proportion of neutral responses (29-36%) suggests that a substantial minority of staff are not yet completely convinced. It is arguably more worthwhile and productive for the PCLI to continue change management efforts with this group, rather than with the tiny minority who disagreed with these statements.

In the key informant accounts of progress towards culture change, five themes were evident: active change management; accountability; reenergising rehabilitation services; providing a focal point for action; and focus on the consumer.

### 6.4.2.1 Change management

The first theme, change management, was most prevalent in the earlier interviews when key informants talked about trying to communicate the context and rationale for change; helping people integrate new processes into what they were already doing; learning from what went well or not so well; and demonstrating successful outcomes for consumers, to reassure reluctant staff and further inspire those who had embraced new ways of working. PCLI program managers and clinicians moved quickly to establish feedback mechanisms so that inpatient staff could see how people were faring post-transition. Success stories were shared informally by staff who were encouraged to visit their former patients, and disseminated more widely at Dialogue Days, in staff meetings and newsletters, and via clever innovations such as the 'postcards from home' written by former patients now living in the community. Demonstrating what is possible for people with the right supports has been an extremely valuable facilitator of culture change at participating sites.

### 6.4.2.2 Accountability

The second theme, accountability, relates to the idea that everyone is responsible for the outcomes of the PCLI consumers, from the frontline staff right up to the LHD executive and the Ministry. As one executive lead explained in the first interviews, the reality that there were people effectively 'locked away' was an uncomfortable thought; staff and managers felt helpless and hopeless about the situation, so 'they would prefer to focus on other things'. The advent of the PCLI shone a spotlight onto this small group of people with exceptionally complex needs and acknowledged that there was no easy or quick solution, it would require whole-system change, working across sectors. More recently, another key informant noted that the PCLI was 'legitimately different' from other programs because it 'challenges everyone in the room':

*I guess that's the other element is accountability. The very fact that you're doing this is serious, we take it seriously and we want to be driven by the advice we're getting. (PCLI executive lead, 2021)*

The other aspect of accountability that has arisen, mainly in LHDs without a history of retaining people for very long stays in hospital, is the issue of discharging people from inpatient stays without robust arrangements for support in place. At some of these LHDs, the organisation is now less willing to accept 'discharging to risk' without quantifying and managing the risk. The PCLI has demonstrated how this can be done and provided a means of doing this 'by having more eyes and more expertise around what is possible and what is achievable' in terms of secure, safe pathways for people with significant risks. It should be noted that although this shift is happening at some sites, at others the change efforts are just beginning and have yet to gain much traction, particularly where there is an entrenched culture of 'good enough' discharges.

Further, one key informant pointed out that it can be 'scary' for clinicians to engage in such high-level decisions and recommendations around supports, which have important implications for the consumer's life, and for which they could be held accountable in future. To minimise risks to all involved, it is essential that the work of transition planning continues to be undertaken within a contemporary clinical governance framework with guidance and ongoing professional development available and high-level backing from the LHD executive and the Ministry. Several LHDs are currently reviewing or creating a formal model of care for mental health rehabilitation, while others have recently done so; this will help strengthen and embed the framework around the PCLI transition processes. The proposed SLS services will also be crucial in enabling ongoing rehabilitation outside hospital and providing safe and supportive options for Stage Two consumers whose needs cannot be met by NDIS models alone:

*The next stage will be having those really good supports in the community to maintain the work that has been done in the inpatient setting. (PCLI program manager, 2021)*

### 6.4.2.3 'Reenergising' rehabilitation services

The third theme has been a recurring element of key informant accounts throughout the evaluation. This is the idea that the PCLI has 'reenergised' rehabilitation, injecting hope and a sense of purpose and prompting review of outdated models of care. In early interviews, the work of the long-stay rehabilitation units were described by various KIs as 'stagnant', 'on the backburner', 'not glossy' and 'not sexy', in contrast to crisis-driven acute units which were perceived as more exciting and satisfying places to work. This attitude was epitomised by one KI who explained that it was too late for most of the long-stay consumers to 'recover' because they were already institutionalised, so it was a matter of 'housing' them in the most cost effective way. The medical model had little to offer them, so it was preferable to place them in the NGO sector with access to allied health therapies, to achieve the best possible outcomes. This person was not alone among the KIs in their 'therapeutic nihilism', which is noted in the literature as a serious obstacle to consumers' recovery journeys (Killaspy, 2014; van der Meer & Wunderink, 2019). This points to the importance of the PCLI as a catalyst for re-examining the role of mental health rehabilitation services and the way they are delivered.

*I think it has provided a reset and a refresh, in terms of maybe giving hope and considering other opportunities, versus this is just the way things are and are always going to be. (PCLI clinician, 2019)*

### 6.4.2.4 A focal point for action

One of the notable achievements of the PCLI in bringing rehabilitation to greater prominence and higher status was the announcement in July 2019 of a Special Interest Group for rehabilitation psychiatry within the Royal Australian and New Zealand College of Psychiatrists (RANZCP). The first step towards recognising rehabilitation psychiatry as a sub-specialty, this resulted from engagement and collaborative efforts with the RANZCP, led by the PCLI's then medical lead. Two workshops for psychiatrists in 2020, co-sponsored by the PCLI and the RANZCP, were well attended. Genuine transformational change in health systems cannot proceed without endorsement and leadership from medical professionals (Best et al., 2012). The collaboration between the PCLI and the RANZCP has laid foundations for building a community of psychiatrists with recognised expertise in treating SPMI and complexity. The hope is that rehabilitation psychiatry in Australia will begin to attract clinicians who favour reform and will be 'seen as a speciality that requires energy and enthusiasm'.

The PCLI has also been a rallying point for allied health and nursing staff who had long felt change was needed but perhaps had become discouraged by lack of support in the workplace and lack of resources in the community. The PCLI processes encourage multidisciplinary care planning, valuing the contributions of all team members, which 'galvanised and outed' a group of staff who had always wanted to work in more recovery-oriented ways and linked them with like-minded people and with the tools and resources they needed. As discussed above, not all staff were pleased with the changes. Nevertheless, the PCLI undoubtedly 'created a different workplace' for nursing, allied health and medical professionals

because it created movement of long stay consumers out of the units, and new people moved into the units, arriving with (on average) higher acuity of mental illness and different treatment dynamics. While this was 'a nuisance' for some staff who preferred the quiet life, for others it created more interest and challenge in their work. Responses to change varied across units within hospitals, depending on the attitudes of middle managers and cultural beliefs about workload. The sustainability of the change will depend, to some extent, on whether resourcing keeps up with the increased workload generated by the flow through these units.

### 6.4.2.5 Focus on the individual consumer

The fourth theme was a greater focus on the consumer as an individual, and redefinition of what constitutes a good discharge plan. This theme was most prominent in the later interviews. Several KIs noted a cultural shift towards thinking and talking about a person's strengths and needs, looking critically at service providers and assessing their capacities, and trying to find 'the right service that fits'. One explained that at their service, people were generally discharged when they were 'well enough' to services that were 'good enough'; that is, the focus was on their biological symptoms and whether they had resolved sufficiently that they could function outside hospital. According to this KI, the PCLI was promoting a shift towards a person being 'well set up' in the community: well integrated and cared for, in a holistic sense.

These observations suggest that staff are internalising the concept of recovery and applying it in their work to a greater extent than previously. The presence of the PCLI clinicians is, however, still an important prompt to this type of thinking. One KI talked about a colleague gently bringing the treating team's attention 'back to the person' and reminding them about the purpose of their work, which was to make sure the person was able to live well in the community, 'and everyone wins'. Another said there was now more information on every person coming through the PCLI pathway, compared with previously, because interactions were more meaningful. Success came from a personalised approach, investing the time to understand the person well and know 'what makes them tick':

*I feel it's just one person at a time. One interaction at a time, that slowly builds momentum. (PCLI peer worker, 2021)*

*So you could see this evolution of staff being more curious about the consumers and actually really investing that time to go, well, what is their story? ... So what got them to this point and how do we get them beyond this point? (PCLI program manager, 2021)*

*So even if they're not using the assessment, they're potentially asking slightly different questions. They're doing more targeted questioning, targeted interventions to support that recovery process. So whether the assessments have been part of that, I don't know. Or is that just the natural capacity building of staff that's occurred over time? I don't know. I think -but potentially we're a bit more aware and effective in how we're working with individuals, because there's a more targeted pathway. (PCLI clinician, 2021)*

KIs acknowledge that the changes are not all due to the PCLI, other service developments have happened concurrently that positively affected culture and practice. Nevertheless, the PCLI is seen as having made a substantial contribution to challenging outdated ways of working and offering more recovery-oriented alternatives. It has empowered PCLI clinicians, peer workers, and others to ask questions and provoke discussion:

*I think we achieved that by just having a PCLI clinician in the room saying, 'This person doesn't have to live in hospital.' And then gradually convincing individual members of the team and dragging teams along. ... certainly the PCLI role gives you a lot more scope to go and sit in any care review and say, oh, why is that? Why do you say that this person can't live outside of the hospital? Why are you saying they need locked accommodation and therefore narrowing your scope to the point where the person can't leave the hospital? (PCLI clinician, 2021)*

# 7 Economic evaluation

This chapter presents findings on whether the PCLI Stage One has resulted in value for money and improved system efficiency, taking into account benefits for individuals who received the PCLI interventions. The scope of the analysis is limited to Stage One because Stage Two PCLI-funded service developments are not yet in place. Therefore results presented in this chapter pertain to **PCLI Stage One** only.

The analysis examined the costs of care for Stage One consumers who had been discharged from hospital at 31 December 2020 (n=156). Detailed information on the methods

for calculating the costs can be found in Section 2.2.4. In summary, four main types of costs were considered: publicly funded health care in hospital and community settings; aged care funding from the Commonwealth; funding provided by NSW Health to MH-RAC partners; and funding for disability supports through the National Disability Insurance Scheme (NDIS). Each of these costs are estimated below, and the chapter concludes with a comparison of costs during the inpatient stay with costs following discharge into community living through the PCLI.

## 7.1 Costs of hospital-based care

The first step was to estimate the ongoing cost for the **index stays** (for consumers with multiple hospital stays, this was the stay that ended in transition to community – see Section 2.2.2 for further information). The ongoing cost for the index stay is an indicator of the costs that would have been incurred had the consumers remained in hospital. The best available estimate of cost was to use the *per diem* values for long-stay outliers of the index stay's last episode. For the 156 PCLI Stage One consumers who had been discharged from hospital it was calculated that the average *per diem* cost was \$969 (SD \$69) which multiplies to an annual average cost of \$353,685 (SD \$25,185). By the end of December 2020 the average time since transition from hospital was 845 days (SD 505) or almost two years and four months.

Three types of post-discharge, hospital-based care costs are relevant to the analysis: subsequent readmissions, ED presentations, and use of community mental health services.

There were 69 (44.2%) Stage One consumers who had at least one hospital inpatient stay subsequent to transition, comprising 960 readmissions<sup>6</sup> with an average length of stay of seven days (SD 42) and an average cost of \$7,903 (SD \$42,910). Overall, the annual cost for readmissions to hospital per PCLI Stage One consumer was \$21,008.

Eleven (7.1%) Stage One consumers presented to the ED at some point after transition to the community, comprising 33 ED presentations.<sup>7</sup> All but two presentations arrived by ambulance. The average cost per ED presentation was \$846 (SD \$308). As costs of ambulance transport were not available, it was assumed that the cost associated with an ambulance transport to ED was the ratio between government contributions and total number of patients (Table 19).

When ambulance transport was added, the average cost per emergency department presentation was \$1,740 (SD \$419). The annual cost for emergency department presentation (including ambulance transport) per Stage One consumer was \$159.

6. Cost analyses undertaken for PCLI Evaluation Report 5: Stage One Outcomes (Williams et al., 2020) were based on a narrower cohort definition and a shorter timeframe therefore we would not expect to replicate those findings exactly here.

7. Further details about consumer journeys after transition are provided in Section 4.5.

**Table 19 Ambulance service activity and expenditure**

Financial year	Government grants/ contributions (2019-20 \$)	Total patients	Average per Patient (2019-20 \$)
2015-16	704,400,000	839,909	839
2016-17	762,500,000	842,947	905
2017-18	835,900,000	866,688	964
2018-19	844,900,000	904,278	934
2019-20	873,400,000	901,845	968

**Note:** No data are yet available for the 2020-21 financial year so it was assumed that the average government revenue per patient was the same as in 2019-20 (\$968).

In total, there were 13,573 community mental health services recorded, which cost on average \$524. Stage One consumers had on average 87 (SD 107) services, of which 42.5% involved a face-to-face contact with the consumer. Ten persons (6.4%) did not receive any services from community mental health teams. The annual cost for community mental health care per PCLI Stage One consumer was \$19,693.

## 7.2 Costs of aged care services

Almost all Stage One consumers transitioned to residential aged care, apart from three who transitioned to private residences and received home care services.

The Commonwealth provides funding ('basic care subsidy') for permanent residents in residential aged care facilities to support the costs of providing personal and nursing services. The amount of the subsidy is based on the assessed need

using the Aged Care Funding Instrument (ACFI) (Aged Care Financing Authority, 2021). The ACFI covers the domains activities of daily living, behaviour and complex health care. Based on the cumulative result of the 12 ACFI questions, each domain is scored as nil, low, medium or high (Australian Government Department of Health, 2017). The amount of the basic care subsidy is the sum of the three domains (Table 20, Australian Government Department of Health, 2021a).

**Table 20 Daily ACFI subsidy**

Level	Activities of daily living	Behaviour	Complex Health Care
Nil	\$0.00	\$0.00	\$0.00
Low	\$38.28	\$8.75	\$16.98
Medium	\$83.36	\$18.14	\$48.37
High	\$115.49	\$37.81	\$69.84

These rates were applicable from 1 July 2020 to 30 June 2021

(<https://www.health.gov.au/resources/publications/schedule-of-subsidies-and-supplements-for-aged-care>).

Consequently, daily ACFI funding can range from \$0 for residents with nil, nil, nil to \$223 for residents with high, high, high. The national average was \$185 in December 2020 (Australian Government Department of Health, 2021b).

ACFI scores for Stage One consumers who transitioned to MH-RAC facilities (MHACPI units or SRACF) were available from these facilities' routine reporting to the Ministry. Across these services the average daily ACFI subsidy was \$155, with MHACPIs receiving higher subsidies (\$164) than SRACFs (\$110). No such data was available for consumers who transitioned to mainstream or generalist aged care. For the

purposes of this analysis it will be assumed that the average daily ACFI funding provided by the Commonwealth was \$155 for all 153 (98.1%) PCLI Stage One consumers who transitioned to residential aged care, or \$56,575 per annum. Hence, the annual cost for residential aged care per Stage One consumer was \$55,487.

To facilitate the transition of PCLI Stage One consumers to residential aged care, partnership agreements were signed between NSW Health and six residential aged care services. These were put in place to formalise the relationship between the LHDs and the services and to provide additional funding

with the aim of improving staffing levels and preparedness to support people with SPMI and complex needs. Two types of services were contracted, MHACPIs and SRACFs. Table 21 provides an aggregated view over the funding provided through the partnership agreements. Outside the PCLI,

NSW Health contractual arrangements exist with two other residential aged care services, one MHACPI and one SRACF. The funding provided to these services has not been included in the costing.

**Table 21 Overview of partnership agreements**

	MHACPIs	Specialist RACFs
Number of services	3	3
Number of operational / funded places <sup>8</sup>	30	25
Recurrent funding for 2020-21 <sup>9</sup>	\$986,163	\$853,786
Annual funding per place	\$32,872	\$34,151
Daily funding per place	\$90	\$94

The annual funding per place was calculated as total funding divided by number of operational or funded places. The corresponding daily funding amount is one 365th of the annual amount. Since the commencement of the PCLI, 42 (26.9%) PCLI Stage One consumers have been transitioned to MHACPI units and 21 (13.5%) were transitioned to SRACFs. For the purposes of this analysis it will be assumed that transitions to MHACPI units have annualised cost of \$32,872 and transitions to SRACFs cost \$34,151. Hence, the annual cost of NSW Health subsidies per consumer was \$8,850 in MHACPI units and \$4,597 in SRACFs.

Through home care packages the Commonwealth provides funding for a range of services and equipment that allow older people to live in private residences. These include personal services, support services, care related services and care management (Aged Care Financing Authority, 2021). Funding ranges from level 1 (basic care) to level 4 (higher care), see Table 22.

**Table 22 Home care package subsidy**

Home Care Package Level	Daily subsidy	Annual subsidy
Level 1	\$24.46	\$8,928
Level 2	\$43.03	\$15,706
Level 3	\$93.63	\$34,175
Level 4	\$141.94	\$51,808

These rates were applicable from 1 July 2020 to 30 June 2021 (<https://www.health.gov.au/resources/publications/schedule-of-subsidies-and-supplements-for-aged-care>).

Three (1.9%) Stage One consumers were transitioned to private residences and received home care. Unfortunately, the cost of their care or their funding level is unknown. For the purposes of this analysis it is assumed that consumers receive funding according to level 3 (\$34,175). Therefore, the annual cost of home care per Stage One consumer was \$657.

8. Fifty beds in Specialist RACFs have been contracted, 25 of which will become available after redevelopment in 2023.

9. The funding amounts do not include unspent funds that were returned to NSW Health.



## 7.3 Costs of disability-related support

Information on NDIS status, types of support and funding for individual PCLI consumers was unavailable. Based on conversations with the Ministry PCLI team and residential aged care providers it is assumed that up until 2019 all Stage One consumers aged less than 65 would be eligible for NDIS while for 2020 only 75% of Stage One consumers aged younger than 65 received NDIS supports. All of those would have a primary psychosocial disability. Although the content and amount of individual funding packages is unknown, it can be assumed that the types of supports received by Stage One consumers would include mental health recovery-oriented services aimed at increasing independence and social participation in the community.<sup>10</sup>

The NDIA produces a quarterly report to disability ministers which provides national and state-specific snapshots of the performance and operations of the NDIA. For NSW, it is reported that the average annualised committed supports for participants with a primary psychosocial disability was \$91,134 in the second quarter of 2020/21 (NDIA, 2020).

There were 60 (38.5%) PCLI Stage One consumers aged younger than 65; 46 were transitioned up until the end of 2019 and 14 during 2020. For the purposes of this analysis it will be assumed that annualised NDIS support was \$91,134 for Stage One consumers aged younger than 65 who transitioned prior to 2020 and \$68,351 for transitions in 2020. For all Stage One consumers this equates to \$33,007 annually for NDIS support.

## 7.4 Total costs

Having estimated in-scope costs for this analysis, the different components can be brought together (Table 23). The highest unit cost is for NDIS support followed by ACFI funding. The

lowest unit cost is for community mental health services; however, these services are provided relatively frequently over the course of a year.

**Table 23 Overview of care cost by type**

	Unit	Cost per unit	Average annual cost per Stage One consumer
Index stay	additional day	\$969	\$353,685
Residential aged care	year	\$56,575	\$55,487
MHACPI	year	\$32,872	\$8,850
SRACF	year	\$34,151	\$4,597
Home care package	year	\$34,175	\$657
NDIS	year	\$91,134	\$33,007
Readmission to hospital	inpatient stay	\$7,903	\$21,008
Emergency department presentation	ED presentation	\$1,740	\$159
Community mental health service	service event	\$524	\$19,693
<b>Total annual cost per PCLI Stage One consumer</b>			<b>\$143,459</b>

Across the PCLI Stage One cohort the average cost of care incurred while living in the community was \$143,459. This amounts to 59.4% reduction compared to the average cost during their index stay.

Costs of care depend on the type of services provided in the community. Table 24 shows the annual estimated cost for the three main types of transition destinations with and without NDIS supports, including costs of hospital-based care (e.g. readmissions).

Transition to community living led to large reductions in average costs regardless of discharge destination and age, ranging between 37.0% and 72.5%. Costs were lowest for consumers who transitioned to a generalist RACF and highest for consumers who transitioned to an SRACF with NDIS support.

10. <https://www.ndis.gov.au/understanding/how-ndis-works/mental-health-and-ndis>

**Table 24 Cost of index stay compared to living in community**

	Annual cost	Cost reduction versus index stay (%)
<b>Index stay</b>	\$353,685	
PCLI Stage One consumer in Generalist RACF	\$97,435	72.5
PCLI Stage One consumer in MHACPI	\$130,307	63.2
PCLI Stage One consumer in SRACF	\$131,586	62.8
PCLI Stage One consumer in Generalist RACF with NDIS	\$188,569	46.7
PCLI Stage One consumer in MHACPI with NDIS	\$221,441	37.4
PCLI Stage One consumer in SRACF with NDIS	\$222,721	37.0

Univariate sensitivity analyses were undertaken to test the robustness of results to changes in input parameters. The estimated price of all parameters was varied by  $\pm 10\%$ . This can be interpreted as a change in price or utilisation, or a combination of both. None of the variations led to cost being higher than the index stay cost. The largest difference

was seen when the cost of the index stay was increased or decreased. This changed the cost reduction by up to 7 percentage points. Changes in ACFI or the NDIS funding led to a change in cost reduction of between 1.6 and 2.6 percentage points. Changes in all other parameters had very minor impact.

## 7.5 Summary of cost comparison

In summary, during their long stay in hospital the average annual cost of care per PCLI Stage One consumer was \$353,685. After the transition into residential aged care the average annual cost of care was \$143,459, which was a reduction by 59.4%. Taken together for the 156 PCLI Stage One consumers who have transitioned to residential aged care or who receive home care this amounts to a reduction in cost for their care of \$32.8M annually.

---

# Part 3

Sustainability

Discussion and recommendations

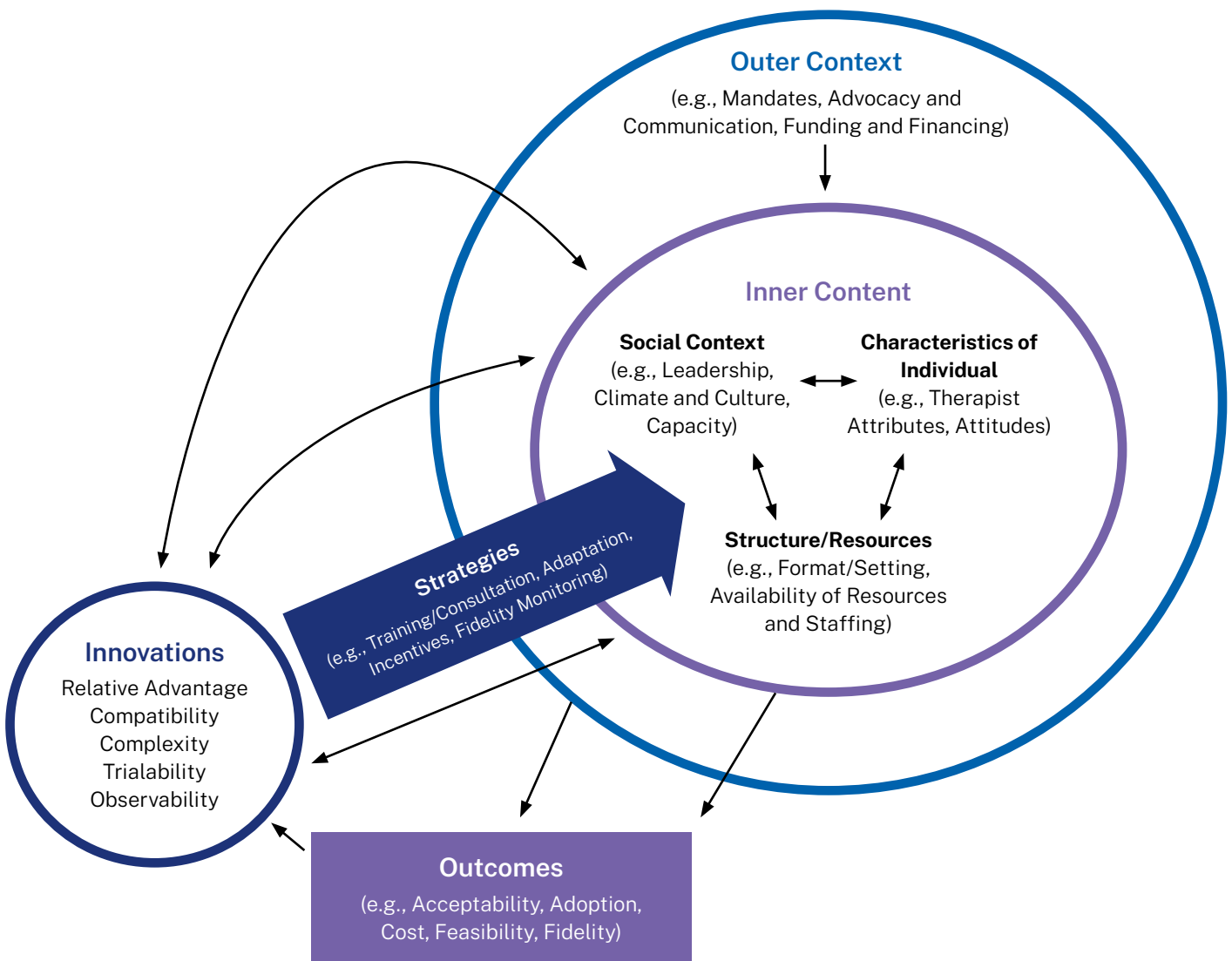


# 8 Sustainability

The overarching goal of the PCLI is to achieve system reform that delivers improved outcomes for consumers, is sustainable and embeds continuous improvement within health services. To achieve this, it has employed a mix of highly centralised program structures and processes, facilitated by a distributive leadership approach that enables implementation to be contextualised at the local level. Effecting change in health services, however, is not a linear process, and the

implementation science literature has identified numerous factors which impact on change (Damschroder et al., 2009, Greenhalgh et al., 2004). Recent analysis of knowledge translation processes within mental health services has identified four 'levels of influence' that contribute to successful and sustainable implementation of practice change, (Aarons et al., 2011; Stirman et al., 2012; Figure 10).

**Figure 10 Multilevel factors in implementation and sustainability (Stirman et al., 2012)**



The success of the PCLI innovation and the individuals involved in implementation have already been discussed (Chapter 6). Characteristics of the innovation and key actors delivering the innovation are two of four crucial influences on sustainability. We start this chapter with a discussion of the role of the 'inner context' in facilitating and sustaining change associated with the PCLI, in particular the leadership and governance

processes, clarity in program parameters and strengthening of community mental health capacity. This is followed by a discussion of the broader policy drivers of the 'outer context' regarding mental health reform, aged and disability services, and 'value-based health care'.

## 8.1 Embedding PCLI processes

This section examines the sustainability of the PCLI ‘inner context’: the new processes introduced into NSW mental health services in order to effect timely transition of long-stay patients, and those at risk of long-stays, into supported and sustainable community living.

### 8.1.1 Strategic leadership and governance

The capacity for the PCLI to achieve system reform has been enabled by the clear objectives and accountabilities of the program and the collaborative approach to program development, implementation and oversight. The governance arrangements have ensured all stakeholders are cognisant of the strategic priority of the program through the inclusion of steering committee processes and cascading KPIs across the Ministry, LHD executive, inpatient, outpatient and PCLI teams. The change management framework –communicated via the quadrant model (Figure 2) -has been important in signalling the rigour and evidence underpinning the program:

*The thing that's certainly impressed me beyond measure was the model ... it overlaid a rigorous approach to the science, to how we might work with consumers who have traditionally had a tough time of it in public mental health services (PCLI executive lead, 2021)*

Perhaps the biggest enabler for the program has been the personal commitment of those in leadership roles within the Ministry who are ‘passionate about patient experience, patient stories ... selling the person rather than a problem’ (PCLI program manager, 2017). Similarly, the involvement of senior medical personnel at Ministry level has added impetus to the program, particularly in situations where local medical leaders may be reluctant to engage with the program (PCLI executive lead, 2021).

Engaged leadership has extended through the Ministry PCLI team and LHD executives at most implementation sites, resulting in PCLI clinicians feeling supported as ‘you’ve got someone who wants to help you overcome those silly barriers that, ... as a clinician, you just couldn’t overcome’ (PCLI clinician, 2018). Strong support at LHD executive level has been seen by KIs as a factor in facilitating change in practice and culture. Strategies such as including the PCLI in the LHD’s strategic plan and as an agenda item for core meetings have helped by keeping the initiative visible, ensuring it was taken seriously. Establishing clear guidance on the aims of the program has helped facilitate staff engagement:

*... the executive have been really clear in their direction that it is not just about transitions and transition numbers. It was about achieving those sustainable transitions and making sure everything is in place. So I think that direction is –I mean for culture change –is really important, because some of that has to come down [from the executive] for people to come on board. (PCLI clinician, 2018)*

From the outset, evaluation findings have been interpreted in the light of the change management literature. The most influential model, which is based on complexity theory, has been the ‘five simple rules’ for transformational change in health systems (Best et al., 2012; see also Chapter 9). This model emphasises the value of designated and distributed leadership and governance processes, and consistent messaging regarding the rationale, responsibilities and accountabilities across inpatient and outpatient mental health services.

Medical leadership and collaborative monitoring and measurement are two other aspects of the model which have been incorporated into the PCLI. One of the next steps for the program will be engaging with psychiatrists around key indicators of outcomes in rehabilitation and recovery (Ministry PCLI team, August 2021). This will build on the growing medical engagement and use of key performance indicators (KPIs) and improvement measures as leverages for system change. KPIs have been successfully incorporated within LHD service level agreements to drive change in practices and processes at the local level, by requiring LHD chief executives to report on progress at quarterly governance meetings. A KPI regarding the *number of mental health consumers with a length of stay of 365 days or longer* (Ministry PCLI team & Suzanna Rona, 2021) has included within LHD service level agreements and proved so effective that it has recently been changed to an ‘improvement measure’, meaning it is only addressed if an issue arises. Importantly, the Ministry has the capacity to escalate the measure back to a KPI if developments fail to progress as planned.

In regards to the PCLI, the logic follows that if practices have changed, fewer people should reach the 365-day mark in their stays; this should be particularly the case for people identified earlier in their stays as potentially complex discharges and in need of PCLI supports. Thus, performance against this measure could indicate the success of system reform as well as providing information to guide program planning (Ministry PCLI team and Suzanna Rona, 2021).

The ideal indicators are meaningful for services and for individual service users:

*So if you can reduce unnecessary hospitalisation and reduce longer stays in hospital that will have good system outcomes and good individual outcomes. (Ministry PCLI team, August 2021)*

## 8.1.2 Defining the target group

One of the strengths of the PCLI has been the very clear inclusion criteria established at the outset: people with severe and enduring mental illness and complex needs who had been inpatients for greater than one year (365 days) and for whom existing pathways out of hospital were not working. Investments in clinical expertise, together with new accommodation and support services, have facilitated the transition of these long term inpatients to less restrictive environments that offer recovery-focused supports. The initial PCLI cohort were, in general, fairly stable in terms of presenting symptoms with limited need for engagement of behaviour specialists to support transition. Subsequent cohorts, however, have far more complex needs predominantly associated with comorbidities such as past trauma, cognitive impairment, drug and alcohol use, which means they have sometimes ‘burnt every bridge’ in terms of family and extended relationships and therefore have a ‘tenuous existence’ in the community. Transition processes for these consumers involves a far greater degree of risk management, with limited services available:

*... to take on that level of risk ... (and) implement quite complex behaviour support plans to ... mitigate and reduce behaviours of concern (PCLI executive lead, 2021).*

As the program has been successfully rolled out, the focus of PCLI clinicians has shifted and at some sites now includes consumers who are at *risk* of long hospital stays, such as people living in the community who are experiencing recurrent short-stay admissions because of their complex needs. Overall, referrals to the PCLI team are now tending to occur at a much earlier point in time of an inpatient stay, generally within two to three months of admission, and have a higher level of complexity.

*In that first wave we just didn't have the, sort of, unique presentations that we get with some people now ... with super complex families or super complex trauma histories, or just super complex stuff... random risky (behaviours) that are really hard to manage (PCLI executive lead, 2021).*

For some of the LHDs that were not included in the first phase of implementation, reviews of patient data and case notes have been undertaken to identify consumers at risk of frequent presentations to hospital. While these consumers do not meet the formal criteria of a consecutive length of stay, the impact of frequent readmissions is similar, described by one PCLI clinician as ‘pinball institutionalisation’ due to consumers bouncing between health services. Similar approaches have been established for LHDs with high levels of homeless and/or transient populations and/or where consumers may attend inpatient units or emergency departments across different LHDs.

The ability of LHDs to adapt the targeting of consumers according to contextual factors and/or emerging challenges has been one of the strengths of the program. The changing profile of consumers in terms of complexity, comorbidity and risk, however, comes with additional challenges for community mental health as well as aged and disability services. These need to be resolved if consumers are to be able to live successfully and sustainably in the community.

## 8.1.3 Infrastructure and tools to inform clinical care

The PCLI ‘Getting to Know You’ processes (described in Section 1.2.5.2) were inspired by early experiences of the pilot program at Bloomfield Hospital, where staff discovered that key pieces of information were missing, like the fact that a person needed spectacles or had a sibling who might not realise they were still alive. Thus, comprehensive assessment and engagement processes became a standard part of the PCLI approach.

Resources were developed to support implementation, notably the *Planning, Assessment and Follow-Up Guide* (NSW Health, 2020a) for clinicians, and the *Journey to Home Guide* (NSW Health 2020b) for use by people transitioning from hospital to the community along with their families and treating teams. Both resources are highly regarded by KIs and have been updated as needed as the program has unfolded. Having access to a range of tools, and encouragement to use them, has enabled staff to fill in gaps in people’s stories and discover their goals, strengths and capacities, as well as identifying their support needs.

The PCLI ‘Getting to Know You’ processes have contributed positively to successful transitions of numerous long-stay consumers. The value of the assessments derives from both the processes involved as well as the outcomes. The conversational approach breaks down formalities and allows for a ‘therapeutic’ interaction with consumers, enabling staff to ‘unearth’ information by asking questions that ‘otherwise wouldn’t have been asked’ and challenging assumptions regarding consumers’ capacity for recovery. Together these processes have enabled the development of tailored transition plans more likely to succeed in the community.

PCLI clinicians have demonstrated growing confidence in adapting assessments to the particular needs of their consumers and local service context. Several LHDs report discussions with consumers now commence at around the 180–200 day mark of an inpatient stay. In some cases, PCLI clinicians are called in earlier, particularly when treating teams have mixed views regarding their capacity to return to the community. A number of LHDs now engage with patients in discussions regarding discharge from the time they enter hospital, as a way of framing the admission as an interim rather than long-term arrangement.

### 8.1.3.1 Challenges of embedding assessments

Australia was one of the first countries in the world to introduce routine outcomes reporting for mental health care (Burgess et al., 2015) and is one of only five countries that regularly collect patient-reported data (outcomes, experiences, or both) in mental health settings (de Bienassis et al., 2021). The challenges of introducing mental health assessment tools and embedding them in routine practice are widely acknowledged. For example, a study of clinicians’ attitudes to what we now refer to as the ‘MH-OAT’ collection, two years after its introduction, found they were equally divided on whether the tools were useful (Callaly et al., 2006). It took at least a decade for those involved in implementing routine outcome measurement to be able to claim that it was ‘embedded in service delivery’ (Burgess et al., 2015, p. 264). In

this context it is unsurprising that the PCLI toolkit is not yet fully embedded in LHDs.

Nevertheless, it is worth looking closely at the evidence from this evaluation to understand what changes might be made to improve the situation. Bringing together qualitative and quantitative sources, we can see that there may be opportunities to improve uptake and ensure a greater proportion of PCLI consumers experience the potential benefits of comprehensive, structured assessment.

The quantitative evidence shows that many transitions have taken place without the use of assessments in care planning. At 30 June 2020, only 24% of second-wave consumers had been assessed and 39% had a transition plan, whereas 61% had been transitioned to the community (Ministry PCLI team & Suzanna Rona, 2021). Transitions to community have always taken place and would continue to do so even without the PCLI, albeit perhaps with less attention to detail. However, it does mean that a substantial proportion of consumers identified as complex and in need of specialised support are missing out on the potential benefits of the PCLI assessment and care planning processes which are designed to ensure sustainable transitions and optimal outcomes.

The qualitative evidence suggests reasons for these gaps in the dataset. The PCLI assessment suite has been a thorny issue for LHDs from both an operational and cultural perspective throughout the evaluation. KIs cite resource constraints within health services as a key barrier to implementation, particularly given the overall number of assessment tools, the number of consumers (particularly the burgeoning second-wave cohort), the need to update training or provide it for new staff, duplication of tools already used in clinical practice and variable access to clinical specialties required to complete some of the tools. Concerns were raised about the practicality of implementing the tools and their clinical utility, particularly in those units where patient discharges were traditionally determined by 'professional judgement'. The lack of integration between the program database and existing patient records was highlighted as a risk, requiring double data entry to enable treating teams to have access to the assessment outcomes. Duplicate record keeping is still occurring, with LHDs using spreadsheets to keep track of consumers and their progress towards transition.

### 8.1.3.2 Barriers to the use of PCLI tools

Some early assumptions have been challenged by the evidence from this evaluation. These assumptions appear to have created barriers to tool use. The 'Getting to Know You' processes were designed primarily for use with people who had experienced very long stays in hospital, and are based on the assumption that a lack of knowledge about those individuals had contributed to long stays. The decision to adopt a standard suite of tools assumed that a similar approach could be applied across the program with similar effectiveness at different sites. Some sites, however, already had cultures of assessment and their own sets of routine tools in place which they were reluctant to discard or substitute with the PCLI tools. More commonly, the PCLI tools have had to compete for priority with other assessments required for specific purposes. There is a strong incentive for clinicians to complete the NDIS assessments, as these are needed to obtain

funding for consumers' disability supports. Similarly, the MH-OAT collection is mandated (Burgess et al., 2015). However, the immediate benefit of completing the PCLI-specific tools has been less obvious to many people at most of the sites.

This is related to another early assumption, that information and communication about the importance of the tools would be sufficiently persuasive to change practice. The experience of previous implementations of routine tools suggests this may have underestimated resistance. In their review of the first decade of the MH-OAT collection, Burgess and colleagues (2015, p. 273) noted that health professionals had 'over time ... come on board':

*...largely because of the gradual process of demonstrating that outcome measurement can be useful for clinical practice, service planning and workforce development. That is not to say that everyone is now an enthusiast, and creating the shift from resistance to acceptance has required significant investment of energy.*

Despite extensive communication efforts throughout the program to date, there remains a lack of clarity around the purpose of the tools, which is related to their inclusion as a program KPI in 2016. The KPI – which required the 'comprehensive assessment' of all initial cohort consumers by a given date – provided impetus for implementation, but also inadvertently encouraged assessment for the sake of data collection alone, often dismissed as a 'tick-box exercise'. Further, the workload burden generated by the requirement to conduct the baseline assessments became a source of tension between the PCLI and inpatient staff and cast a long shadow over subsequent implementation efforts.

It is a brutal truth that "no outcomes measure is of any value unless it is completed at least twice" (McDonald & Fugard, 2015). In the case of the PCLI tools, it has proven very difficult to obtain follow-up measures reliably after consumers transition to community living, and thus to demonstrate outcomes (that is, changes in health status). KIs have highlighted various barriers associated with this task, including 'losing track' of individuals who are discharged by community mental health teams earlier than the expected two-year follow-up. Some consumers prefer not to engage with the follow-up assessments. One KI said it did not 'sit comfortably' with them to be asking people to complete assessments if they had been discharged from community mental health teams and were therefore no longer a mental health patient.

There is a high likelihood that those who currently receive PCLI follow-up assessments are systematically different from those who do not. They may be, on average, more unwell – or more cooperative – or located in LHDs with relatively well-resourced community teams, just as a few plausible examples. Any consistent differences between those with and without follow-up data will tend to bias outcomes.

Finally, there is a large number of tools in the PCLI toolkit. The PCLI suite of assessment tools was selected by an expert group and the range of tools was chosen to encourage a multidisciplinary, person-centred approach to care planning. Although most KIs were generally in favour of assessment, they tended to describe the PCLI suite as far larger than necessary and creating 'overload' when combined with the MH-OAT collection and other locally used tools:

*I suspect strongly that the program has underestimated the weight of that assessment schedule that they provided, on top of the existing assessments that are required to be done as a part of ordinary practice. (PCLI executive lead, 2017)*

### 8.1.3.3 Improving the use of the PCLI assessment toolkit

It would be nice to be able to say the barriers described here have eased over time, but these kinds of comments have been made throughout the evaluation and still continue, indicating that people remain unconvinced about the rationale for, or extent of, the PCLI suite of assessment tools. One KI recently summed up the situation by saying that they could see the value in capturing information and showing the strengths and needs of individuals through the use of assessment tools, but wanted to see:

*... a more desirable assessment suite for clinicians to be able to access to support and understand people better. (PCLI program manager, 2021)*

The mention of 'access' in this quote underlines the urgent need to make the tools and their scores more readily accessible and useable in routine practice.

### 8.1.4 Sustainable practice change

All those associated with the PCLI—from the Ministry PCLI team through to executive leads and program managers, peer workers and clinicians—have worked hard to develop, implement and establish new ways of working. The surveys of front-line staff offer another viewpoint on the extent to which this has been achieved.

Findings from the second staff survey show that front-line inpatient staff across the six primary implementation sites have observed changes in practice since the advent of the PCLI. The survey questions acknowledged that not all the change they might have witnessed would be due to the PCLI. Instead, the goal was to detect any and all changes noticed during the implementation period. More than half of the respondents agreed or strongly agreed with the following statements on practice change:

- Continuity of care between inpatient and community settings has improved (72%)
- Access to clinical and support services and permanent accommodation options has increased (66%)
- Care coordination between service providers has improved (57%)
- Staff are more aware of available clinical and support services and permanent accommodation options (54%)
- Identification of individuals at risk for long-stay admission has improved (52%)

A substantial number of respondents selected a neutral response to these items which may indicate ambivalence. There were low levels of endorsement for two items—consumers being involved in planning their own care, and staff

understanding how to support self-directed care—highlighting key areas for further development (see Appendix 2 for full results).

Less than half of the respondents were confident that changes brought about by the PCLI were sustainable, indicated by levels of endorsement (agree or strongly agree) for these items:

- The changes resulting from the PCLI are sustainable (48%)
- Our mental health service has greater capacity and resources to minimise long stays in hospital as a result of the PCLI (48%)
- The PCLI has changed attitudes to long-stay mental health consumers (46%)

The survey findings complement the other sources of evidence and confirm the perception by KIs that although there has been substantial progress towards embedding the PCLI processes in routine practice, there is still considerable work to do.

### 8.1.5 Strengthening community mental health care

The success of the PCLI is premised on the ability of community mental health teams to support consumers with complex SPMI needs living in the community. Under the program, consumers are effectively shepherded from their long-stay inpatient settings to their new homes with the support and oversight of highly skilled clinicians and MDTs, whose remit includes service development and capacity building activities with community partners. The handover of responsibilities from the PCLI to community teams is facilitated through the joint participation on clinical oversight processes and expected to occur once the consumer is settled. To date, OPMH community teams have played a key role in providing ongoing support to PCLI Stage One consumers transitioning to aged care services. Supporting consumers within disability services, however, has been more difficult due to the variability of services provided under the NDIS. Barriers that continue to need addressing include resourcing levels in community teams, lack of clarity regarding roles and responsibilities for tasks (e.g., capacity building with community partners, PCLI assessments) and limitations of community partners' abilities to support consumers with high levels of complexity and comorbidity.

Several KIs noted that community teams were 'overburdened' and 'under the pump' due to staff shortages and turnover, and that communication pathways between inpatient and community settings were often not robust. Concerns were raised that within a resource constrained environment, community teams may perceive consumers living in group homes and in receipt of NDIS funding as less of a priority compared to 'people on your books who are living in their own house with less services' (PCLI program manager, 2021). However, the accommodation and psychosocial support provided under the NDIS does not provide the level of expertise needed for these consumers. Further, both disability and aged care services are characterised by staffing profiles that are



relatively low skilled and highly casualised, which precludes the ability to ensure consistent and coherent individualised support is available to consumers following transition. One interviewee described mental health within NDIS funded services as ‘a real political football’ and in the absence of any major policy changes, it is clear that ‘the goodwill and the unfunded support of health districts to provide this capacity development to service providers’ will fall to community mental health teams, consequently:

*... there needs to be that additional investment in to communities into having very specialised community teams for complex and persistent mental health ... we’re going to have increasing numbers of people who require case management, if not for the entirety of their lives, for significant periods. (PCLI program manager, 2021)*

With the shorter lengths of inpatient stays and increased complexity of consumers living in the community, it is clear that there will be an ongoing need for the provision of clinical and behavioural support services from community mental health teams.

## 8.2 Policy alignment

Within the implementation science literature, the policy environment provides the ‘outer’ layer that sets the overarching framework for, and driver of, change. For the PCLI, this includes the mental health, aged care and disability reforms at the national and NSW levels, resources provided to implement and embed organisational change, within the context of the value based health care agenda of the NSW government.

*... whole-of-community, whole-of-life and person-centred approach to mental health; providing easily navigated, coordinated and balanced community-based services that are offered early to meet each individual’s needs and prevent escalating concerns (Australian Government, 2021).*

### 8.2.1 Mental health care reform

The PCLI is a key strategy of the NSW Government’s mental health reform agenda, as outlined in the NSW Mental Health Commission’s report *Living Well: A Strategic Plan for Mental Health in NSW 2014–2024*. Recurrent funding has been provided in recognition of what the Mental Health Commission of NSW notes is ‘the vital role that home plays in recovery and healing from mental health issues’ (Mental Health Commission of NSW, 2018, p. 3). The PCLI reflects the aspirations of the *Fifth National Mental Health and Suicide Prevention Plan* which, in turn, is designed to meet international ‘norms and standards ... as the minimum acceptable standard for health policy’ (COAG Health Council, 2017, p. 11). Central to the social and policy context is the concept of ‘recovery’, whereby mental health services are:

There have been entrenched barriers to delivering recovery-oriented services, not least of which are the historical infrastructure, cultures and attitudes. While the PCLI has broken through some of these barriers, including through the closure of some of the more antiquated long-stay inpatient wards, there continue to be constraints to embedding recovery-oriented services more generally. One example is the structural separation of youth and adult mental health services which has precluded the development of a ‘consistent evidence-based approach to people with major psychosis’ (Ministry PCLI team, 2021) across the age spectrum. Another is the limited availability of services ‘outside the hospital system that (are) sustainable ... and which support recovery in the community’ (Ministry PCLI team, 2021).

*... centred on and adapts to the aspirations and needs of people. It requires a shared vision and commitment at all levels of an organisation. It draws strength from, and is sustained by, a diverse and appropriately supported and resourced workforce that includes people with lived experience of mental health issues in their own lives or in close relationships (AHMAC, 2013, p.5)*

The centrality of the consumer has been reflected in both the language and practice of the program from the outset, from the framing of the program as ‘My Choice: Pathways to Community Living Initiative’ and development of resources such as the *Journey to Home Guide* for consumers and family carers. As such, it aligns closely with the objectives of the National Mental Health Commission’s Vision 2030 regarding the need for:

On a broader level, the siloed nature of government bureaucracies and limited opportunities for cross-portfolio and inter-jurisdictional collaboration present systemic barriers to delivering recovery-oriented support. As such, the conclusion of the recent Royal Commission into Victoria’s Mental Health System aptly describes what needs to happen within all jurisdictions to improve outcomes for consumers:

*The system’s foundations need reform. Structural challenges, such as inadequate approaches to outcomes measurement, poor system planning and weaknesses in monitoring service providers, as well as inadequate partnering with the Commonwealth Government, have all contributed to an uncoordinated system, with large service gaps (State of Victoria, 2021, p.16)*

Against this backdrop, the designers of the PCLI have demonstrated significant prescience in addressing the ‘outer context’ elements of the change management paradigm (Stirman et al., 2012) by aligning the program with the broader policy directions, developing partnerships across sectors, and leveraging off the opportunities presented in the NDIS roll-out.

## 8.2.2 Reform agendas in aged care and disability sectors

Parallel to the reforms within mental health services, the aged care and disability sectors have experienced significant changes in recent decades in terms of governance and accountability, funding and financing, and workforce reform. Given the PCLI is predicated on robust partnerships across sectors, changes in these sectors have presented challenges for the PCLI and for mental health reform more generally. Both have experienced significant challenges, culminating in Royal Commissions within each sector: the Royal Commission into Aged Care Quality and Safety ('Aged Care Royal Commission', Pagone G, and Briggs L, 2021) and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission', Sackville et al., 2020).

A contributing factor has been the distribution of portfolio responsibilities between levels of government and within governments, resulting in lack of coordination across services for those experiencing mental health problems. The PCLI has made targeted investments to improve coordination, establishing cross-sector networks and capacity building activities; clinical governance processes and care pathways; and funding for specialist service developments (MHACPI, SRACFs, SLSs). As policy barriers have presented themselves, the Ministry has successfully negotiated resolutions with government agencies, for example, the NDIA regarding NDIS assessments, funding and care planning, and the Department of Health in regard to ACAT approvals for Stage One consumers with issues of ageing who are aged under 65 years.

The PCLI has exposed the different operational, regulatory and cultural contexts between health services and aged and disability partners. Both sectors are characterised by staffing profiles with high levels of casualisation and turnover and relatively low levels of training and wages. Both Royal Commissions, supported by the international evidence, have highlighted the relationship between staff skill levels, mix and consistency on quality and safety, suggesting PCLI consumers with behavioural changes due to their SPMI and/or cognitive impairment may be at risk within these contexts (Eagar et al., 2019, Cortis and van Toorn, 2020).

In practice, few consumers have returned to hospital due to the inability of their new homes and services to support them. KIs report that the majority of Stage One consumers have transitioned to mainstream aged care services without intensive ongoing PCLI involvement. This indicates that the intensive consultation, selection and matching processes that have been developed by PCLI clinicians to ensure the service meets the needs of the consumer, and the partnerships established between community mental health teams and these services have worked well.

However, it is clear that the investments provided under the PCLI will need to continue, both within the Ministry and LHD levels, particularly given there are many as-yet unknown impacts that are expected to arise from the Royal Commissions. Both Commissions are clearly focused on enhancing the rights of their respective population groups; consequently, there are likely to be greater calls on government to tighten restrictions to those existing service models that are deemed to compromise the rights

of individuals, and enhance investment into more suitable service options. The Aged Care Royal Commission has already recommended that from 1 January 2022 no person under the age of 45 lives in and under 65 years enters residential aged care, and that no person under the age of 65 is living in aged care from 1 January 2025 [Recommendation 74, Pagone G. and Briggs L. (2021)]. The Interim Report of the Disability Royal Commission has also indicated its support for this recommendation (Sackville, R. 2020 page 56). This presents a challenge for the long-term viability of the SRACF model, which has been designed to accommodate some people with early ageing issues associated with SPMI.

A recurring concern among KIs was lack of governance and oversight within the disability sector, particularly the potential disconnect between the providers of accommodation services and individual workers employed to support consumers. Additionally, several KIs raised concerns about the sustainability of the NDIS, and likelihood of further tightening of funding that will be available for consumers. In regards to the aged care sector, it is clear that the issues identified by the Royal Commission will not be resolved readily and there will continue to be a need for clinical support provided to consumers in those settings.

The uncertainties facing the disability and aged care sectors will require ongoing oversight, engagement and program development activities by the Ministry, as well as addressing emerging cross-jurisdictional or intra-government policy issues that are likely to arise. Further, the NSW Government will continue to need to work closely with the Australian Government to ensure the issues regarding safety, quality and sustainability of the aged care and disability sectors that have been identified in the Royal Commissions are appropriately addressed.

Additionally, it is clear that LHDs will continue to require dedicated funding to facilitate the transition of long-stay patients and better support those at risk of long-stay admissions, and provide ongoing clinical support for consumers living within the community. LHDs will also need to ensure there are clear accountability and governance processes that are working well to support ongoing communication and linkages between inpatient and community teams.

## 8.2.3 Value-based health care

Value-based health care, the dominant philosophy driving NSW Health policy, emphasises quality of outcomes over quantity of service provision (Porter, 2010). Importantly, the central premise of value-based health care is to deliver the outcomes that matter most to patients, which may include regaining or maintaining function and social participation (Koff & Lyons, 2020). In recent years, the move from volume to value has been a key element of NSW Health strategic planning (e.g., NSW Health, 2019). Based on the concept of the 'quadruple aim' for best-practice health care planning (Bodenheimer & Sinsky, 2014; Sikka et al., 2015), in NSW value is defined across four domains: improved experiences for people, families and carers; improved experiences for service providers and clinicians; improved cost efficiencies of the health system; and, improved health outcomes for the population (Koff & Lyons, 2020).

The PCLI is well-placed to capitalise on the value agenda and has already begun to do so, for example by translating the knowledge from program documents and previous evaluation reports into a high-level summary report structured around the quadruple aim to demonstrate alignment with NSW Health policy directions (Feyer et al., 2021).

Several foundations of value-based health care are present in the PCLI, including the spread of successful models of care, a focus on safety and quality, and developing networks to promote long-term change (Koff & Lyons, 2020). With its shift towards complex care rehabilitation for people with SPMI, the PCLI aims to ensure that the right services are available, using strategies such as shared decision making with consumers and carers, workforce development within hospitals, and boosting resources and capacity in community service providers—all consistent with the ‘population medicine’ approach to delivering value<sup>11</sup> (Gray, 2017).

There is, however, one area of significant weakness which will need to be addressed to position the PCLI for sustainability, and that is rigorous measurement of outcomes. The ability to demonstrate outcomes that are meaningful to patients is critical to value-based care (Koff & Lyons, 2020; Porter, 2010) including mental health care (de Bienassis et al., 2021). In the value domains of *patient and provider experiences*, there are opportunities to improve the selection and use of outcomes tools and the infrastructure around those tools in order to maximise their utility in routine clinical care (Section 8.1.3). In the value domains of *health outcomes and care effectiveness and efficiency*, it is vital to find ways to improve data quality and completeness. The Ministry can assist LHDs by providing an accessible way to store and display the data, guidance on interpreting it, and timely and sophisticated feedback to LHDs on how they compare with others and/or with an agreed standard (benchmarking).

The Ministry has undertaken a major upgrade of the database in recent years, utilising the expertise of a consultant firm and encouraging participation by the major users in the redesign and user testing. This has made the database ‘user friendly’ for data input and output but has not addressed the other reasons for missing data. There is still no compelling reason to open or use the database, apart from entering the data required for the evaluation. This is evident from the most recent interviews with KIs; for example, one said they had opened the database ‘maybe three times to enter data’ but had not used any of its functions, such as generating reports for the LHD. Another said they generally ‘block out’ time before a deadline (for the evaluation data) and input as much as they can, ‘or as much as I’ve been able to convince the clinicians to actually complete’ (PCLI clinician, 2021). However, the improvements in database functionality are appreciated: one KI said the new function which allows transfers of information across LHDs (when consumers transition across district boundaries) was very welcome and made the database a more useful platform.

### 8.2.3.1 Demonstrating the value of the PCLI

An emerging issue which will need to be addressed by the Ministry PCLI team is the difference between the PCLI cohort in the database and the target group for PCLI intervention. This has serious implications for accurately recording the work done by PCLI teams and their contribution to improved outcomes for people with SPMI and complex needs, particularly at the LHDs that do not have long-stay units.

As described above (Section 8.1.2) the definition of the PCLI cohort has been expanded to include those ‘at risk’ of long hospital stays. It is much more difficult to place definitive boundaries around this group and the scope of the program activities is likely to vary according to the workload and resources available in each LHD and over time as fewer and fewer of the initial cohort consumers remain in hospital. As one KI put it, the new definition introduces ‘grey, fuzzy edges around PCLI’.

Another KI pointed out that a great deal of the work the PCLI clinicians were undertaking was not with ‘the true PCLI cohort’ and therefore was not entered into the database. Both of these KIs were concerned about possible inconsistencies in the PCLI data collection unless there was clear guidance from the Ministry PCLI team about the intended function and purpose of that dataset. There is also a risk of missing some of the most impactful work of the PCLI:

*... often some of the best work a PCLI worker might do might be where the consumer doesn’t even know that they’ve been involved. (PCLI clinician, 2019)*

In a recent interview, a KI talked about PCLI clinicians being ‘pulled into conversations around clients who will be a complex discharge’, even when those people will only be in hospital for a few days. When asked how they kept track of this work with clients outside the traditional definition of the PCLI cohort, they answered, ‘We don’t keep track very well ...’ The KI did not favour a system of recording these consultations because it would be ‘just more paperwork ... impossible’. Although this attitude is completely understandable given clinicians’ natural preferences for spending time with consumers rather than administrative tasks, there may be benefits in designing a simple way of recording activity to demonstrate outcomes.

Quite apart from assisting the future evaluation of the PCLI, it may be worth considering as a way to expand the PCLI’s definition of success beyond the original aims of transitioning long-stay consumers out of hospital and preventing future long stays. The program is now heading towards a broader mission of ‘complex care rehabilitation’ (Ministry PCLI team, 2021). This will require a broader and more inclusive definition of outcomes which encompasses the difference that PCLI can make for complex consumers who have had, or are ‘at risk of’, long stays in hospital and the value it can add to the mental health system.

11. The ‘population medicine’ definition of value is most useful where health services are accountable for health outcomes across regions or populations (e.g., the LHDs in NSW), in contrast to the American model which defines value as outcomes over delivery price, optimised within a program or organisation (Gray, 2017).

Important steps are already being taken towards equipping the program to measure and demonstrate its value. The Ministry PCLI team has recently undertaken a project examining current and potential data sources for the PCLI to allow the development of headline and monitoring indicators and the measurement of progress against implementation targets and outcomes against the quadruple aim (PCLI team & Suzanna Rona, 2021). Preliminary investigations have been completed

and next steps mapped out, which will involve collaboration with stakeholders such as data custodians, consultants ARTD (who are developing the PCLI database) and LHDs. Goals for this work include identifying new and extended indicators, working with LHDs to improve data quality and reliability, and exploring options for accessible reporting and data presentation.

## 8.3 Stage Two service developments

---

The PCLI is fundamentally a partnership approach to supporting consumers with SPMI whose needs have not been met by traditional community services. For Stage One consumers and those in Stage Two with relatively stable needs, the program has built on existing program infrastructure such as the Commonwealth's residential aged care program and the NDIS, and NSW Health programs such as HASI Plus, supplemented by new inputs (funding, clinical expertise) and processes (assessments, clinical governance processes). However, as noted above, these services are limited in terms of their operational models and staffing capabilities, and are not suitable for the many Stage Two consumers with very complex needs and comorbidities due drug and alcohol use, intellectual or cognitive impairment, past trauma and who are a risk to themselves or others. For example, although it offers more intensive support than HASI, and has been useful for some Stage Two consumers, the level of staffing and clinical expertise available through HASI Plus has not been sufficient for people with significant behavioural issues (NSW Health, 2018).

While the NDIS has no doubt opened up options for consumers, the sector has also seen a burgeoning of disability service providers advertising a range of services which, as KIs have repeatedly found, in practice cannot meet consumers' complexity and high support needs. In some cases, providers of SIL services have relinquished care of their residents when they were admitted to hospital. KIs also indicated delays in consumers being assessed and having plans approved, and care coordination often falling to the health service rather than designated NDIS-funded support coordinators. Lack of ongoing oversight by support coordinators also put clients at risk of having their NDIS funding run out prematurely.

The Ministry PCLI team has invested significant time to evaluate existing models of care, analyse consumer assessment data, consult across sectors, and collaborate with consumers and their families to identify, design and refine the investments required. The proposed new purpose-designed model of care represents:

*a paradigm of systemic care – working across both hospital and community sectors, and coordinated and integrated at LHD and state levels with our partners in care – community managed organisations (CMOs) [NSW Health (2018) Approach to Modelling of Stage 2 PCLI Services, Version 2, p.6]*

The model proposed addresses the barriers and challenges consumers experience in the community, with the view to deliver 'wrap-around' services on the ground that include clear pathways between health services and 'home'. It is underpinned by the principles of co-production with consumers, family and staff; collaboration across health and community services; and strengths-based, recovery-orientated care; and supported by state-wide governance arrangements. Services will be delivered through a network of non-acute inpatient units and rehabilitation programs provided by multidisciplinary teams with peer workers, and will be contemporary, evidence-based, innovative and demonstrate 'therapeutic optimism':

*It's sort of saying, it's okay if this one doesn't work. Let's look again, let's keep looking, let's keep looking. So I think that has to really be quite a flavour through this program (Ministry PCLI team, August 2021)*

A three-tiered model of Specialist Living Support services has been developed to cater to those who are unable to be supported in mainstream NDIS-funded group homes (Figure 11) and a brokerage funding program for those consumers requiring 'atypical' top-up support. Crucially, the expectations and accountabilities of all partners are clearly articulated.

Figure 11 Proposed Specialist Living Support models for Stage Two

SLS	Target Group and Program	Designed Environment
<b>SLS1 Specialist Living Support 1</b>	<p><b>L/S high needs</b> with capacity for graded rehabilitation.</p> <p>24/7 clinical care, daily living support and active community-oriented rehabilitation for high levels of psychiatric disability and/relapse/harm minimisation approaches for co-occurring D&amp;A, developmental needs.</p>	<p>Clusters of <b>10x 1 bedroom self-contained apartments</b> allowing for 24/7 space for staff and communal meeting spaces.</p> <p>Embedded and LHD in-reach clinicians.</p> <p>LOS: 'as long as you need'.</p> <p>Support for throughput, to more independent living if appropriate.</p>
<b>SLS2 Specialist Living Support 2</b>	<p><b>L/S very high needs</b> and poor functioning require high structure and stabilising rehabilitation.</p> <p>24/7 daily living support and clinical care for very high psychiatric/behavioural and /or disability and complex care co-morbidities eg cognitive impairment, intellectual disability, ABI, bariatric, medical.</p>	<p>Specifically designed <b>duplexes of 5 places</b> with 24/7 staff and communal spaces and flexible quiet areas with good supervision capacity. Could be scaled for value to 2 duplexes side by side (10 beds).</p> <p>Embedded and LHD in-reach clinicians -skilled in range of conditions.</p> <p>LOS: 'as long as you need'.</p> <p>Support for throughput, to more independent living if appropriate.</p>
<b>SLS3 Specialist Living Support 3</b>	<p><b>L/S high needs step-down</b> from hospital with capacity for active rehabilitation.</p> <p>24/7 active rehab in domestic setting with ability to step back up to hospital for short periods of re-stabilisation, if necessary.</p>	<p>Trial of transition program specifically designed in a <b>domestic type facility of 10x 1 bed large spaces</b> including three studio spaces with accessible communal and 24/7 staff areas and quiet and active areas.</p> <p>Overall clinical responsibility: LHD with NGO and embedded and LHD in-reach clinicians.</p> <p>LOS: Average of 12 months with step-down to hASI, PCLI SLS1 or 2 or other.</p>

# 9 Discussion

---

The discussion, recommendations and conclusions for this final evaluation report are intended to support the future direction of the PCLI as the program moves forward into 2022 and beyond. They are framed using the ‘simple rules’ for large-system transformation in health care:

1. Engage individuals at all levels in leading the change;
2. Establish feedback loops;
3. Attend to history;
4. Engage physicians;
5. Involve patients and families (Best et al., 2012)

Each ‘simple rule’ defines a domain of action, and successful implementation relies on effective action within each domain: leadership; collaborative monitoring and measurement; history and context; clinical engagement and co-design; and person-centred care. In this chapter, we bring together evidence from each of the four evaluation components in relation to these five domains and an additional domain that we believe has been instrumental in creating positive change through the PCLI. The discussion highlights achievements and work remaining, leading to recommendations around the future development of the PCLI.

## 9.1 Leadership

---

The PCLI is becoming established but is not yet embedded in routine practice across LHDs. Culture change towards more multidisciplinary, recovery-oriented care is occurring, particularly at the primary implementation sites which have had a longer implementation time and therefore a larger ‘dose’ of the PCLI intervention. However, at some sites change efforts are just beginning and have yet to gain much traction, particularly where there is an entrenched culture of ‘good enough’ discharges. The findings of the staff survey confirm the perceptions by KIs that although there has been substantial progress, there is still considerable work to do.

Further, there remain some significant structural barriers to be overcome in the reform process. One is the limited availability of services outside the health system which are equipped with the resources and expertise to promote consumers’ mental health recovery in the community. Another is the separation of services within health, and even within mental health, resulting in silos which prevent a consistent, evidence-based approach to providing continuity of care for people with major psychosis. Although the PCLI has played a role in breaking through some structural barriers (for instance, through the closure of more antiquated long-stay wards) there remain constraints on embedding recovery-oriented approaches across the system.

For these reasons, it is essential that the Ministry retains strategic direction and decision-making about resource allocation for the PCLI. The scale of the effort needed to sustain the gains of the PCLI requires a coordinated approach as it is too complex and substantial to be reasonably left to the LHDs. The experience of mental health service delivery in NSW confirms that people who need access to community-based models of mental health care do not choose their homes based on LHD boundaries. Hence, maintaining state-wide leadership and networks established through the PCLI is crucial.

In the language of implementation science, the Ministry PCLI team provides ‘designated’ leadership to support the ‘distributed’ leadership by staff at LHDs; when these align, sustained commitment to transformational change is more likely to occur (Best et al., 2012). While the Ministry provides the necessary resources, strategy, and governance structures, the local teams act as ‘champions’ for the PCLI. The PCLI should continue to be driven by state-wide strategy and resourcing. Otherwise, consistency of implementation relies on clinical directors of mental health services and psychiatrists in individual units being able to balance the needs of complex care rehabilitation and transition planning with other operational imperatives. Continuing with the designated and distributed leadership model reduces the risk of fragmentation that may result if leadership is left solely with LHDs.

The overarching structure of the PCLI empowers peer workers, allied health professionals and nursing staff who want to work in a recovery-oriented way as they are able to align their individual efforts with a state-wide strategic direction. The distributed leadership model has encouraged mental health clinicians to innovate locally and to collaborate through facilitated PCLI networks. There are many examples of where this capacity to network and share lessons has strengthened implementation.

It is recommended that the Ministry:

1. Retain the PCLI as a distinct and named program, with state-wide leadership and control over resources, until there is sufficient evidence that PCLI processes are embedded in LHDs and structural barriers to recovery-oriented practice are addressed at state level.
2. Retain the distributed leadership model that is in place for the foreseeable future.

## 9.2 Collaborative monitoring and measurement

At this point in the program, it would be worthwhile to revisit the PCLI-specific assessment tools, especially those recommended for use at follow-up after transition. It is evident from the incompleteness of the available data that the PCLI-specific tools are not yet embedded in workflows. According to KI accounts, the large number of tools creates major challenges for collecting and recording assessment data and for using it in meaningful ways to inform practice. There is an urgent need to review and rationalise the assessment suite to make the tools and their scores more readily accessible and useable in routine practice and to improve the completeness and accuracy of the dataset used for monitoring and evaluation.

These two important uses are inter-dependent: obtaining complete and high-quality baseline and follow-up data to demonstrate program outcomes is reliant on embedding the PCLI suite of assessment tools into usual workflows within the participating services. For the purposes of evaluation, a clear and consistent set of outcome measures and associated tools is needed, whereas clinical use is individualised. A challenge moving forward will be balancing the tension between these two uses of assessments. Clinicians require a level of professional discretion in choosing tools within categories, while recognising that certain information is essential to develop a full picture of how individuals are progressing. A deeper understanding of the reasons behind the poor completion of the PCLI-specific tools may assist in addressing the continuing issue of missing data, particularly the lack of follow-up assessments.

Experiences of a pioneering mental health outcomes project in the UK demonstrated that ‘carrots’ (e.g., regular feedback of data and its practical use by teams) tend to work better in the long term than ‘sticks’ (e.g., targets for completion linked with financial or other implications; McDonald & Fugard, 2015). Published evidence suggests several ways to improve routine mental health outcomes data collection (Burgess et al., 2015; de Bienassis et al., 2021):

- Rationalising the suite of measures to reduce the burden of collection;
- Ensuring that measures focus on constructs that matter to consumers and carers;
- Integrating measures into existing systems of care;
- Providing straightforward guidelines on the timing of data collection;
- Protocol-driven systems to ensure new and existing staff are trained in the use of the tools;
- Greater emphasis on the clinical uses of outcome measurement so that data collection adds obvious and immediate value to care.

It is also important to allow sufficient time for the investment in routine outcomes measurement to yield benefits in terms of reflective practice by clinicians and improved outcomes for consumers (McDonald & Fugard, 2015).

For the purposes of demonstrating program outcomes and value, it would be sensible to prioritise clearly the tools most useful for the majority of consumers and ensure these are collected at baseline and follow-up. This will include the MH-OAT collection and a small number of PCLI-specific tools, which should include some patient-reported measures, consistent with the value-based health care agenda. The other tools in the PCLI suite should continue to be available as needed for specific clinical purposes. The Ministry PCLI team should continue efforts to improve the useability of the database and eventually enable prompt, preferably real-time, feedback to inform practice and quality improvement at LHD level. It would be timely to examine these issues as the program expands through diverse LHDs across NSW and gets ready to engage with a new set of community partners for Stage Two service developments.

It is recommended that the Ministry:

3. Strongly support LHDs to use the routine assessment tools (MH-OAT) at baseline and follow-up for demonstrating outcomes, along with a small selection of PCLI-specific, person-centred tools that provide insight into personal recovery and quality of life.
4. Continue to make the full PCLI assessment suite available for clinical purposes. Incentivise clinicians to use these tools through providing ongoing improvements to the PCLI database, facilitating training, and exploring and addressing sources of clinician resistance.

## 9.3 History and context

---

The PCLI has learned from historical failures in deinstitutionalisation and has used this knowledge to focus on ensuring person-centred, sustainable community living. It has built upon care processes that have been occurring in mental health services for decades through providing additional resources, impetus and accountability for change (see *PCLI Evaluation Report 6* for details). The PCLI has leveraged cleverly off the NDIS for the benefit of consumers with psychosocial disability. However, any changes to the rules and policies about access to that funding source will have major implications for the substantial number of individuals who have transitioned to the community with support from NDIS packages.

Currently the health system is focused on value-based health care and the quadruple aim. The PCLI aligns well with this framework as it works to improve patient and carer experience and supports service providers with training and embedding of transition processes. The economic evaluation demonstrated efficiency and substantial savings to the broader health system and evidence of the effectiveness of care is progressively being demonstrated. Instrumental to moving forward has been the sharing of 'success stories' as this has helped instil hope to inspire and sustain the engagement of all stakeholders.

Throughout the COVID-19 pandemic it has been more difficult to transition people to community environments, particularly to aged care, given the risks for vulnerable populations. The PCLI teams have adapted to the constraints associated with lockdowns and their impacts on transition planning. This suggests that the PCLI model should be sustainable as it remains fit for the current context and is able to be adapted to significant changes in context.

When the PCLI was originally conceived the goal was to get people out of hospital who had been inpatients for a long time and ensure this pattern would not be repeated. Implementation has now expanded to include LHDs that have not historically had long-stay patients (because they do not have these kinds of facilities) but do have 'pinball institutionalisation' occurring through recurrent admissions, long stays in acute wards or referral to the larger hospital sites. There have been adjustments to the model so that it is now not just about preventing long stays but identifying people with exceptionally complex presentations and working with them, their families, and diverse service providers, to improve outcomes. While the focus on preventing long hospital stays remains central to the vision of the PCLI, there is also a need to invest further in understanding the optimal length of stay for rehabilitation purposes, and ensure that people with SPMI and complexity have access to appropriate services regardless of which LHD they reside in. The job of the PCLI moving forward is to continue building capacity -across services and sectors- to provide the best possible care for people with these issues.

It is recommended that the Ministry:

5. Recognise that a shift is occurring in the program that should be formalised through adjustment to the stated goals of the PCLI, including how activity is tracked and how outcomes are measured, to reflect the increasing focus on complex care rehabilitation.

## 9.4 Clinical engagement and co-direction

---

A culture change is occurring within the long-stay wards of inpatient mental health facilities in the LHDs of focus. It is becoming a more outwardly focused and recovery-oriented culture. When patients are admitted, staff are alert as to whether the patient is potentially likely to have a long stay and start planning to address barriers to discharge. There is hope and optimism and it is no longer assumed that a hospital is a place where someone could or should stay for life. There is greater recognition and respect for the capacity of external services to care for complex consumers appropriately with the support of community based mental health services and strengthened understanding that many people can have a much better life outside of hospital. It is important, however, that rehabilitation and transition planning does not come to be seen as someone else's business, but is seen as business as usual (Newman & Emerson, 1991). There are opportunities to strengthen recovery orientation and improve rehabilitation within hospitals by learning from good practice happening elsewhere.

Early successes have been important in inspiring further efforts and sharing these success stories has worked well for the PCLI. To continue this change, it would be worthwhile to introduce quality assurance processes where PCLI teams regularly review and audit the progress of transitioned consumers who are living in the community, to inform continuous improvement and adaptation in the program.

No transformational change in the health system is likely to succeed without the engagement of medical personnel. The power and influence of this group is entrenched in clinical governance structures of health systems. Doctors can be held accountable by law if things go wrong for the patient. The NSW Mental Health Act (2007, amended 2015 and 2017) assigns ultimate responsibility for decision making to psychiatrists, whose roles include care planning, providing advice and consultation, and promoting safety and quality in care. Consequently, it is essential for them to be involved in, and satisfied with, transition planning for long-stay consumers.



Engagement of medical staff in the PCLI appears to have reached a tipping point through sustained effort to consult and inform, working with the RANZCP, and using world experts to educate and inspire clinicians and to build a positive identity for rehabilitation psychiatry. The Ministry should build on these successful efforts and continue to work with the RANZCP to improve the recognition of rehabilitation psychiatry as a specialist area. To complement these efforts, the PCLI should continue to foster a multidisciplinary approach to care through empowering nursing and allied health staff to have input into clinical discussions and case reviews and actively encouraging therapeutic optimism and recovery-oriented practice.

It is recommended that the Ministry:

6. Integrate audit and quality improvement processes to track the sustainability of the health and wellness and social integration of transitioned individuals.
7. Continue efforts to build a strong professional identity for rehabilitation psychiatry.
8. Continue to invest resources into LHDs to strengthen multidisciplinary in care planning for complex patients.

## 9.5 Consumer and carer engagement

---

Engaging with consumers and family carers in care planning and shared decision making is an intrinsic part of the PCLI. The clear guidance provided by program documents – the *Planning, Assessment and Follow-Up Guide* (NSW Health, 2020a) and the *Journey to Home Guide* (NSW Health 2020b) – has established consistent procedures and high expectations for consumer involvement and other key aspects of recovery-oriented practice.

It is particularly important that the PCLI continues to support and promote strategies for providing individualised, flexible care that appropriately balance safety measures with individual dignity and freedom (Slemon et al., 2017). Staff in mental health services should continue to promote a sense of consumer and carer choice of accommodation and support options while balancing this with the person's capacities, needs and risks. Staff in the aged care and disability sectors will continue to require access to upskilling opportunities including formal training, modelling and mentoring. Building relationships with the PCLI consumers is key, so that the staff of accommodation and support services can understand whether a consumer's behaviours simply reflect personal choices or whether they might indicate underlying issues of concern.

The evaluation has validated the need for the Stage Two SLS services as there remains a significant group in hospital awaiting these accommodation models. The NDIS is unable to provide the level of clinical care needed and this can only be resolved by the Ministry developing these alternatives. There will be an ongoing requirement for a balanced approach to managing individuals' physical and mental health needs.

A greater focus on active rehabilitation and meaningful occupation could be beneficial, especially for those Stage One consumers who do not have access to NDIS-funded opportunities for social and community participation activities. Our experience of interviewing consumers, carers, aged care providers and mental health professionals for this evaluation suggests that, regardless of age or level of disability, many people served by the PCLI have a strong need to take part in activities that are sufficiently challenging, sociable and useful to be engaging and satisfying. A continuing commitment to mental health rehabilitation remains important following

transition and should be a key aspect of both the Stage One MH-RAC services and the proposed Stage Two SLS service models.

Formal support for carers should be considered as there are limited resources for carer liaison within LHDs and there is significant trauma experienced by carers including feelings of grief and loss. These issues affect their health and wellbeing and their receptiveness to the PCLI model of care. If they could be linked into appropriate supports this may be helpful, for example the Ministry-sponsored Family and Carers Mental Health Program may be an option.

It is recommended that the Ministry:

9. Maintains support, resources and strategies to assist providers to maintain social connections during COVID.
10. Encourages a focus on consumers' physical health care needs when they leave hospital through supporting access to GPs and programs to self-manage chronic health conditions and healthy lifestyle opportunities, as this is a group with significantly increased morbidity associated with chronic health issues.
11. Considers providing funding for post-transition activities in MH-RAC partnerships and proposed PCLI Stage Two service models that will assist people to continue working towards personal recovery, meaningful occupation and social integration.

## 9.6 Cross-sector engagement and capacity building

---

*PCLI Evaluation Report 5* flagged the need for a sixth rule in transformational change as the ecosystem to support people with SPMI is broad. This additional rule is essential to the optimal functioning of the Stage One MH-RAC models and Stage Two SLS services. The issue of de-institutionalisation is indeed a 'wicked problem'. It requires sustained cross-sector cooperation so that the social determinants that influence health, including housing, employment, social participation and poverty are addressed to address the complex needs of people with SPMI. Aged care, disability care, health and social care providers need to work together to provide the wraparound supports essential to quality of life for these individuals.

One of the most valuable contributions of the PCLI is that it has broken silos within health and between the health, aged and social care sectors. The bridging role of the PCLI clinicians is vital, as is their flexibility to work across settings and sectors and link people with each other, with information, and with the

diverse services needed to manage a successful transition. This essential, facilitating and relationship-building role is highly visible in Stage One through the ongoing work within the MH-RAC partnerships. From what we have learned from these partnerships, there will be a similar need for Stage Two teams who can span the boundaries between mental health and disability psychosocial care to work in partnership with the SLS services, as well as continuing their consultation-liaison with community mental health services and community providers funded through the NDIS.

It is recommended that the Ministry:

12. Continue to ensure that the additional positions funded through the PCLI are designed and used by the LHDs in the most appropriate ways to support complex care rehabilitation and community transition of people with SPMI and complex needs.

## 9.7 Conclusion

---

The evaluation of the PCLI has spanned over four years, from January 2017 to August 2021. During this time, the five 'simple rules' of transformational change in large health care systems (Best et al., 2012) have been a useful framework for reflecting on program implementation and we believe they can provide a succinct guide for the future. Of these elements, the most critical appear to be the strategic overview from the Ministry PCLI team, the financial and other resources for LHDs, and the encouragement of culture change towards recovery orientation in inpatient mental health services. Efforts to engage doctors by establishing a positive identity for psychiatric rehabilitation are also likely to be transformative.

The overarching goal of the PCLI is to achieve system reform that delivers improved outcomes for consumers, that is sustainable and embeds continuous improvement within health services.

The PCLI is occurring within the complex system of NSW Health mental health care delivery. Systems have emergent properties and can take on a life of their own, so effecting change is not linear. It would be advantageous for future evaluations of the PCLI to focus on this systems perspective, as it is not a traditional program fixed in scope and timeframe. The PCLI has built on the NSW mental health reform agenda, and will continue to adapt in response to aged care and disability policy changes and shifts in the current service delivery framework, through embedding processes to support strategic direction and implementation.

Nothing stays the same in the fast-paced environment of health care. This requires the Ministry to ensure that the PCLI has the enabling conditions, resources and guidelines that are necessary – and to monitor the situation, to see what emerges. The PCLI change management approach capitalises

on the independence and skills of the dedicated mental health clinicians who work with people with SPMI on a daily basis. As time progresses there will be fuzzy boundaries around what the PCLI is as opposed to what are actually organic developments in the NSW mental health system. This makes it important to keep track of progress as the PCLI is not yet ready to be left alone to the invisible forces of the broader health system. There is not yet confidence that the changes are sustainable with inpatient staff and ongoing work is needed to embed these changes, so it is not yet time for the Ministry to let the PCLI go. Transitioning vulnerable people out of hospital successfully will always require the flexibility and expertise for cross-sector working and well-resourced community-based mental health resources with intensive case management to ensure that transitions are well supported and sustainable.

The ultimate test of success and sustainability was encapsulated by one KI very early in the program. Interviewed in 2017, this person said the PCLI was not about the housing itself, or even about the clinical and functional supports available. It was about giving the person the chance to have ordinary, everyday interactions with people who may or may not also have a mental illness. Then they are truly *living* in the community.

# References

---

- Aarons, G. A., Hurlburt, M., & Horwitz, S. M. (2011). Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Administration and policy in mental health*, 38 (1), 4–23. <https://doi.org/10.1007/s10488-010-0327-7>
- ABS (2020). Australian National Accounts: National Income, Expenditure and Product, June 2020, Cat. no. 5206.0, Series ID: A2304687R. Canberra: Australian Bureau of Statistics.
- Access Economics (2010). Extended Care Paramedic Program – updated economic evaluation. Unpublished report.
- Aged Care Financing Authority (2021). Ninth report on the Funding and Financing of the Aged Care Industry. Australian Government Department of Health: Canberra.
- Australian Government (2021). Vision 2030 for Mental Health and Suicide Prevention. <https://www.mentalhealthcommission.gov.au/mental-health-reform/vision-2030>
- Australian Government Department of Health (2010). *National Standards for Mental Health Services 2010*. Retrieved from [www.health.gov.au](http://www.health.gov.au).
- Australian Government Department of Health (2017). Aged Care Funding Instrument (ACFI) User Guide. Retrieved from: <https://www.health.gov.au/resources/publications/aged-care-funding-instrument-acfi-user-guide>.
- Australian Government Department of Health (2021a). Schedule of Subsidies and Supplements for Aged Care. Retrieved from: <https://www.health.gov.au/resources/publications/schedule-of-subsidies-and-supplements-for-aged-care>.
- Australian Government Department of Health (2021b). Aged Care Funding Instrument (ACFI) Monthly Reports. Retrieved from: <https://www.health.gov.au/resources/publications/aged-care-funding-instrument-acfi-monthly-reports>.
- Australian Health Ministers’ Advisory Council (2013). A national framework for recovery-oriented mental health services: policy and theory. Canberra: Department of Health and Ageing. <https://www.health.gov.au/sites/default/files/documents/2021/04/a-national-framework-for-recovery-oriented-mental-health-services-policy-and-theory.pdf>
- Australian Institute of Health and Welfare (2021). GEN. Canberra: AIHW. Retrieved from: <https://www.health.gov.au/resources/publications/aged-care-funding-instrument-acfi-user-guide>
- Bazeley, P. (2013). *Qualitative Data Analysis. Practical Strategies*. London: Sage.
- Best A., Greenhalgh T., Lewis S., Saul JE., Carroll S and Bitz J. (2012). Large-system transformation in health care: a realist review. *Milbank Quarterly*, 90, 421-456.
- Bodenheimer T., & Sinsky C. (2014). From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med*. 12 (6): 573-6. doi:10.1370/afm.1713. PMID: 25384822; PMCID: PMC4226781.
- Brackertz, N., Wilkinson, A. & Davison, J. (2019). Trajectories: the interplay between mental health and housing pathways. A short summary of the evidence, AHURI Research Paper, Australian Housing and Urban Research Institute Limited, Melbourne, <https://www.ahuri.edu.au/sites/default/files/migration/documents/Trajectories-the-interplay-between-mental-health-and-housing-pathways.pdf>
- Burgess, P., Trauer, T., Coombs, T., McKay, R., & Pirkis, J. (2009). What does ‘clinical significance’ mean in the context of the Health of the Nation Outcome Scales? *Australasian Psychiatry*, 17 (2), 141-148. doi:10.1080/10398560802460453
- Burgess, P., Trauer, T., Coombs, T., McKay, R., & Pirkis, J. (2009). What does ‘clinical significance’ mean in the context of the Health of the Nation Outcome Scales? *Australas Psychiatry*, 17 (2), 141-148. doi:10.1080/10398560802460453
- Carlström ED., & Ekman I. (2012). Organisational culture and change: implementing person-centred care. *Journal of Health Organization and Management*, 26 (2), 175-191.
- Carroll JS., & Quijada MA. (2004). Redirecting traditional professional values to support safety: changing organisational culture in health care. *Quality and Safety in Health Care*, 13 (Suppl II), ii16-ii21.
- Case, A., Byrd, R., Claggett, E., DeVeaux, S., Perkins, R., Huang, C., . . . Kaufman, J. (2014). Stakeholders’ Perspectives on Community-Based Participatory Research to Enhance Mental Health Services. *American Journal of Community Psychology*, 54(3-4), 397-408.

Chua, K. C., Brown, A., Little, R., Matthews, D., Morton, L., Loftus, V., & Banerjee, S. (2016). Quality-of-life assessment in dementia: the use of DEMQOL and DEMQOL-Proxy total scores. *Quality of Life Research*, 25 (12), 3107-3118.

Commonwealth of Australia (2013). A national framework for recovery-oriented mental health services: Guide for practitioners and providers.

Coombs, T., Reed, C. & Rosen, A. (2016). Developing the living in the community questionnaire: reporting the social outcomes of mental health care. *Asia Pacific Journal of Social Work and Development*, 26 (2-3), 178-189.

Copeland, M.E. (2003) Self-Determination in Mental Health Recovery: Taking Back Our Lives. UIC NRTC 2003 National Self-Determination & Psychiatric Disability Conference Papers.

Corrigan, P.W., Phelan, S.M. (2004). Social Support and Recovery in People with Serious Mental Illnesses. *Community Ment Health J*, 40, 513–523. <https://doi.org/10.1007/s10597-004-6125-5>

Cortis, N., & van Toorn, G. (2020). Working in new disability markets: A survey of Australia's disability workforce Sydney: Social Policy Research Centre, UNSW Sydney. <http://doi.org/10.26190/5eb8b85e97714>

Council of Australian Governments Health Council (2017). The Fifth National Mental Health and Suicide Prevention Plan. Canberra: Commonwealth of Australia.

Damschroder, L.J., Aron, D.C., Keith, R.E. et al. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Sci*, 4, 50. <https://doi.org/10.1186/1748-5908-4-50>

Davis, L., Fulginiti, A. and Kriegel, L. (2012). Deinstitutionalization? Where have all the people gone? *Current Psychiatry Reports*. 14, 259-269.

Eagar, K., McNamee, J., Gordon, R., et al. (2019). The Australian National Aged Care Classification (AN-ACC). The Resource Utilisation and Classification Study: Report 1. Australian Health Services Research Institute, University of Wollongong. ISBN: 978-1-74128-295-5.

Faculty of Psychiatry of Old Age (2004). The management and accommodation of older people with severe and persistent challenging behaviours in residential care. Sydney, NSW: The Royal Australian and New Zealand College of Psychiatrists, New South Wales.

Feyer A-M, Faraway C and Dickson M (2021). PCLI Stage One Summary Report. Prepared for the NSW Ministry of Health by Health Consulting Collaborative, Sydney Australia. Fixsen, DL., et al. (2005).

Implementation Research: A Synthesis of the Literature. Tampa, FL: University of South Florida, Louis de la Parte Florida Mental Health Institute, The National Implementation Research Network (FMHI Publication #231).

Fries BE., Schneider DP., Foley WJ., Gavazzi M., Burke R & Cornelius E. (1994). Refining a case-mix measure for nursing homes: Resource Utilization Groups (RUG-III). *Medical Care*, 32(7), 668-85.

Gale, NK., Heath, G., Camero, E., Rashid, S and Redwood S (2013). Using the framework method for the analysis of qualitative data in multidisciplinary health research. *BMC Medical Research Methodology*, 13,117-125.

Gee, M., Bhanbhro, S., Cook, S & Killaspy, H. (2016). Rapid realist review of the evidence: achieving lasting change when mental health rehabilitation staff undertake recovery-oriented training. *Journal of Advanced Nursing*, 73 (8), 1775-1791.

Gélinas, I., & Gauthier, L. (1994). *Disability assessment for dementia (DAD). User's Guide*. Retrieved from: [https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Geriatrie/MA\\_TNC\\_DAD\\_manual.pdf](https://www.inesss.qc.ca/fileadmin/doc/INESSS/Rapports/Geriatrie/MA_TNC_DAD_manual.pdf)

Gray, M. (2017). Population healthcare: the third dimension. *Journal of the Royal Society of Medicine*, 110, (2), 54-56.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P. & Kyriakidou O. (2004). Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Quarterly*, 82 (4), 581-629.

Griffiths, K., Jorm, A., & Christensen, H. (2004). Academic Consumer Researchers: A Bridge Between Consumers and Researchers. *Australian and New Zealand Journal of Psychiatry*, 38(4), 191-196.

Hancock, N., Bundy, A., Honey, A., James, G., & Tamsett, S. (2011). Improving Measurement Properties of the Recovery Assessment Scale With Rasch Analysis. *American Journal of Occupational Therapy*, 65 (6), e77-e85. doi:10.5014/ajot.2011.001818

Hancock, N., Bundy, A., Tamsett, S., & McMahan, M. (2012). Participation of mental health consumers in research: Training addressed and reliability assessed. *Australian Occupational Therapy Journal*, 59(3), 218-224.

- Hancock, N., Scanlan, J. N., Honey, A., Bundy, A. C., & O'Shea, K. (2015). Recovery Assessment Scale-Domains and Stages (RAS-DS): Its feasibility and outcome measurement capacity. *The Australian and New Zealand journal of psychiatry*, 49 (7), 624-633. doi:10.1177/0004867414564084
- Happell, B., Ewart, S., Platania-Phung, C., & Stanton, R. (2016). Participative mental health consumer research for improving physical health care: An integrative review. *International Journal of Mental Health Nursing*, 25(5), 399-408.
- Health Outcomes International (2011). Evaluation of the Mental Health Aged Care Partnership Initiative (MHACPI) (Unpublished).
- Health Policy Analysis (2013). Economic evaluation of the Mental Health Aged-Care Partnership Initiative –Final evaluation report. Sydney: NSW Ministry of Health.
- Hegney, D., Buikstra, E., Eley, R., Fallon, T., Gilmore, V. & Soar J. (2007). Nurses and Information Technology: Final Report. Commonwealth of Australia.
- Hodges, J. (2005) Inclusion of mental health consumers on research teams. *Psychiatric Services*, 56(9), 1158.
- IHPA (2018). National Hospital Cost Data Collection Report: Public Sector, Round 20 (Financial Year 2015-16). Sydney: Independent Hospital Pricing Authority. Retrieved from: [https://www.ihpa.gov.au/sites/default/files/publications/nhcdc\\_cost\\_report\\_round\\_20\\_financial\\_year\\_2015-16\\_0.pdf](https://www.ihpa.gov.au/sites/default/files/publications/nhcdc_cost_report_round_20_financial_year_2015-16_0.pdf)
- IHPA (2019). National Hospital Cost Data Collection Report: Public Sector, Round 21 (Financial Year 2016-17). Sydney: Independent Hospital Pricing Authority. Retrieved from: [https://www.ihpa.gov.au/sites/default/files/publications/national\\_hospital\\_cost\\_data\\_collection\\_australian\\_public\\_hospitals\\_cost\\_report\\_round\\_21\\_2016-17.pdf](https://www.ihpa.gov.au/sites/default/files/publications/national_hospital_cost_data_collection_australian_public_hospitals_cost_report_round_21_2016-17.pdf)
- IHPA (2020a) National Efficient Price Determination 2020-21. Sydney: Independent Hospital Pricing Authority.
- IHPA (2020b). National Hospital Cost Data Collection Report: Public Sector, Round 22 (Financial Year 2017-18). Sydney: Independent Hospital Pricing Authority. Retrieved from: [https://www.ihpa.gov.au/sites/default/files/round\\_22\\_nhcdc\\_report\\_public\\_sector\\_round\\_22\\_2017-18\\_-\\_pdf\\_version.pdf](https://www.ihpa.gov.au/sites/default/files/round_22_nhcdc_report_public_sector_round_22_2017-18_-_pdf_version.pdf).
- IHPA (2021). National Hospital Cost Data Collection Report: Public Sector, Round 23 (Financial Year 2018-19). Sydney: Independent Hospital Pricing Authority. Retrieved from: [https://www.ihpa.gov.au/sites/default/files/publications/round\\_23\\_2018-19\\_nhcdc\\_report\\_public\\_sector.pdf](https://www.ihpa.gov.au/sites/default/files/publications/round_23_2018-19_nhcdc_report_public_sector.pdf)
- Irmiter, C., McCarthy, J., Barry, K., Sollman, S. and Blow, F. C. (2007). Reinstitutionalization following psychiatric discharge among VA patients with serious mental illness: A national longitudinal study. *Psychiatric Quarterly*. 78, 279-286.
- Katsikitis, M., Lane, B., Ozols, I., & Statham, D. (2017). Consumer and carer perspectives in the development of a mental health research, treatment and teaching facility: A thematic analysis. *Journal of Psychiatric and Mental Health Nursing*, 24(7), 534-544.
- Kessler, R.C., Andrews, G., Colpe, L.J., Hiripi, E., Mroczek, D.K., Normand, S.L.T., & Zaslavsky, A.M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine*, 32 (6), 959-976.
- Killaspy, H. (2014). The ongoing need for social services for people with complex mental health problems. *Psychiatric Bulletin*, 38 (6), 257-259.
- Killaspy H (2019). Contemporary mental health rehabilitation. *Epidemiology and Psychiatric Sciences* 28, 1-3. <https://doi.org/10.1017/S2045796018000318>
- Killaspy, H., Marston, L., Omar, R. Z., Green, N., Harrison, I., Lean, M., Holloway, F., Craig, T., Leavey, G. and King, M. (2013). Service quality and clinical outcomes: An example from mental health rehabilitation services in England. *The British Journal of Psychiatry*, 202, 28-34.
- Koff, E., & Lyons, N. (2020). Implementing value-based health care at scale: the NSW experience. *Med J Aust*, 212 (3). doi: 10.5694/mja2.50470
- Lycett, M., Rassau, A., & Danson, J. (2004). Programme management: a critical review. *International Journal of Project Management*, 22(4), 289-299. doi:<https://doi.org/10.1016/j.jiproman.2003.06.001>
- Macdonald AJ. (1999). HoNOS 65+ glossary. *The British journal of psychiatry : the journal of mental science*, 175 (192). <https://doi.org/10.1192/bjp.175.2.192c>
- Masso, M., Quinsey, K., & Fildes, D. (2016). Evolution of a multilevel framework for health program evaluation. *Australian Health Review*, 41, 239-245.

- Masso, M., Coombs, T., Williams, K., Bird, S., Westera, A., Kobel, C., Moxham, L., Fildes, D., & Gordon, R. (2017). *Pathways to Community Living Initiative Evaluation Plan*. Wollongong, NSW: Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.
- Masso, M., & McCarthy, G. (2009). Literature review to identify factors that support implementation of evidence-based practice in residential aged care. *International Journal of Evidence-based Healthcare*, 7, 145-156.
- Matheson, S.L. & Carr, V.J. (2015). *Transitioning long-stay psychiatric inpatients to the community*. Schizophrenia Research Institute, Sydney.
- Maxwell, J. & Chmiel, M. (2014). Generalization in and from qualitative analysis. In *The SAGE handbook of qualitative data analysis* (pp. 540-553). SAGE Publications Ltd, <https://www.doi.org/10.4135/9781446282243>
- McInroy, L.B. (2016). Pitfalls, Potentials, and Ethics of Online Survey Research: LGBTQ and Other Marginalized and Hard-to-Access Youths. *Social Work Research*, 40 (2): 83-94.
- Mental Health Commission of NSW (2018). *Paving the way home: lessons from My Choice: Pathways to Community Living Initiative – Spotlight on Reform*. Sydney: Mental Health Commission of NSW.
- Morgan, V., Waterreus, A., Carr, V. et al (2017). Responding to challenges for people with psychotic illness: Updated evidence from the survey of high impact psychosis. *Australian & New Zealand Journal of Psychiatry*, 51, 124-140.
- National Disability Insurance Agency (2020) NDIS Quarterly Report to disability ministers Dec 2020.
- National Disability Insurance Agency (2020). Data and insights. <https://data.ndis.gov.au/>
- National Mental Health Commission's Vision 2030 for Mental Health and Suicide Prevention <https://www.mentalhealthcommission.gov.au/mental-health-reform/vision-2030>
- Neale, J. (2016). Iterative categorisation (IC) a systematic technique for analysing qualitative data. *Addiction*, 111, 1096-106.
- Neale, J. (2020). Iterative categorisation (IC) (part 2): interpreting qualitative data. *Addiction*, 116, 668-676.
- Newman, I. & Emerson, E. (1991). Specialised Treatment Units for People With Challenging Behaviours. *Journal of the British Institute of Mental Handicap*, 19 (3), 113-119.
- NHMRC (2014) National Statement on Ethical Conduct of Research 2007, updated March 2014. Retrieved from <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018> on 15 May 2015.
- NSW Health (2006). *NSW Service Plan for Specialist Mental Health Services for Older People (SMHSOP) 2005-2015*. NSW: A new direction for Mental Health. NSW Department of Health: North Sydney. Retrieved from: <https://www.health.nsw.gov.au/mentalhealth/resources/Pages/nswsmhsop-serviceplan-2005-2015.aspx>.
- NSW Health (2015). *My Choice: Pathways to Community Living Initiative, Getting to Know You, Planning and Assessment Booklet*, April 2015.
- NSW Health (2016) *My Choice: Pathways to Community Living Initiative Project Development Guidelines*. Working Version 1, April 2016.
- NSW Health (2017). *NSW Older People's Mental Health Services Service Plan 2017-2027*. Retrieved from: [https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2017\\_022.pdf?utm\\_source=newsletter\\_1817&utm\\_medium=email&utm\\_campaign=communitynet-sector-resources-publications-e-news-19-january-2018](https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2017_022.pdf?utm_source=newsletter_1817&utm_medium=email&utm_campaign=communitynet-sector-resources-publications-e-news-19-january-2018)
- NSW Health (2018) *Approach to modelling of Stage Two PCLI services*. Version 2. North Sydney, NSW: Mental Health Branch, NSW Ministry of Health.
- NSW Health (2020a). *My Choice: Pathways to Community Living Initiative Planning, Assessment and Follow up Guide – A guide for clinicians facilitating planning, assessment and follow up for people moving into the community after a long stay in hospital*. Version 2. North Sydney, NSW: Mental Health Branch, NSW Ministry of Health.
- NSW Health (2020b). *My Choice: Pathways to Community Living Initiative Journey to Home Guide – A guide for people moving to the community after a long stay in a mental health facility, as well as their families, carers, workers and clinicians*. Version 2. North Sydney, NSW: Mental Health Branch, NSW Ministry of Health.
- Novella, E J. (2010). Mental health care in the aftermath of deinstitutionalization: A retrospective and prospective view. *Health Care Analysis*. 18, 222-238

- Pagone, G., Briggs, L., (2021) Royal Commission into Aged Care Quality and Safety Final Report -Care, Dignity and Respect <https://agedcare.royalcommission.gov.au/publications/final-report>, accessed 28 September 2021
- Perkins, R. & Repper, J. (2014). Recovery versus risk? From managing risk to the co-production of safety and opportunity. *Mental Health and Social Inclusion*. ISSN: 2042-8308
- Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T., Strathdee, G., Loftus, L., McCrone, P., & Hayward, P. (1995). The Camberwell Assessment of Need: the validity and reliability of an instrument to assess the needs of people with severe mental illness. *The British Journal of Psychiatry: the journal of mental science*, 167 (5), 589–595. <https://doi.org/10.1192/bjp.167.5.589>
- Porter, ME. (2010). What is value in health care? *N Engl J Med*. 363, 2477-2481  
DOI: 10.1056/NEJMp1011024
- Reynolds, T., Thornicroft, G., Abas, M., Woods, B., Hoe, J., Leese, M., & Orrell, M. (2000). Camberwell Assessment of Need for the Elderly (CANE). Development, validity and reliability. *Br J Psychiatry*, 176 (5), 444-452. doi:10.1192/bjp.176.5.444
- Rosen, A., Hadzi-Pavlovic, D. & Parker, F. (1989). The life skills profile: a measure assessing function and disability in schizophrenia. *Schizophrenia Bulletin*, 15(2), 325-37.
- Sackville, R., Bennett, B., Galbally, R., Mason, A., McKewin, A., Ryan, J., Atkinson, R., (2020) *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Interim Report* <https://disability.royalcommission.gov.au/system/files/2020-10/Interim%20Report.pdf> accessed 28 September 2021
- Shergill, SS., Shankar, KK., Seneviratna, K., & Orrell, MW. (1999). The validity and reliability of the Health of the Nation Outcome Scales (HoNOS) in the elderly. *Journal of Mental Health*, 8 (5), 511-521.
- Sikka, R., Morath, JM., Leape, L. (2015). The Quadruple Aim: care, health, cost and meaning in work. *BMJ Quality and Safety*, 24 (10): 608-10. doi: 10.1136/bmjqs-2015-004160. Epub 2015 Jun 2. PMID: 26038586.
- Slade, M., Amering, M., & Oades, L. (2008). *Epidemiology and Psychiatric Sciences*, 17, 128-137.
- Slemon, A., Jenkins, E., & Bungay, V. (2017). Safety in psychiatric inpatient care: The impact of risk management culture on mental health nursing practice. *Nurs Inq.*, 24 (4) e12199. doi: 10.1111/nin.12199. Epub 2017 Apr 18. PMID: 28421661; PMCID: PMC5655749.
- Smith, SC., Lamping, DL., Banerjee, S., Harwood, R., Foley, B., Smith, P., & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9 (10), 1-93, iii-iv. doi:10.3310/hta9100
- State of Victoria (2021). Royal Commission into Victoria's Mental Health System, Final Report, Summary and recommendations, Parl Paper No. 202, Session 2018–21 (document 1 of 6) page 16). <https://finalreport.rcvmhs.vic.gov.au/>
- Steering Committee for the Review of Government Service Provision (2020). Report on Government Services 2020. Canberra: Productivity Commission.
- Stirman, SW., Gutner, CA., Langdon, K., & Graham, JR. (2016). Bridging the Gap Between Research and Practice in Mental Health Service Settings: An Overview of Developments in Implementation Theory and Research, *Behavior Therapy*, 47, (6), 920-936. ISSN 0005-7894
- Stirman, SW., Kimberley, J., Cook, N., Calloway, A., Castro, F., & Charns, M. (2012) The sustainability of new programs and innovations: a review of the empirical literature and recommendations for future research. *Implementation Science*, 7, 17-36. <https://doi.org/10.1186/1748-5908-7-17>
- Thompson, C., Williams, K., & Masso, M. (2018). Pathways to Community Living Initiative –Evaluation Report 1: Building the foundation for transformational change. Wollongong: Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.
- Thompson, C., Williams, K., Morris, D., Lago, L., Kobel, C., Quinsey, K., Eckermann, S., Andersen, P., & Masso, M. (2014). HWA Expanded Scopes of Practice Program Evaluation: Extending the Role of Paramedics Sub-Project Final Report. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.
- Turnpenny, A., Caiels, J., Crowther, T., et al. (2015) Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT). Discussion Paper 2891. Canterbury, UK: Policy Research Unit in Quality and Outcomes of person-centred care (QORU), University of Kent.
- van der Meer, L., Wunderink, C. (2019). Contemporary approaches in mental health rehabilitation. *Epidemiology and Psychiatric Sciences*, 28, 9-14. <https://doi.org/10.1017/S2045796018000343>

Waldemar, AK., Sidse, MA., Peterson, L. & Korsbek, L. (2016). Recovery-oriented practice in mental health inpatient settings: a literature review. *Psychiatric Services*, 67 (6), 596-602.

Wheeler, AJ., Roennfeldt, H., Slattery, M., Krinks, R., Stewart, V. (2018). Codesigned recommendations for increasing engagement in structured physical activity for people with serious mental health problems in Australia. *Health Soc Care Community*. 26, 860-870. <https://doi.org/10.1111/hsc.12597>

Williams K, Kobel C, Bird S, Westera A, Thompson C, O'Shea P, Coombs T and Grootemaat P (2019) Pathways to Community Living Initiative – Evaluation Report 4: Strengthening Partnerships Through Collaboration. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong, Wollongong.

Williams K, Westera A, Kobel C, O'Shea P, Coombs T and Thompson C (2020) Pathways to Community Living Initiative – Evaluation Report 5: Stage One implementation and outcomes. Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong, Wollongong.

Wing, J., Curtis, R., & Beevor, A. (1996). HoNOS: Health of the nation outcome scales. Report on Research and Development. London: Royal College of Psychiatrists.



# Appendix 1: Staff survey results

**Table 25 Round 2 staff survey results**

Domain	Item	Agree n (%)	Neutral n (%)	Disagree n (%)	Total n
Need	People with complex mental illness can and should be supported to live in the community	64 (87.7)	8 (11.0)	1 (1.4)	73
	The PCLI will promote development of community-based services for people with complex mental illness in NSW	59 (80.8)	10 (13.7)	4 (5.5)	73
	The PCLI is a logical next step in mental health reform	48 (65.8)	17 (23.3)	8 (11.0)	73
Local implementation	The rationale and objectives of the PCLI were clearly communicated to me at an early stage in the program	36 (48.0)	22 (29.3)	17 (22.7)	75
	Training programs were adequate to prepare me for practice changes required by the PCLI	24 (32.0)	24 (32.0)	27 (36.0)	75
	I understand how to implement PCLI activities	32 (43.2)	28 (37.8)	14 (18.9)	74
	Our mental health service has sufficient resources and support to implement PCLI activities	23 (31.1)	25 (33.8)	26 (35.1)	74
	There is an identified leader / champion of the PCLI in my workplace	54 (73.0)	12 (16.2)	8 (10.8)	74
	PCLI assessment tools help me understand consumers' needs	27 (37.0)	28 (38.4)	18 (24.7)	73
	PCLI assessment processes help me understand a consumer's capacity for transition to community	27 (36.5)	31 (41.9)	16 (21.6)	74
	I receive regular, up-to-date information on PCLI's progress	27 (36.5)	29 (39.2)	18 (24.3)	74
	There is a clear commitment from the PCLI leadership team to the objectives of the PCLI	45 (60.8)	22 (29.7)	7 (9.5)	74
Practice change (general)	Continuity of care between inpatient and community settings has improved	54 (72.0)	15 (20.0)	6 (8.0)	75
	Identification of individuals at risk for long-stay admission has improved	38 (52.1)	21 (28.8)	14 (19.2)	73
	Staff better understand how to support self-directed care	22 (29.3)	32 (42.7)	21 (28.0)	75
	Information exchange within and between services has improved	36 (48.6)	23 (31.1)	15 (20.3)	74
	Care coordination between service providers has improved	42 (56.8)	21 (28.4)	11 (14.9)	74

Domain	Item	Agree n (%)	Neutral n (%)	Disagree n (%)	Total n
Practice change (recovery)	Stigmatising and discriminatory attitudes are more likely to be challenged	34 (45.9)	23 (31.1)	17 (23.0)	74
	Consumers are more involved in planning their own care	28 (37.3)	33 (44.0)	14 (18.7)	75
	Care is more person-centred	43 (58.9)	21 (28.8)	9 (12.3)	73
	Recovery-oriented approaches to care have been embedded	37 (49.3)	27 (36.0)	11 (14.7)	75
	Staff encourage and support consumers to develop and enhance links in the community	45 (62.5)	22 (30.6)	5 (6.9)	72
	Service provision is driven by hope and optimism for the consumer's future	43 (57.3)	24 (32.0)	8 (10.7)	75
Practice change (new)	Staff are more aware of available clinical and support services and permanent accommodation options	40 (54.1)	23 (31.1)	11 (14.9)	74
	Access to clinical and support services and permanent accommodation options has increased	49 (66.2)	15 (20.3)	10 (13.5)	74
Sustainability	The PCLI has changed attitudes to long-stay mental health consumers	33 (45.8)	28 (38.9)	11 (15.3)	72
	The PCLI has increased the skills and capabilities of the mental health workforce	32 (43.8)	25 (34.2)	16 (21.9)	73
	Our mental health service has greater capacity and resources to minimise long stays in hospital as a result of the PCLI	34 (47.9)	24 (33.8)	13 (18.3)	71
	The changes resulting from the PCLI are sustainable	35 (47.9)	27 (37.0)	11 (15.1)	73
	PCLI assessment tools are used routinely to guide discharge planning	19 (26.4)	31 (43.1)	22 (30.6)	72
Achievements	The PCLI will result in fewer long-stay mental health admissions in the future	35 (47.3)	26 (35.1)	13 (17.6)	74
	The PCLI has shown that people with complex mental illness can live safely in the community	39 (53.4)	28 (38.4)	6 (8.2)	73
	The PCLI has shown that people with complex mental illness can be appropriately supported out of hospital	49 (66.2)	15 (20.3)	10 (13.5)	74
	The PCLI has developed good contemporary models of care for people with complex mental illness	33 (45.2)	29 (39.7)	11 (15.1)	73
	The PCLI has been successful in supporting long-stay mental health consumers to transition into community living	49 (66.2)	17 (23.0)	8 (10.8)	74

# 10 Responses to the Round 2 staff survey

Survey methods are presented in Section 2.3. In Round 1, 338 invitations were issued and 86 individuals responded from five sites. All respondents rated at least 31 of the 33 Likert scale items. Response rates by site ranged from 20% to 31%. The overall response rate was 25.4%. In Round 2, 75 individuals responded from six sites. It was not possible to calculate response rates overall or by site for Round 2 as some sites did not track the number of invitations issued.

For the five-point Likert scale questions – which were condensed into three points: agree (strongly agree and agree), neutral, and disagree (disagree and strongly disagree) – greater agreement with the statements can be interpreted as a more positive view regarding an aspect of the PCLI. On average across all items, 51.8% of respondents provided a positive rating, 31.3% neutral, and 16.9% negative. Full results are presented in Table 25 and described below.

Respondents were asked to rate their agreement with three statements related to the **need for the PCLI**. There was an extremely high level of agreement among respondents with all three items in the domain, higher than any other domain in the survey. Almost 90% of respondents agreed that people with complex mental illness can and should be supported to live in the community, and just over 80% of respondents agreed that the PCLI will promote development of community services for people with complex mental illness. Around 65% of respondents agreed that the PCLI is a logical next step in mental health reform.

Respondents were asked to rate their level of agreement with nine statements pertaining to **local implementation** of the PCLI. These items were designed to measure program activities and achievements relating to the concept of change management. There was a high level of agreement for two items, which related to clear commitment from the PCLI leadership team to the objectives of the PCLI (60.8%) and having an identified leader / champion of the PCLI in the workplace (73.0%). Considerably fewer respondents reported agreement with remaining items in this domain (<50%), and more respondents disagreed rather than agreed to those items relating to training, resources and support.

This relatively critical view of many respondents towards implementation of the PCLI were reflected in **open-ended comments** provided by 22 respondents. Comments from only two respondents were positive; they praised PCLI staff as “fantastic advocates for consumers” and described the “excellent” initiative “supporting clinical teams to discharge long-stay patients more quickly and to more suitable, supportive and sustainable environments”. Criticisms from the other 20 respondents covered a range of issues, largely applicable to both hospital and community settings, including lack of resourcing for additional work (especially

assessments), lack of communication and consultation, inadequacy of training (and orientation of new staff) and concerns about assessment (e.g. tokenistic rather than to tangibly improve recovery outcomes, issues with interpretation). Several respondents expressed serious concerns about complex patients following transition to the community, including the level of ongoing care and support available and the level of interaction with others.

Respondents were asked to rate their level of agreement with a series of statements relating to **practice changes** they had observed since the implementation of the PCLI. The question acknowledged that not all of the change they had witnessed may be due to the PCLI; the goal was to identify any changes noted during the implementation period. On average 53.1% of respondents agreed with these statements. Five items measured practice change in general. A high proportion of respondents agreed that improvements were evident in continuity of care between inpatient and community settings (72.0%). The majority of respondents also agreed there has been improvements in identification of individuals at risk for long-stay admission (52.1%) and care coordination between service providers (56.8%). Substantially fewer respondents agreed that staff better understand how to support self-directed care (29.3%).

Six items related specifically to **practice change linked with recovery orientation** in mental health services, and two additional practice change statements were included in the Round 2 survey (relating availability of, and access to, clinical and support services and permanent accommodation options). While a relatively low proportion of respondents agreed that consumers are more involved in planning their own care (37.3%), a higher proportion of respondents reported agreement for all other items (≥45.9%).

Respondents were also asked what they felt were the **most important changes** introduced as a direct result of the PCLI. Forty-two respondents provided a response in Round 2. The most common theme related to successfully supporting the transition of long-stay hospital patients into the community (including continuity of care and post-discharge support, resulting in reduced relapse and readmission). Another common theme related to resources, particularly in terms of additional staffing, but also including the availability of supported accommodation and support services, and government investment more generally. Several respondents reported attitudinal (and culture) changes towards long-stay patients were the most important change resulting from the PCLI, including reduced stigma and improved team attitudes in terms of being recovery oriented and embracing a more proactive and community/service-linked approach to discharge. Two respondents mentioned the role of the PCLI in facilitating consumers’ access to NDIS funding. A small

number of respondents perceived that there had been no changes as a direct result of the PCLI (with one remarking that any improvements in their LHD's discharge planning and options for long-stay patients were due to the NDIS rather than the PCLI), or that the most important change was negative (including increased paperwork and confusion around role delineation).

Five items about **whether the PCLI is likely to make lasting change** to the mental health system measured the domain of program sustainability. The level of agreement for each item was relatively low (<50% of respondents). In particular, more respondents disagreed rather than agreed that PCLI assessment tools are used routinely to guide discharge planning.

Respondents were asked to rate their agreement with five 'big picture' statements, which explored their perception of the **progress towards achieving key PCLI program goals**. Responses were generally positive; on average, 55.7% of respondents agreed (and approximately 13.0% disagreed) with the five statements. The two items with highest proportion of respondents (66.2%) in agreement related to the PCLI having been successful supporting long-stay consumers to transition into community living and having shown that people with complex mental illness can be appropriately supported out of hospital.

When asked '**What could be done differently if the PCLI was starting again tomorrow?**', a range of suggestions were provided by 38 respondents. The most frequent recommendations were resource-related. Many respondents indicated a higher level of funding was required to ensure an adequate number of staffing positions and hours, as well as sufficient training and education (both for staff in hospitals and those in community managed organisations). Several respondents also highlighted the need for accommodation options to be available from the program's commencement.

Other common themes in responses were increased consultation and improved communication, in particular around providing clearer role delineation (but also about the appropriateness of transitioning individual patients into

community), and utilisation of assessment tools that reflect individuals; needs for living in the community. In terms of post-discharge support, several respondent felt follow-up needed improvement, with one suggesting that a model of community care that mimics the rehabilitation / long-stay wards would benefit some patients who require more structure and professional support than what community managed organisations can offer. One respondent felt greater acknowledgement of the impact that the NDIS has had in contributing to increasing the number of long-stay patients discharged from hospital was required.

Twenty respondents provided **final comments about the PCLI**. Just under half of these were positive, commending the initiative, however some qualified their comments, for instance noting that work remains to be done, or acknowledging other factors that have contributed to success (e.g. "Combined with NDIS, the PCLI has brought about a revolution in the care of the chronically mentally ill").

One respondent was particularly negative about the PCLI, stating they viewed the initiative as "fragmented and inconsistent and a waste of valuable senior clinicians". Another had some concern that consumers are being rushed out of hospital too quickly and as a result vital information is not being gathered from hospital nursing staff.

One respondent clearly articulated the gravity this initiative has to patients:

*There is a fragile institutionalised person, sometimes with little family support, at the end of these decisions, and we owe it to them to get it right first time... There is no room for experimentation and error.*

Another commented on the multiple challenges facing mental health consumers:

*In a system that discriminates on many levels – health, social, community and welfare services – all of these have to be negotiated in an environment that purports to be assisting but does not have the capacity to cope with the needs of persons with a serious mental illness.*

## 10.1 Differences within the Round 2 sample

The questionnaire asked respondents to indicate their **professional group** and **years working in mental health**. Of the 75 respondents to Round 2, 35 were allied health professionals, 25 nursing professionals, 7 peer workers, 5 coordinator/manager/leaders, 2 medical professionals, and 1 'other'. On four items there was a statistically significant difference between professional groups: allied health professionals were most positive, while nursing professionals were most negative. On six items there was a statistically

significant difference between groups based on years of experience: those with least experience working in mental health (less than five years) were more likely to have positively changed their views of the PCLI over time and were also more likely to have positive views on four of the five other items for which a difference was found (statistics available on request from the authors).

## 10.2 Differences between Round 1 and Round 2

Over the two time points, on average across all statements, the proportion of respondents providing positive ratings increased modestly while the proportion of respondents providing neutral and negative ratings decreased modestly. Results are presented in Table 26.

**Table 26 Overall staff views of the PCLI in Round 1 and Round 2**

Time point	Agree (%)	Neutral (%)	Disagree (%)
Round 1 (2018)	48.9%	32.8%	18.3%
Round 2 (2020)	53.7%	31.8%	14.6%

**Note:** Agreement indicates more positive views of the PCLI and its impacts

In both rounds, there was an extremely high level of agreement (or strong agreement) among respondents with all three items in the domain 'Need for the PCLI' (80% on average for both rounds). However, in Round 2 the proportion of respondents in agreement (or strong agreement) only increased for one of the three items ('The PCLI will promote development of community-based services for people with complex mental illness in NSW').

In both rounds, the average level of agreement (or strong agreement) among respondents for the nine items in the domain 'Local implementation' was 45%. However, in Round 2 the proportion of respondents in agreement (or strong agreement) decreased for six of the nine items.

In terms of practice changes observed since the implementation of the PCLI, five items measured practice change in general and six items related specifically to practice change linked with recovery orientation in mental health services (an additional two questions were asked in Round 2 and are not included in this comparative analysis). The average level of agreement (or strong agreement) among respondents for the general domain was 43% in Round 1 and this increased to 54% in Round 2. The average level of agreement (or strong agreement) among respondents for the recovery orientation domain was 46% in Round 1 and this increased to 52% in Round 2. Within both domains, the proportion of respondents in agreement decreased for only one item ('Staff better understand how to support self-directed care' and 'Consumers are more involved in planning their own care').

The domain of 'Program sustainability' was measured by five items asking staff members to rate their level of agreement with statements about whether the PCLI is likely to make lasting change to the mental health system. As one item from Round 1 was substituted with a new item in Round 2, this analysis only compares the four common items. The average level of agreement (or strong agreement) among respondents for this domain was 40% in Round 1 and this increased to 49% in Round 2. The proportion of respondents in agreement (or strong agreement) increased for each item over time.

In terms of the 'big picture' (specifically perceptions about progress towards achieving key PCLI program goals), respondents were generally positive in both rounds; on average 52% of Round 1 respondents agreed (or strongly agreed) with the five statements, and this increased to 58% in Round 2. The proportion of respondents in agreement (or strong agreement) increased for each item over time. Similar themes were identified through qualitative analysis of open-ended comments in both rounds.

Despite the trends reported above, statistically significant differences between Round 1 and 2 were observed for only two items, as presented in Table 27. For these items, Round 2 respondents were significantly more likely to have a positive response compared with Round 1 respondents.

**Table 27 Differences between Round 1 and Round 2 survey responses**

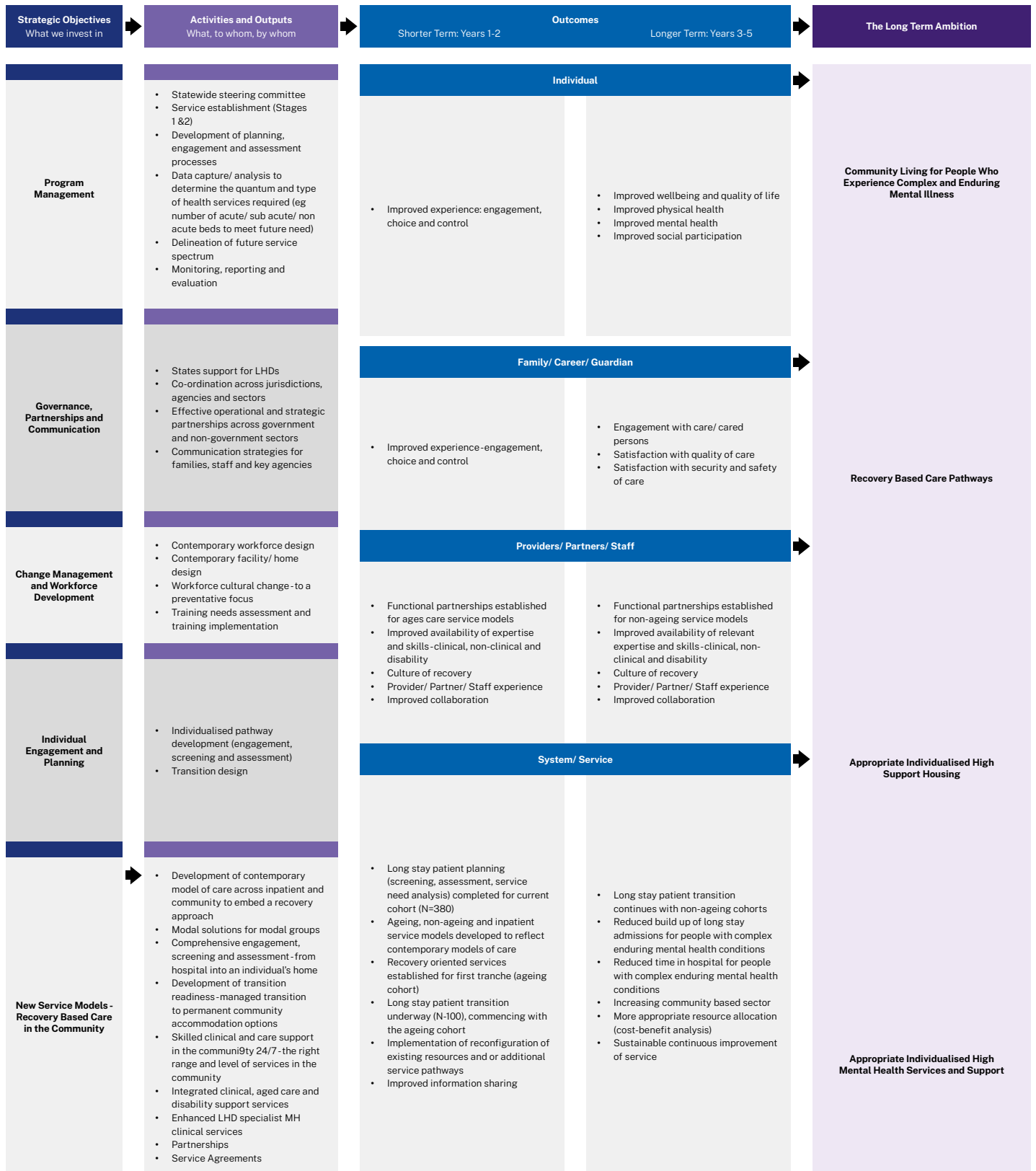
Domain	Item	Round	Agree n (%)	Neutral n (%)	Disagree n (%)	P
Practice change (general)	Continuity of care between inpatient and community settings has improved	Round 1 (n=86)	39 (45)	32 (37)	15 (17)	0.000
		Round 2 (n=64)	48 (75)	13 (20)	3 (5)	
Sustainability	Our mental health service has greater capacity and resources to minimise long stays in hospital as a result of the PCLI	Round 1 (n=86)	29 (34)	29 (34)	28 (33)	0.008
		Round 2 (n=62)	33 (53)	19 (31)	10 (16)	

## 10.3 Summary

- On average across all statements, 51.8% of respondents provided a positive rating, 31.3% neutral, and 16.9% negative (greater agreement with the statements can be interpreted as a more positive view regarding an aspect of the PCLI).
- There was an extremely high level of agreement among respondents with all three items in the domain 'The need for the PCLI'.
- Items within the domains of 'Implementation' and 'Sustainability' had the smallest proportions of respondents reporting agreement.
- In terms of progress towards achieving key PCLI program goals, respondents were generally positive; on average 55.7% of respondents agreed (and approximately 13.0% disagreed) with the statements in this domain.
- Statistically significant differences were observed between professional groups (allied health had the most positive views while nursing had the most negative views) and between years of experience working (those with least experience working in mental health were most likely to have positively changed their views about the PCLI over time and were most positive about several aspects of the PCLI).
- Over the two time points (Round 1 and 2), on average across all statements, the proportion of respondents providing positive ratings increased modestly while the proportion of respondents providing neutral and negative ratings decreased modestly.
- In the 2020 survey, compared with two years earlier, respondents were significantly more likely to agree that there have been improvements in continuity of care between settings, and that health services were better resourced to minimise long stays in hospital as a result of the PCLI.

# Appendix 2: PCLI program logic

## Pathways to Community Living Initiative Program Logic May 2016



# Appendix 3: Consumer outcomes analysis – additional tables

**Table 28 K10 at baseline**

Levels of psychological distress (K10)	Stage One (N=227)		Stage Two (N=777)	
	n	%	n	%
Score under 20 (likely to be well)	93	55.7	477	63.8
Score 20-24 (Likely to be a mild mental disorder)	23	13.8	113	15.1
Score 25-29 (Likely to have a moderate mental disorder)	24	14.4	72	9.6
Score 30 and over (Likely to have severe mental disorder)	27	16.2	86	11.5

**Table 29 LSP-16 at baseline**

LSP-16 subscales	Stage One (N=227)			Stage Two (N=777)		
	n	mean	SD	n	mean	SD
Withdrawal	197	48.0	26.7	720	35.1	23.7
Self-care	197	53.9	25.5	720	38.7	20.9
Compliance	197	36.5	31.4	720	22.6	21.5
Antisocial	197	35.2	29.5	720	22.1	22.5
<b>Total</b>	<b>197</b>	<b>44.5</b>	<b>24.2</b>	<b>720</b>	<b>30.6</b>	<b>18.0</b>

**Table 30 HoNOS at baseline**

HoNOS subscales	Stage One (N=227)			Stage Two (N=777)		
	n	mean	SD	n	mean	SD
Behaviour	169	9.6	11.5	775	10.2	13.7
Impairment	171	30.2	19.1	777	18.6	17.8
Symptom	165	27.6	16.7	766	23.5	19.7
Social	158	27.1	21.4	744	27.3	25.1
<b>Total</b>	<b>154</b>	<b>24.3</b>	<b>13.9</b>	<b>736</b>	<b>21.5</b>	<b>17.2</b>



**Table 31 HoNOS 65+ at baseline**

HoNOS 65+ subscales	Stage One (N=227)			Stage Two (N=777)		
	n	mean	SD	n	mean	SD
Behaviour	156	12.0	10.3	29	12.9	12.5
Impairment	157	39.8	23.3	31	29.0	19.6
Symptom	148	28.8	19.4	30	31.9	24.4
Social	144	31.9	21.5	29	35.8	29.5
<b>Total</b>	<b>135</b>	<b>28.7</b>	<b>14.7</b>	<b>27</b>	<b>29.6</b>	<b>20.2</b>

**Table 32 RUG-ADL at baseline**

RUG-ADL scores	Stage One (N=227)		Stage Two (N=777)	
	n	%	n	%
<b>Bed mobility</b>				
Independent or supervision only	114	71.3	22	84.6
Limited physical assistance	20	12.5	2	7.7
Other than two person physical assist	5	3.1	1	3.9
Two or more person physical assist	21	13.1	1	3.9
<b>Toileting</b>				
Independent or supervision only	89	55.6	16	61.5
Limited physical assistance	33	20.6	7	26.9
Other than two person physical assist	6	3.8	2	7.7
Two or more person physical assist	32	20.0	1	3.9
<b>Transfer</b>				
Independent or supervision only	104	65.0	20	76.9
Limited physical assistance	29	18.1	4	15.4
Other than two person physical assist	3	1.9	1	3.9
Two or more person physical assist	24	15.0	1	3.9
<b>Eating</b>				
Independent or supervision only	110	68.8	21	80.8
Limited physical assistance	30	18.8	5	19.2
Extensive assistance/total dependence/tube fed	20	12.5	0	0.0

**Table 33 RAS-DS at baseline**

RAS-DS domains	Stage One (N=227)			Stage Two (N=777)		
	n	mean %	SD	n	mean %	SD
Functional recovery	49	75.8	17.4	274	78.8	14.3
Personal recovery	49	69.4	20.3	274	78.7	15.4
Clinical recovery	46	59.4	21.4	270	72.4	19.4
Social recovery	46	67.2	22.9	270	73.5	18.3

**Table 34 LCQ at baseline – consumers reporting good to excellent**

LCQ items	Stage One (N=227)			Stage Two (N=777)		
	N	n	%	N	n	%
Overall wellbeing	33	16	48.5	204	135	66.2
Over ability to get support	31	18	58.1	206	135	65.5
Overall: sense of being part	27	15	55.6	201	126	62.7
Overall ability to achieve	31	19	61.3	201	142	70.6
Overall happiness	29	16	55.2	200	141	70.5
Overall hopefulness	31	19	61.3	203	151	74.4
Have you say: opinion respected	30	17	56.7	204	150	73.5
Have you say: friend and family	31	18	58.1	204	129	63.2
Have you say: carer	30	15	50.0	204	139	68.1
Have you say: Community	31	18	58.1	203	134	66.0
Have you say: Control in life	30	17	56.7	204	139	68.1
Physical health	31	19	61.3	204	154	75.5

N = Number of available assessment

n = Number of consumers reporting good to excellent

**Table 35 CAN-C at baseline**

Perspective	Stage One (N=227)		Stage Two (N=777)	
	n	%	n	%
<b>Consumer</b>				
No need	25	56.8	125	45.5
No Unmet need	4	9.1	62	22.5
Unmet need	15	34.1	88	32.0
<b>Staff</b>				
No need	0	0.0	14	5.1
No Unmet need	0	0.0	57	20.7
Unmet need	44	100.0	204	74.2

**Table 36 CANE at baseline**

Perspective	Stage One (N=227)		Stage Two (N=777)	
	n	%	n	%
<b>Consumer</b>				
No need	66	85.7	3	75.0
No Unmet need	4	5.2	0	0.0
Unmet need	7	9.1	1	25.0
<b>Carer</b>				
No need	72	93.5	4	100.0
No Unmet need	1	1.3	0	0.0
Unmet need	4	5.2	0	0.0
<b>Staff</b>				
No need	18	23.4	2	50.0
No Unmet need	7	9.1	1	25.0
Unmet need	52	67.5	1	25.0
<b>Researcher</b>				
No need	39	50.6	2	50
No Unmet need	4	5.2	0	0
Unmet need	34	44.2	2	50

**Table 37 M-DAD at baseline**

Domain	Stage One (N=227)			Stage Two (N=777)		
	n	mean %	SD	n	mean %	SD
Basic ADL	124	43.7	33.5	267	64.9	29.5
Instrumental ADL	124	11.1	14.5	267	31.4	27.9
Initiation	124	27.0	22.7	267	45.4	27.6
Planning	124	24.3	19.9	267	45.2	25.4
Effective performance	124	23.8	19.9	267	46.1	28.1

**Table 38 DemQOL at baseline**

Domain	Stage One (N=227)			Stage Two (N=777)		
	n	mean %	SD	n	mean %	SD
Feelings	25	57.5	18.9	27	54.9	15.8
Memory	25	72.0	23.8	25	66.0	25.7
Everyday life	22	63.5	22.8	26	63.1	22.5
Overall quality of life	24	50.0	34.1	26	48.7	31.6
<b>Total</b>	<b>22</b>	<b>64.2</b>	<b>15.7</b>	<b>25</b>	<b>60.1</b>	<b>15.7</b>



# Notes



NSW Ministry of Health  
1 Reserve Road  
St Leonards NSW 2065

**T:** (02) 9391 9000  
**W:** [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

SHPN (MH) 220183  
ISBN 978-1-76023-118-7 (print);  
ISBN 978-1-76023-119-4 (online)

