Evaluation of the Intellectual Disability Mental Health (IDMH) National Disability Insurance Scheme (NDIS) Residual Functions Program

Evaluation report

Christiane Purcal, Peri O'Shea, Karen R Fisher, Janelle Weise, Fredrick Zmudzki, Preeyaporn Srasuebkul, Adrian Walker, Julian Trollor

Prepared for: NSW Ministry of Health

May 2021

Contents

Appendix E

Abbreviations

3DN	Department of Developmental Disability Neuropsychiatry at UNSW Sydney
AMHOCN	Australian Mental Health Outcomes and Classification Network
AR-DRGs	Australian Refined Diagnosis Related Groups
CALD	culturally and linguistically diverse
HRQoL	Health related quality of life
IDMH	Intellectual Disability Mental Health
K10	Kessler Psychological Distress Scale (K10). The K10LM is a consumer-completed 10 item questionnaire designed to measure psychological distress. K10LM stands for ñLast Monthòwhere the usual rating period is at the interval of 4 weeks.
LHD	Local Health District
Ministry	NSW Ministry of Health
NDIS	National Disability Insurance Scheme
NOCC	Mental Health National Outcomes and Casemix Collection
NSW	New South Wales
QALY	Quality Adjusted Life Year
SHN	Specialty Health Network
SPRC	Social Policy Research Centre
UNSW Sydney	University of New South Wales

Executive summary of the report

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called ‘Residual Functions Program’ or ‘program’ for short) is a NSW Health program funded by the NSW Government from 2018 to 2021. It aims to improve service access to better support people who experience both mental health issues and intellectual disability.

The Social Policy Research Centre (SPRC) at UNSW Sydney, together with the Department of Developmental Disability Neuropsychiatry at UNSW Sydney (3DN), evaluated the Residual Functions Program between December 2019 and February 2021.

This evaluation report summarises the findings of the evaluation. The qualitative findings are from interviews and focus groups with program consumers, their families, service providers and other stakeholders in NSW. The quantitative and economic findings are from administrative data from NSW Health.

Program characteristics

The central part of the program provided funding to ten Local Health Districts and two Specialty Health Networks across NSW to improve clinical support and build service capacity and coordination. The programs varied widely to respond to different local needs. Programs identified and addressed a range of challenges that affected their local implementation. The challenges were partly due to COVID-19 and the short timeframe of the program.

Implementation of the program

Coordination and engagement: Coordination improved across health and other service providers, and with consumers and families. Providers appreciated having a local contact point for coordination between mental health and NDIS for people with highly complex care needs. Consumers and families liked the more coordinated, multi-disciplinary support.

Consumer access to services: Consumers received direct clinical support they had not been able to access before. This included clinical support in a community setting that was better focused on both mental health and intellectual disability needs. The support was offered closer to where consumers lived. Providers made consumers feel comfortable and respected when they came to the services. It was sometimes difficult to find out about the program. A shortage of services limited access to support.

Capacity of health services, disability and other support: Building capacity of services worked best where the Residual Functions Program combined training courses or webinars, with using the new knowledge in practical work like case meetings or direct consumer support. Intellectual disability and mental health service providers said that now they better understood each other's approach and the different kinds of support that consumers needed. They could also ask the local program contact person for advice. Most said the short-term funding of the program would make it difficult to maintain changes.

Availability of data: There was not enough quantitative data about consumers with intellectual disability and mental health challenges and their individual needs. Data were not shared enough between the mental health and disability sectors.

Culturally safe services: Service providers engaged interpreters and drew on mainstream culturally specific services, such as migrant resource centres or Aboriginal Medical Centres. Most consumers and families said the inclusive and respectful nature of the program services made them feel safe. Some consumers and families said safety strategies to meet the needs of people with intellectual disability and mental health problems were more important than cultural needs.

Impact of COVID-19 on implementation: COVID-19 slowed down program implementation. Staff recruitment was slow, and some training and coordination

ind

Outcomes for consumers and families

The outcomes are largely from the qualitative data. It was difficult to make firm conclusions about outcomes and changes from the quantitative data, as this was collected over 3 months for most analyses and the sample was too small.

When Sally started on the program, the doctor listened to Sallyǿs story,
acknowledged h 713.82 679.06 0.48006 0.f*QQq0.000008871 0 595.32 841.92 reW* nBT/F1 12 Tf

the program tried to make sure their mental health and intellectual disability needs were addressed as well as their physical needs. Hospital staff tried to start making links for the consumer to NDIS as soon as possible. But to do so, they needed better data

1 Introduction

The Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program (called óResidual Functions Programô or óprogramô for short) aims to develop services to better support people who experience co-occurring mental health issues and intellectual disability.

The NSW Ministry of Health (the Ministry) funded the Residual Functions Program for three years until 2021.

Funding has been used to establish three Streams of activities to improve the capacity of mainstream mental health services to work more effectively with people living with intellectual disability and co-occurring mental illness as well as their families. The three Streams are:

Support for LHDs and SHNs (Stream 1): 10 NSW Local Health Districts (LHDs) and 2 Specialty Health Networks (SHNs) were funded to enhance clinical and capacity building services (**Appendix C**).

Support for ID Health Teams (Stream 2): The Ministry funded an IDMH Clinician in each of the six Intellectual Disability Health Teams across NSW to provide clinical and capacity building supports.

Centralised coordination (Stream 3): The Residual Functions Program also allows for the centralised, coordinated management of capacity building activities and resources that support the improved clinical care of people living with intellectual disability and co-occurring mental illness.

Program logic

The program logic is a document that lists the program activities and intended outcomes. The program logic shows how different aspects of the program fit together:

program inputs, activities and outputs

process outcomes

and outcomes for direct consumers.

The evaluators used the program logic for the Residual Functions Program to measure how the program was going. The program logic was developed with the Ministry and refined during the evaluation. The Residual Functions Program Logic is in **Appendix A**.

- LHD managers
- other stakeholders.

The sites were agreed with the Ministry and included one LHD in the Sydney area and one regional LHD. In addition, we conducted interviews and focus groups with other stakeholders. These included representatives from program locations across consumers. Data were not available to measure what happens for people who are in the program for longer or after they leave the program. For this reason, the analysis could not include consumer pathways, or medium or longer term outcomes.

The economic evaluation developed a Markov model framework to assess cost effectiveness of the program. The model used the core base case (which is the partial analysis of available linkage data as a lower boundary) to extend conservative cost effectiveness scenarios. The scenarios included potential benefits for estimated Stream 1 consumers, potential outcomes for families and carers, and possible preventable deaths avoided. The scenarios were built using supplementary data sources and from what was known in the literature about mental health outcomes.

Appendix B has a summary of available data sources, outcomes and timeframes for the economic modelling. This includes details of program cost data, outcomes, target populations and the Markov model approach as well as limitations for the program cost effectiveness analysis.

More detail about the evaluation methods can be found in the evaluation plan (Purcal et al. 2020) and at **Appendix B**.

3 Program characteristics

This section describes the characteristics of the Residual Functions Program. The characteristics include the:

- program aims and activities
- demographic profile of consumers.

Findings about the program aims and activities came from the program documents, which are analysed in this section. Program documents were available for the Residual Functions Program Stream 1 (LHDs & SHNs - as outlined in **Section 1**). The available program documents from LHDs and SHNs were:

- Expressions of Interest
- Progress reports.

Findings about the consumer profile are based on the quantitative data that were routinely collected as part of the program.

3.1 Program aims and activities

The program aims to develop mainstream mental and physical health care capacity that will improve access for people with intellectual disability and mental health needs.

The **Expressions of Interest** for Stream 1 programs showed the focus and intended outcomes for each organisation and location, and the start dates -4.04 Tf1 TJETQ EMC[(fxi,s00387 1 12 Tf)1 0 [(inclu)ET7nBT/F1 1
(**Appendix C**). The programs 0 G[(Th)1 0 0 11 0 0 1 510.46 623.74 Tm0 g0 G -0.096 Tc[(,)] TJET

program

The progress report template included fields titled óOverall status and key issues summaryô and óCritical risks/issues and action planô. We analysed the responses in these fields across the 40 available progress reports.

A wide range of consumers took part in the interviews.

> They were consumers who lived in family homes, in supported living or in custody. No-one we spoke to lived independently.
>
> They ranged in age from children to older people.
>
> Some had no previous contact with mental health services or the NDIS, others had a long history of both, and some were in-between.
>
> Many consumers had high support needs, some had medium and few had low support needs.

In the interviews, there was also a wide range of families and carers of program consumers. Some had lots of support in their caring role

4 Implementation of the program

The evaluation assessed how the Residual Functions Program was implemented, that is, how it was put into practice and what could be improved. This type of research is also called process evaluation. The main intended implementation (or

- starting a community of practice (this is providers sharing their experiences in a group)
- working on Memoranda of Understanding (these are agreements about how to work together).

On the ground, coordination and engagement with the NDIS included:

- identifying appropriate providers
- developing mental health resources for providers
- supporting consumers to prepare for NDIS applications and reviews, like organising assessments, developing goals and liaising with NDIS providers and NDIA planners.

Disability service providers (NDIS) and health professionals were eager to engage with the program and found it helpful. They appreciated having a local contact point for coordination between mental health and NDIS. Better collaboration meant that disability services focus groups, the providers and stakeholders who had used the ISR program regretted its loss. They said it had built up a network of knowledge about who could support consumers to address their needs, particularly consumers in inpatient care or custody. They felt that the Residual Functions Program had potential to fill the gap to some extent, but they were sceptical whether it could offer the level of intensive support that ISR had provided.

The programQq0.000008871 0 595.32 841.92 reW* nBT/F1 12 Tf1 0 0 1 167.54 758.6t2 reW* nBT

Mental health providers and key stakeholders mentioned the same issue. This suggests information about the program could be better promoted.

Generally, a shortage of services limited access to support. Some gaps mentioned were, for example, professionals to do assessments, and NDIS services in rural areas. As program services were intensive and time limited, the number of people who could potentially access the program might also be limited. Many interviewees were concerned that some of the direct services offered by the program might not continue if the program ends.

The program might benefit from:

- wider promotion
- more services generally being available for people with intellectual disability and mental health.

4.3 Capacity of health services, disability and other support

Capacity building in the Residual Functions Program included both training and on-the-job collaboration in working with consumers.

4.4 Availability of data

Service providers and other stakeholders said that data collection about people with intellectual disability and mental health problems was inadequate. They saw this as a barrier to

governance structure with committees that functioned well to unite experience, and more buy-in from the managers in the LHDs, Ministry and health settings.

Mental health staff said it had been good to have the flexible funds from the program to address gaps in the system.

5 Outcomes for consumers and families

The evaluation assessed outcomes of the Residual Functions Program for consumers and families. Intended outcomes are listed in the program logic (**Appendix A**). This section discusses:

- Health and wellbeing
- Services in the community (also called ambulatory services)
- Emergency department presentations
- Hospital admissions
- Length of hospital stays
- Impact of COVID-19 on outcomes.

Quantitative data were available only for Stream 1 of the program. Details of the quantitative results are in **Appendix G**.

5.1 Health and wellbeing

Louise was referred to the program as part of her discharge plan from hospital ... Louise's medication was changed, and she became more settled and engaged. Now Louise's parents, Pat and Raj, are really enjoying her company – they had almost forgotten how funny she could be! The program also helped Pat and Raj apply for NDIS, and Louise is getting to know and trust new people who can help with personal care ... In a few weeks Louise is going to try respite in a house that theypaelp with

Mental health improvements for consumers seemed to be largely because of more frequent, person-centred and trauma-informed approaches. This included a review of past treatments, medication and new NDIS support. As a result, consumers reported more confidence and independence and being more engaged in social activities:

> Now Iôm

the program identified mental and physical health needs that led to planned hospital stays.

There is some evidence from the interviews and focus groups that consumers in the program reduced contact with hospitals for their mental health. That could mean they were managing their intellectual disability and mental health with access to support in the community (**Section 5.2**).

Consumers in Stream 1 did not have a statistically significant change in the length of hospital stays (per person per month). The rate of re-admissions to a mental health inpatient facility was 19.4% before participating in the program and 29.4% after participating in the program. However, this change in the re-admission rate was not statistically significant, perhaps due to the small sample size.

The interview participants said that when a consumer entered the hospital, the program tried to ensure their mental health and intellectual disability needs were addressed as well as their physical needs. For example, when a consumer needed a scan, health workers might offer sedation to make the scan more comfortable for the consumer. Interviewees agreed the program was in its early stages. They said its collaborative approach offered an opportunity to learn from past experiences:

> … drawing on some examples where things have not gone very well, where somebody's repeatedly gone to ED and then ended up in hospital … it's good to use that as a learning exercise and say … at what point could we have … done things a little bit differently. (Staff)

Mental health staff said that they needed to make links for a consumer between mental health services and NDIS quickly, as soon as they were admitted to hospital. This was because it took a long time to organise NDIS support. The longer they waited to make links to NDIS, the longer the consumer had to stay in hospital. Making these links required appropriate data about consumers' intellectual disability (**Section 4.4**).

The program might benefit from:

- supporting hospital staff with good data about a consumer's characteristics, diagnosis and service needs and use, so they can link patients to the NDIS quickly, reducing the consumer's time in hospital
- following up consumers 12 months after participating in the program to see what impact the program had on contact with hospitals.

5.4 Impact of COVID-19 on outcomes

The assessed outcomes of the Residual Functions Program for consumers and families may have been impacted by COVID-19.

Many consumers said they missed out on community activities during the COVID restrictions (**Section 4.6**). Some service providers in supported accommodation were surprised at the positive spirit of consumers despite the changes. This observation helped to revise some preconceived ideas about consumers. Some providers also credited the ongoing support for consumers via the program during this time.

Some consumers found the social isolation difficult, and their mental health got worse during COVID. Others seemed to prefer the quiet times, and providers said they found it hard to encourage them back into their communities. Some key stakeholders spoke about the wider negative effect of COVID-19 on mental health and how it may increase the need for mental health programs.

Families applauded supported accommodation for increasing staff during COVID to replace day programs. Also, families said that contact with the consumers in supported accommodation did not suffer during COVID because of staff efforts to facilitate phone calls and COVID-safe visits.

The program might benefit from learning from COVID-19 for future crises, for example:

- how to address mental health issues that are due to social isolation.

6 Economic evaluation

The economic evaluation examined outcomes and benefits to consumers and families, the costs of the program, and an estimate of the number of consumers in the program over the short and long term. The analysis takes a base case of the quantitative outcome data for Stream 1 consumers and extends the base case by using conservative scenarios about further potential outcomes. It estimates program cost effectiveness for consumer groups during the study period and for potential outcomes over the following five years. This section provides a summary of the economic evaluation. Further detail is in **Appendix H**.

The program aims to develop mainstream mental and physical health care capacity that will improve access for people with intellectual disability and mental health needs. Without the program they might not have access or only have partial access. With the program, consumers and their families may have improved health, wellbeing and life expectancy.

The economic evaluation is based on the available consumer outcomes presented in Section 5. The economic modelling also used related findings from the 2020 Productivity Commission Inquiry into Mental Health. The evidence from that Inquiry is important because it can be applied to extend the analysis in the Residual Functions Program economic evaluation.

The Productivity Commission Inquiry examined service planning and reform in the wider mental health system. It recommended expansion of mental health services in Australia based on evidence of outcome effq0.595.32 84Tm0 C000008871 0 595.3aboutco 2 Tf1 0 0

6.1 Consumers in the program

The program Stream 1 provided funding to 10 LHDs and 2 SHNs. Stream 2 funded program clinicians to support the six ID Health Teams (Section 1). The number of Stream 1 consumers increased during the 12 months of the evaluation in 2019-20, Figure 1. By June 2020, 124 Stream 1 consumers had direct program support. The number of Stream 2 consumers was estimated based on the pre-program plan (Cvejic, Eagleson, Weise, & Trollor, 2018) because data about the actual number of consumers were not available. Stream 3 estimates were not included, although many consumers would also receive indirect benefits not captured in the conservative economic evaluation here.

Figure 1 Residual Functions Program total estimated consumer entries by month to June 2020

Sources: NSW3(0)-3(1)6(9)] TJETQq0.000008871 0 595.32 841.92 reW* nBT/F1 12 Tfs by started in 2019-20. The expected total program had diagnoses associated with high costs of care. One quarter of admissions were for consumers with borderline personality disorders (15%) or schizophrenia (10%). Appropriate service use for consumers with these conditions can lead to positive outcomes and reductions in health service costs (Meuldijk, McCarthy, Bourke, & Grenyer, 2017; Hall, Caleo, Stevenson, & Meares, 2001).

Emergency department

Rates of emergency department presentations for Stream 1 consumers did not change (Section 5). Slight reductions were observed for emergency presentations that led to an inpatient admission and urgent presentations. The interviews indicated self-reported reductions in emergency use because of regular community clinical care.

Community mental health

The rates of community mental health treatment days, including increased access to clinical psychologists, visiting medical officer psychiatrist and psychiatric registrars all increased (Section 5). The interviews found the same benefit. This is reflected in the economic modelling through the increased cost of community-based support and the related K10 mental health outcome scores.

6.4 Health outcomes

Change in health and wellbeing of consumers in Stream 1 seemed positive but was not statistically significant due to the small number of post program K10 scores, as explained in Section 5.1. People in the interviews said that better access to support had improved the mental health and wellbeing of consumers reporting protocols and common quality of life instruments including the Australian developed Assessment of Quality of Life (AQoL) (Mihalopoulos, Chen, Iezzi, Khan, & Richardson, 2014). This work includes the K10, which is part of Residual Functions Program reporting.

Table 3 Residual Functions Program and NSW community mental health K10 scores 2018-19

	Residual Functions Program				NSW community mental health (NOCC)		
Diagnosis	**n**	**%**	**K10 before**	**K10 after**	**n**	**%**	**K10 before**

Figure 3 shows that cost effectiveness would increase if it was assumed that the program achieves even a small (0.2 QALY) improvement for a single family member or carer. Only interview data were available to support this assumption. Family and carer outcomes data are not currently measured in the program.

Figure 3 Program cost effectiveness – benefit to consumers, family and carers

Source: NSW Ministry of Health Mental Health Branch: program cost data and data linkage Stream 1. Residual Functions Program cost data.

Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Assumption of 0.2 QALY improvement for one family member or carer. Estimated over a 5 year timeframe.

Potential deaths avoided

An additional perspective to analyse cost effectiveness is to consider potential deaths avoided due to better access to services in the program. The program did not collect data about premature death, but the outcomes analysis showed better access to health services (Section 5), which reduces the risk of premature death. As many as 38% of deaths of people with intellectual disability may be avoidable if people had better access to health care (Trollor, Srasuebkul, Xu, & Howlett, 2017).

Figure

Appendix A Program logic for IDMH NDIS Residual Functions Program

Program aim: To improve the capacity of mainstream mental health services to work more effectively with people living with intellectual disability and co-occurring mental illness, and with their families and carers

Program logic summary

1. LHD programs	- Clinical services - Consultation liaison - Capacity building - Education	- Health and service providers have better partnerships - Health services offer better specialist support - IDMH consumers leave hospital faster - IDMH consumers have better access to support - Mainstream clinicians provide better support to people with IDMH - More and better data on IDMH consumers and services	- Improved wellbeing - Fewer visits to emergency - Fewer hospital admissions - Less time in hospital - More use of out0 G[.$17 0ntpeeides

Full program logic

Inputs	Activities	Outputs	Process outcomes	Outcomes for direct consumers
Funding				

Inputs	Activities			Outputs	Process outcomes	Outcomes for direct consumers
			Capacity Building		specialist care for people with intellectual disability and co-occurring mental illness and for their families and carers Improved patient flow through acute MH facilities due to better coordination and discharge planning	HoNOS, HoNOSCA, NDIS] Improved cost effectiveness of mainstream mental health services based on healthcare cost offsets for outcomes mentioned above
	South West Sydney LHD	NDIS Pathways Clinician	Consultation Liaison Capacity Building			
	Southern NSW LHD	IDMH Clinic	Clinical service Consultation Liaison Capacity Building			
	Western NSW LHD	IDMH Clinic	Clinical service Consultation Liaison Capacity Building			
	Western Sydney LHD	Clinical team	Clinical service Consultation Liaison Capacity Building			
<u>Stream 2: IDMH Clinicians</u> An IDMH Clinician was funded in each of the six ID Health Teams across NSW, to provide clinical and capacity building supports Locations: Northern Sydney LHD South East Sydney LHD - Kogarah Assessment Service Sydney LHD South West Sydney LHD Hunter New England LHD Western NSW LHD	- facilitate improved access to appropriate psychological and mental health care for people with intellectual disability and mental health - may provide assessment and short term clinical care - support the increased capacity of the Ministry and mental health staff to build skills and confidence to work with people with intellectual disability and mental health				Mainstream clinicians: - have more exposure to people with ID - can access expert support and advice from IDMH clinician - report increased capacity and confidence to provide care for people with ID - report improved access to specialist	

Inputs	Activities	Outputs	Process outcomes	Outcomes for direct consumers
<u>Stream 3: Capacity Building</u> Centralised management of capacity building activities and resources in addition to Streams 1 and 2.	a state-wide, coordinated approach to developing and providing resources that support the improved clinical care of people with co-occurring intellectual disability and mental health, and improved support for their families and carers	Capacity building resources	diagnostic and assessment services Improved data on: - Service activities - Prevalence of people with ID in MH services - Access to MH services for people with ID - Codesign of metal health services delivery	

Appendix B Details of evaluation methods

The evaluation assessed the processes, outcomes and economic costs and benefits

Step 2: Service providers made initial contact with the consumers or family members, provided information about the evaluation and obtained permission to pass their contact details on to the evaluators or to set up an interview time.

Recruitment of service provider staff and other stakeholders: Service provider managers in the fieldwork sites identified suitable staff for the interviews and asked them if they would like to participate. Other stakeholders were invited by the Ministry to participate.

Consent processes

Participation in the interviews or focus groups was voluntary. All participants must be freely able to give their consent to participate.

The **consent process for consumers**

ii) rates of unplanned in-patient admissions

iii) re-admission rates to inpatient facilities

iv) length of stay in an inpatient facility

v) treatment days in ambulatory mental health services

measured at a time of increased risk may reflect regression to the mean (Linden, 2013).

Attributing improvements (or deterioration) of outcomes to the Residual Functions

Appendix C Stream 1 programs: focus, outcomes and start dates

Organi-sation/ Location	Program focus	Proposed outcomes	Start date[1]
Central Coast LHD	0-12-year-old clinical service	Established pathways between services to	

Key issues in reports	Challenges mentioned in reports	[redacted]
		[redacted]
Quality control	Maintain standard of services after program finishes	[redacted]
COVID-19	Precludes service provider visits in prison, thereby precludes holistic support	[redacted]
	Delay in program start	[redacted]
	Delay in program progress	[redacted]
NDIS pathway	Support for psychosocial NDIS applications in custody ended 1/6/20 ï causes service gap	(none offered)
Geography	Non-metro location restricts access to specialty psychiatry clinic	FlexibiBT/FBA59.67 Tm0 G[(Non)] TJ

Appendix E Profiles of consumers and families

The names are not those of any person interviewed. The stories are composites of more than one consumer story as told to us by consumers, families and staff.

Sally

Sally wants to find paid work. When Sally was a young girl, she was abused and neglected. Until recently Sally lived in a house where she often felt scared of the people she lived with. When Sally moved into her current home, she did not trust her new support workers and housemates. At first she stayed in her room and did not communicate with them very much.

When Sally started on the program, the doctor listened to Sally's story, acknowledged her trauma and helped her to understand how her childhood experience had affected her behaviour. The doctor also gave her different medication. Sally then found it easier to talk with others in her home. Now she loves to spend time with her housemates. Sally then worked with the support workers to extend her social circle, first to the day centre and then to paid employment.

Jim

Jim likes spending time in the bush with his grandfather on weekends. Jim lives in supported accommodation with three other people and a support worker. He communicates without speech. Sometimes Jim gets upset and he shouts at the people he lives with or the support worker. Jim had to take lots of medication, which made him sleepy and feel a bit sick. Sometimes Jim felt even too tired and sick to go into the bush with his grandfather.

Since joining the program, the support workers at Jim's home are doing some training about intellectual disability and mental health. They are also working with Jim and his mental health team to come up with ways to help Jim when he gets upset. Jim now takes less medication and he is not so sleepy. Last weekend Jim and his grandfather went fishing and Jim was really looking forward to sharing the photos of his catch with his housemates.

Louise, Pat and Raj

Pat and Raj have 3 children. Their youngest, Louise, is aged 38 years, and lives with them. Louise has intellectual and physical disability and a mood disorder. Louise needs daily support with personal care and needs constant company except for a few hours. Pat and Raj love Louise and would do anything for her. Responsibility for her care has meant that they have been unable to spend long visiting their other children and grandchildren as Louise can get upset and agitated if they visit is more than an hour. Pat and Raj, who are both in their early seventies, have also been worried about what will happen to Louise when they become too old to care for her.

About 6 months ago Louise was taken to the emergency department by ambulance after she became very agitated and tried to hurt herself. Louise spent a few days in the inpatient unit before being discharged home with Pat and Raj. This had happened many times before. Pat and Raj were frustrated that Louiseǒs mood settled at the hospital but there did not seem to be a plan for any long-term change afterwards to prevent future emergency visits, which were traumatic for Louise and them.

This time however, Louise was referred to the program as part of her discharge plan from hospital. Pat and Raj were invited to participate in making a plan with Louise and her new care team. They were asked what they wanted for Louise and themselves. Louiseǒs medication was reviewed and she became more settled and engaged. Now Pat and Raj are really enjoying Louiseǒs company ï they had almost forgotten how funny she could be! The program also helped Pat and Raj apply for NDIS and Louise is getting to know and trust new people who can help with personal care. Louise is still living at home with Pat and Raj but last week they took a couple of their grandchildren to the movies, leaving Louise at home with her new carer to watch Netflix. In a few weeks Louise is going to try respite in a house that they all visited. Louise is excited about the cats that live there. Pat and Raj are no longer dreading the future.

Appendix F Stream 1 Capacity building activities

Summary of Capacity Building Activities as reported in Stream 1 progress reports

	Category	Number (%)*
Distribution of Activities	Formal face to face learning	158 (14%)
	Group supervision	40 (3%)
	Clinical Supervision	16 (1%)
	Inservice	153 (13%)
	Individualised 1:1 activities	349 (30%)
	Other	437 (38%)
Distribution of Disciplines		

Appendix G Quantitative results

Summary of health service use patterns, participant wellbeing and mental health outcomes before and after enrolment in Stream 1 programs

Participant Demographics

Table 1: Demographics of participant in Stream 1 of the Intellectual Disability Mental Health National Disability Insurance Scheme Residual Functions Program* (N=124) up to September 2020

Variable	Category	n (%)
Sex	Female	50 (40)
	Male	74 (60)
Indigenous status	Indigenous	10 (8)
	Non-indigenous	114 (92)
Born in Australia	No	12 (10)
	Yes	112 (90)

*Data available for 9 of the 12 locations

Emergency Department Presentations to a NSW Health Facility

Table 2: Regression analysis of the rates of emergency department presentations per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=55)	Before (Reference)	1	-	-
	After	1.28	0.83 ï 1.98	0.27

Table 3: Descriptive characteristics of emergency department presentations before and after commencing Stream 1

Variable	Category	One year before program commencement n (%)

Admitted patients to a public NSW hospital

Table 4: Regression analysis of rates of

Table 8: Regression analysis of rates of admitted patient episode to a psychiatric facility per person per month before and after commencing Stream 1

		IRR	95% CI	p
Self-control case series regression (n=42)	Before (Reference)	1	-	-
	After	1.3	0.73-2.31	0.37

Table 9: Regression analysis of length of stay per admitted patient episode to a psychiatric facility per person per month before and after commencing Stream 1

Table 13: Activity provided by the ambulatory mental health services before and after commencing Stream1^

Activity Code*	One year before program

Mental health outcomes

Table 15: Regression analysis of HoNOS scores before and after commencing

working towards filling gaps and addressing barriers in the services available to people who need support due to mental ill-health, and their families and carers

remove

Program costs

The Stream 1 health data linkage provided statistically significant results indicating increased hospital admissions as well as increased access to community mental health services, section 5. These increased health services following entry to program reflect a positive interim program outcome for the study group sample. The economic modelling includes the estimated cost of this improved health service increase but follow up data on associated health outcomes is yet to be established.

Prior research has shown that health services and costs in people with intellectual disability are higher than the general population including higher unmet needs and lower use of preventative and generic mainstream health services (Salvador-Carulla & Symonds, 2016). This research also reports that people with intellectual disability and comorbid mental disorders have the highest rates of specialised health service use and cost. In the case the program is improving access to identify unmet needs and improve the use of preventative and mainstream services, the associated cost offsets could potentially be substantial.

Hospital admissions

The quantitative analysis shows a statistically significant increase in the rates of admitted patient episodes per person per month for the Stream 1 consumer study group. While the rate of hospital admissions increased there was no increase in the average length of stay (LOS) per admission before and after entry to the program.

Review of the hospital admission Diagnosis Related Groups (DRGs) indicates the average LOS, while not changing significantly before and after program entry, reflected higher than average LOS for NSW reported DRGs. This is consistent with research showing higher use of health services for people with intellectual disability. The consumers have a high proportion of diagnoses associated with high costs of care. One quarter of admissions were for consumers with borderline personality disorders (15%) or schizophrenia (10%). Appropriate service use for consumers with Taat cha3( )8(a)-3(o)-3(sitive)6(-i)12(n)-3(p8(e)-3(6)5(a)-6(p)4(u)-3(tco)4(m)-6(e)-3(s)it)10(h)-3( ) these conditions can lead to positive outcomes and reductions in health service costs. (Meuldijk, McCarthy, Bourke, & Grenyer, 2017) (Hall, Caleo, Stevenson, & Meares, 2001).

The health needs and costs for schizophrenia are also high for individuals, their families, the health system and often longer term persistent societal implications including through employment loss (Knapp, 2000). This provides supp* nBT/F/F1 iis provides supp

cess tre a(m)et chfu5(ll)4(o)vedectio-5(d)6(h)i-3(t)6(h)-3(e)-3( )8(g)-3(cti-3(n)6(o)-3(m)-6(ic)10(m)-6(o)6((cc6(m

Emergency department

There was no significant change in the overall rates of emergency department presentations for Stream 1 consumers, although slight reductions were observed for ED presentations resulting in an admission and for urgent ED presentations. The qualitative interviews indicated self-reported reductions in ED because of newly established regular care through a psychiatrist for the first time.

Community mental health

The Stream 1 program data show a statistically significant increase in the rates of community mental health treatment days, including increased access to clinical psychologists, visiting medical officer psychiatrist and psychiatrist registrars. The qualitative interviews also reported that most consumers were accessing services in the community rather than through hospitals.

This is reflect

identified in the quantitative analysis are aimed to leverage this recommended increased capacity for people with intellectual disability.

consumers reporting K10 scores after entering the Residual Functions Program. The quantitative analysis presented in section 5 indicates improvements in K10 scores following entry to the Residual Functions Program but did not establish statistically significant results due to the small sample of consumers who reported before and after entry scores.

To examine and verify the program K10 results figures were compared to NOCC reporting through the Australian Mental Health Outcomes and Classification Network (AMHOCN, 2019). Figures were reviewed for the study group available through the program data linkage compared with NSW adults receiving mental health ambulatory services during 2018-19, Table 7. The reported NOCC scores are based on new referral consumers (before program entry) and the subsequent 91-day review point following commencement of support services.

Table 7 Residual Functions Program and NSW community mental health K10 scores 2018-19

	Residual Functions Program	NSW community mental health (NOCC)

The purpose of this comparison is not to imply that the program group may have better K10 outcomes, although this appears plausible. This comparison is primarily used to validate that the reported program improvements are within NSW reported ranges and although the small sample was not sufficient to establish statistical significance the results are not only consistent with NOCC outcomes but are likely to be conservative with the program group showing a mean K10 improvement of 2.1 compared with larger sample comparative diagnoses of at least this level and 7.1 for the total group.

The quantitative analyses also examined the proportion of consumers changing K10 category based on ranges for low, medium, high and very high total scores. Again, although the study group sample size was limited, particularly for scores following program entry, there was a reduction in the number of consumers reporting high and very high scores to the moderate normal level, reflecting as improvement from a clinically significant range to a non-clinically significant range.

Program cost effectiveness

The Residual Functions Program cost effectiveness modelling integrates all program costs and the available Stream 1 changes in health service costs, combined with estimated QALYs gained through proxy K10 transformations (Mihalopoulos et al., 2014). As presented in the methodology the available data provide only partial details on the total target program population, only interim outcomes through health service use, and limited clinical endpoints to examine program costs in terms of outcomes.

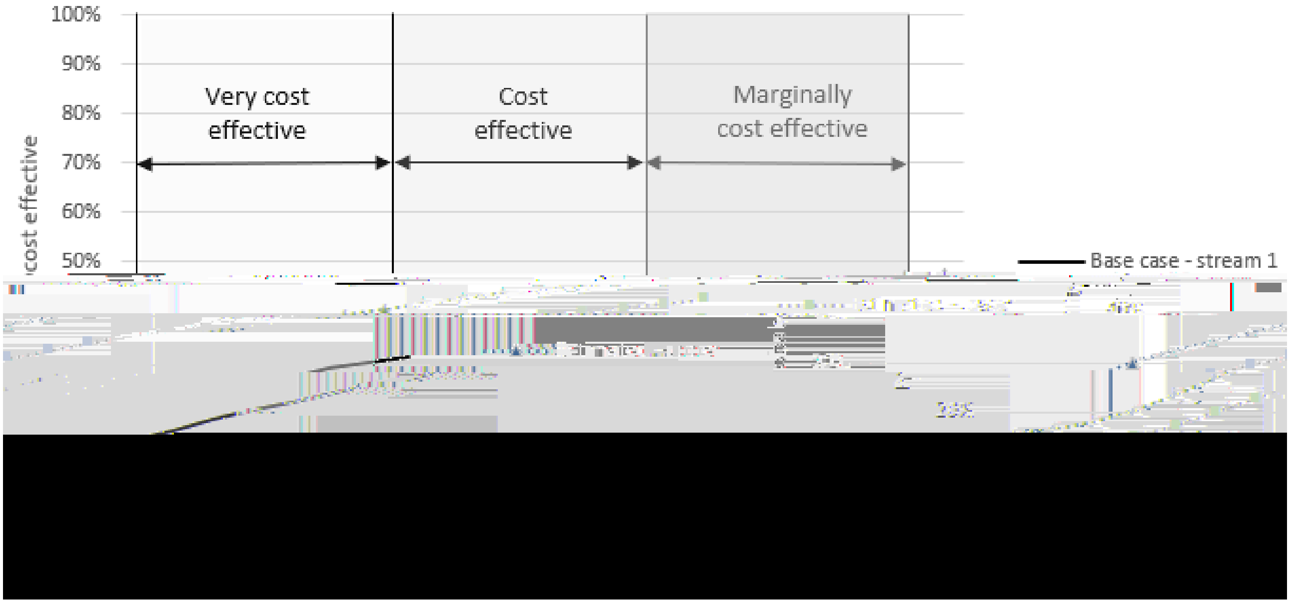
Given the limited data and high level of uncertainty the modelling approach is conservative and aimed to develop a framework to examine additional plausible outcomes. The model base case includes all program costs but includes only a subset of potential benefits based on the study period short term timeframe. In this context, although the Residual Functions Program does not yet have available data on these outcomes, there are potentially substantial lagged additional benefits to the program.

Incremental cost effectiveness ratios have been estimated based on the mean cost before entry and following engagement in the Residual Functions Program and the associated estimated QALY gain for the study group. The Markov model specification includes variation across all parameters as standard deviations and the cost effectiveness ratio estimates were assessed using probabilistic sensitivity analyses. This provides nonparametric bootstrapping resampling to examine the joint uncertainty across all model parameters. This section presents the estimated program cost effectiveness results for the initial base case followed by extended scenarios considering family and carers and potential avoidable ID deaths prevented.

Program base case – Stream 1 program consumers

The economic Markov model results are presented as scatter plots of cost effectiveness estimates across cost-effectiveness planes, provided in Economic evaluation . The distribution of estimates reflects the high variation in model parameters, consistent with the limited linkage datasets and small sample sizes. In this section the base case bootstrap replications are presented as cost effectiveness acceptability curves, representing the likelihood that the Residual Functions Program is cost effective at increasing levels of willingness to pay (WTP) per QALY, Figure 8. The levels of cost effectiveness are shown based on ranges identified by the Productivity Commission Mental Health Report (Productivity Commission, 2020), reflecting increasing cost effectiveness in segments further to the left of the figure. The program base case reflects low probability of being even marginally cost effective at around 30%. The base case results are as expected as they are based on the partial Stream 1 consumer outcomes combined with total Residual Functions Program costs. The base case provides an estimated lower boundary based on Stream 1 available data linkage consumer numbers (shown as solid black line).

Figure 8 Program cost effectiveness – base case benefit to consumers



Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data.
Notes: Total cumulative figures include known Stream 1 plus estimated ranges for Stream 2. Figures estimated over 5 year model timeframe.

The Stream 2 program data linkage was not available during the evaluation period, but it is known that program clinicians have been supporting consumers. Including the reach of the number of Stream 2 consumers increases estimated cost effectiveness as average program cost per consumer decreases. To represent total estimated program consumer numbers two supplementary variations have been run based the program pre-program scoping study (Cvejic et al., 2018)

from entry to the Residual Functions Program, and a further assumed reduction based on 5 deaths avoided, Figure 10. In addition to these conservative scenarios being based on low percentage reductions in avoidable deaths, the outcome would be equivalent if multiple individuals cumulatively extended life years to the same 2.6 QALY level. The model discounts all costs and outcomes at 3.5% per annum.

Figure 10 Program estimated cost effectiveness – deaths avoided 3 scenarios

Source: NSW Ministry of Health Mental Health Branch: program data linkage. Residual Functions Program cost data. The model discounts all costs and outcomes at 3.5% per year.
Notes: Stream 1 consumers only. Figures estimated over 5 year model timeframe.

The Productivity Commission report also notes the association of mental health and the high number of suicides in Australia. In 2018 it is reported that 65% of the 3,046 people who took their own lives in 2018 had a mental illness (Productivity Commission, 2020). Additionally, there were high numbers of attempted suicides of between 30,000 to 90,000 in 2018 with severe implications for individuals, their families and the health system. Given these statistics the Productivity Commission report includes a priority recommendation that Commonwealth, State and Territory Governments should agree to an explicit target to reduce the gap in life expectancy

Notes: Cost effectiveness is the estimated costs per QALY. * Marginally cost effective range. ** Cost effective range. *** Very cost effective range. Figures estimated over 5 year model timeframe.

In the scenario of avoidable ID deaths prevented the estimated incremental QALY gains are more substantial, contributing to more significantly cost-effective ranges. Although the two scenarios are outlined independently it is plausible that a combination of family and carer benefits with avoidable ID deaths could result with proportional increased estimated program cost effectiveness. These potential scenarios are presented as conservative plausible examples of program benefits subject to longitudinal assessment when data are available.

Other potential extended outcomes

In addition to the evaluation quantitative and qualitative findings and economic model scenarios there are a range of interrelated outcomes potentially resulting from improved health access through the Residual Functions Program.

The qualitative interviews found that program support was seen as accessible as it was affordable and was offered closer to where consumers lived. The possibility of health closer to home brings savings in transport costs and travel time for consumers and family or carers. As the evaluation has been undertaken during the COVID-19 pandemic it has been shown that some program health supports were effective through increased telehealth consultations. This may continue or scale further as a convenient and effective form or care.

The qualitative data show that the Residual Functions Program is building capacity of health services, disability and other supports through combined training courses or webinars, practical work, case meetings or direct consumer supports. This capacity building is developing improved coordination between intellectual disability and mental health service providers to better understand consumer needs as well as provide network contacts for advice. These indirect outcomes may be lagged and diffused and are difficult to identify and quantify. For this reason, the benefits related to capacity building Stream 3 activities are not currently incorporated into the evaluation effectiveness and related cost effectiveness.

The program implementation was impacted by COVID-19 resulting in delayed implementation and disruption to consumer support services. The extent of the impact of the pandemic is difficult to assess but may have retrained outcomes for the evaluation study period.

People with mental illness in contact with the criminal justice system tend to have complex needs, including substance use comorbidities and cognitive and intellectual disabilities (Baldry et al. 2015). NSW data linkage indicates that ID represent over twice the proportion of people aged to 24 years appear in corrective services datasets compared to a control cohort (17.9% vs 7.1%) (Reppermund et al., 2019). Where the Residual Functions Program is providing improved access and mental health it is plausible that progression of mental health conditions is being avoided and escalation of episodes that could result in contact with police, the courts or corrective services may be avoided along with related costs.

It is well recognised that mental health may affect participation and productivity for those who are employed, as well as presenting barriers to gaining and maintaining employment for those outside the workforce (Productivity Commission, 2020). This established research has demonstrated positive ou connectedness, with better mental wellbeing, with lower rates of depression and anxiety as well as a key role in mental health recovery. The Residual Functions Program is likely to be contributing to these outcomes but are not reflected in the current economic assessment.

Economic modelling results

This appendix presents the program cost effectiveness model bootstrap replications on cost effectiveness planes for the base case and avoidable deaths prevented scenarios. These estimated cost per QALY scatterplots provide the basis for cost effectiveness acceptability curves presented section 6. The results emphasise the high variation in model parameters due to the small sample sizes and skewed service use of the study group. The ellipses indicate 95% confidence intervals for the estimates, beginning with the base case. Values to the right of the centre line indicate positive QALY gains following entry to the Residual Functions Program, at increasing cost as shown on the y axis. The scatterplot shows a willingness to pay (WTP) of $50,000 per QALY as the diagonal dotted line. Green point estimates to the right and below the WTP line represent estimated cost-effective proportion of estimates.

Figure 11 Program cost effectiveness scatter plot - base case

Source: NSW Ministry of Health Mental Health Branch: program data linkage.
Ellipse indicates 95% confidence interval, WTP Willingness to pay

The additio 95% c

Figure 12 Program Cost Effectiveness scenario 2 ï 1 life saved (2.6 QALYs)

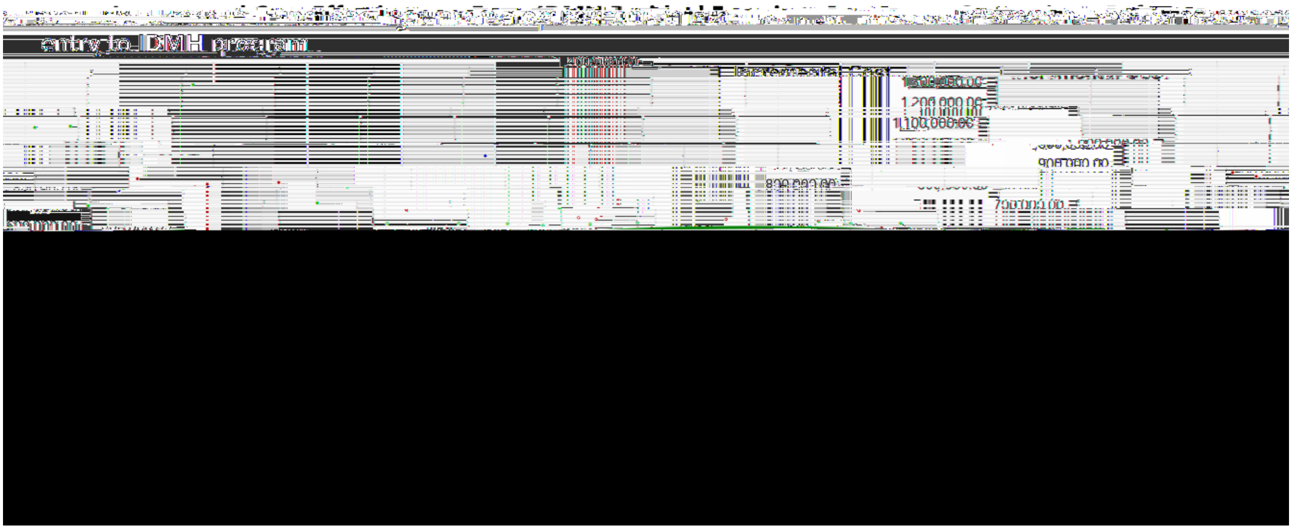


Figure 13 Program Cost Effectiveness scenario 2 ï 2 life saved (5.2 QALYs)

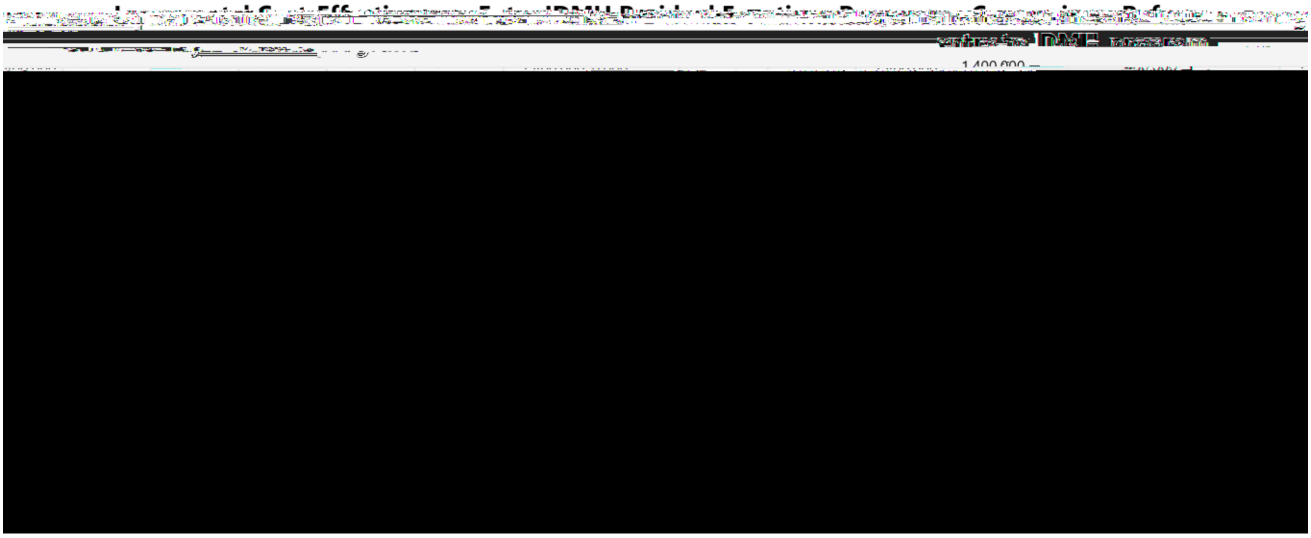
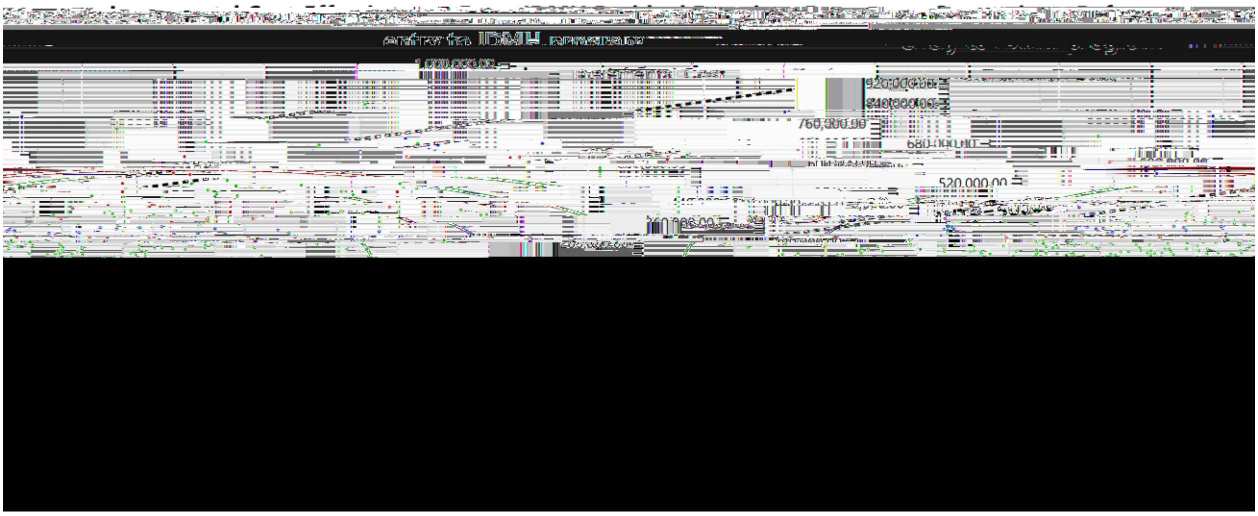


Figure 14 Program Cost Effectiveness scenario 2 ï 5 life saved (13 QALYs)



Summary

The economic component of the evaluation examined Residual Functions Program

New South Wales, Australia: a data linkage cohort. *BMJ Open, 9*(9). doi:10.1136/bmjopen-2019-031624
Salvador-Carulla, L., & Symonds, S. (2016). Health services use and costs in people