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Department of Health and Aged Care

Key findings report: Evaluation of the Patient
Pathways Program Pilot

October 2022

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Department of Health and Aged Care.



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1 Introduction

This report presents the key findings arising from an evaluation of the Patient Pathways Pilot (PPP) Program.

1.1 Background

In April 2018, CC-DR initiated contact with the then Australian Government Minister for Health, in relation to funding a pilot for a 'Patient Pathways Program (Pilot)' which culminated in a proposal and budget that was submitted on 23 May 2018. This proposal was accepted by the Australian Government Department of Health (DoH or 'the Department') and a grant agreement to the value of \$1.56m was entered into with a commencement date of 28 June 2018. The program activity would occur through to 31 December 2021, followed by final reporting and grant completion on 28 February 2022. In November 2021, the grant agreement was extended to August 2022, with program activity to be completed in June 2022. Additional funding of \$170,000 was provided for this latter period, however, did not include additional funding for the National Patient Organisations (NPOs).

In putting together this pilot program proposal, the CC-DR aimed to address three key challenges for consumers and service providers alike; 1) navigating a complex health system and engaging the community in decisions about health, 2) reducing duplication and increasing collaboration and 3) keeping up to date on all that the Australian health system has to offer.

1.2 The CC-DR Patient Pathway Program Pilot

The PPP Program had three components: (1) establishment of the telehealth nurse service in a minimum of 10 not-for profit national patient organisations (NPOs)¹ for various disease types; (2) audit of NPOs in relation to telehealth support and establishment of a patient pathways network; and (3) a NPO annual briefing and conference. The evaluation considered all three components with a particular focus on the first as the principal intervention.

The CC-DR proposed NPOs as being best placed to provide a navigation program as there was an existing demand for such services (often the first point of call for patients when they are newly diagnosed) and many were already providing such a service either formally or informally.

Following the announcement of the PPP program in January 2019, CC-DR released a call for expressions of interest to identify patient organisations that wanted to participate in the pilot and receive funding to support a telehealth nurse within their organisation. Reportedly, more than 550 patient organisations were identified and invited to apply for funding. There were over 30 applications received and these were reviewed by an independent review committee, including an observer to ensure that all decisions were aligned with the published grant criteria.

The following table provides a summary of the NPOs engaged in the pilot at some point during the period March 2019 – June 2022. Not all organisations participated for the whole period, however, 11 were involved from the outset and a total of 18 (including CC-DR) participated in the program at some point over the total time period for the pilot.

¹ Documentation relating to the PPP pilot uses terms such as National Patient Organisations (NPOs) and patient organisations with an understanding that the funded 'organisations' being referred to might be national, jurisdiction specific or in fact a support group rather than a formally incorporated organisation. For ease of description we have referred to all participating organisations/groups as NPOs in this report.

Name of Organisation	Disease focus
Emerge Australia	Myalgic encephalomyelitis /Chronic Fatigue Syndrome
Mito Foundation	Mitochondrial disease
Metabolic Dietary Disorders Association	Inborn errors of metabolism (IEM)
Eating Disorders Victoria	Eating disorder/serious mental illness
Cerebral Palsy Support Network	Cerebral Palsy
Maddie Riewoldt's Vision	Bone Marrow Failure Syndromes
Save Our Sons Duchenne Foundation	Duchenne and Becker Muscular Dystrophy
Crohn's & Colitis Australia	Crohn's disease & Ulcerative colitis (inflammatory bowel disease)
Pancare Foundation	Upper gastrointestinal (GI) cancers, such as pancreatic, liver, stomach, biliary and oesophageal cancers
Tuberous Sclerosis Australia	Tuberous Sclerosis Complex
Genetic Alliance Australia	Rare genetic conditions/diseases
Syndromes without A Name Australia	Child with an undiagnosed or rare genetic condition
Genetic and Rare Disease Network	Rare genetic conditions/diseases
Genetic Support Network Victoria	Rare genetic conditions/diseases
Centre for Community Driven Research	Auspecting a select number of patient 'organisations'
NMOSD Australia	Neuromyelitis optica spectrum disorders - autoimmune demyelinating diseases that specifically attack and inflame optic nerves (optica), the spinal cord (myelitis), and some other specific locations in the brain.
Ehlers Danlos Syndromes	Group of hereditary disorders of connective tissue; vary in ways they affect the body and in their genetic causes.
Liver Cancer Support Australia	Liver cancer

1.3 Evaluation Methodology

This evaluation was planned with a comprehensive mixed-methodology and included a cost consequence analysis. Abt Associates would typically take a highly participative (or co-design) approach to the design and implementation of their evaluation projects. This had been proposed for the evaluation of the PPP program, however, this has for various reasons not been possible in this evaluation.

In terms of engaging CC-DR and all participating NPOs in qualitative interviews, only six NPOs (approximately half) agreed to engage in a consultation process.

Whilst a comprehensive amount of quantitative data is available, deidentified/non re-identifiable source data, extracted directly from the database (i.e. raw data) was reportedly not able to be provided because of commitments to patients that this would not be shared. Hence, the evaluation relied on our analysis of CC-DR-provided aggregate data that does not allow for correlation between data categories. Accordingly, inferences drawn have been kept to a minimum, and used where we have a high level of confidence as to the reliability thereof. As independent evaluators, without access to raw data, we are also not able to verify the accuracy of the data we are reporting.

The cost consequence analysis was not undertaken given the limited qualitative and quantitative evidence of impact and the unavailability of annual income and expenditure statements.

Program related documentation was the other key source of information for the evaluation that included; Patient Pathways Program Pilot submission for funding, Commonwealth Standard Grant Agreement between the Department of Health and the CC-DR, Patient Pathways Program Annual Reports (Jan 2019, Nov 2019, Nov 2020, Nov 2021) and a range of other documentation that is publicly available on the CC-DR websites including a PPP Governance and Financial document.

A literature review was undertaken to seek evidence of best practice relating to the efficacy and cost-effectiveness of different health system navigation support models in Australia and internationally, against a baseline of no navigation program. The primary aim of the literature review was to inform future Commonwealth policy options and funding decisions in relation to health system navigation programs in delivering improved patient outcomes within the Australian health care environment. Accordingly, a stand-alone literature review has been provided to the Department, with key issues integrated into the pilot evaluation findings where relevant. Additionally, we were able to access via two of the NPOs, relevant literature relating specifically to their disease group.

Key Evaluation Questions

The Department determined four key evaluation questions to be addressed as part of the evaluation and these have been used to frame the key findings report.

- KEQ 1: What difference is the PPP making? (Effectiveness)
- KEQ 2: To what extent was the PPP implemented in an efficient manner (Efficiency)
- KEQ 3: How appropriate and fit for purpose is the PPP's current design? (Appropriateness)
- KEQ 4: How effective has the implementation of the plan been to date and what can we learn from it? (Implementation)

2 Key findings

2.1 Implementation

The following section present key findings in relation to the implementation of the PPP program.

Extent of program reach

In terms of implementing the PPP program, it has been able to provide access to 2,804 people (addressing a broad range of health conditions) over a 22 month period, or approximately 127 people per month. People predominantly came to know about the service through a website, Facebook, support groups or internal NPO channels, that would broadly support the hypothesis that a health condition-focussed peak patient organisation is seen as an appropriate source of advice, guidance and support.

The people that accessed the service were predominantly patients and/or their next of kin (92.4%). The characteristics of the people accessing the service (e.g. gender and age) were largely consistent with those associated with the relevant conditions themselves, and/or more general trends in health seeking behaviour.

Notably the majority of people (53.2%) accessing the PPP program were from higher socio-economic areas. This may indicate a relationship between socioeconomic status, existing health literacy, and easier access (including financial) to services and supports under the PPP. However, 25.4% of people who accessed the service were from moderate socio-economic areas and 17.5% low, illustrating access for people from all socio-economic areas.

Equitable reach in terms of the clients jurisdiction and geographic location was largely achieved.

- Whilst the PPP program on the whole appears to be Victorian centric (43.6% of all clients), when analysing the program at the NPO level, for many of the services the reach is national and to some extent relatively proportional to state and territory populations. Putting Eating Disorders Victoria aside which we assume has a specific remit for servicing Victoria, there would be benefit in each of the NPOs reflecting on their own 'reach' data and considering how this could potentially be extended.
- At both the whole of program and NPO level the reach of the telehealth nurse service across all geographical regions in Australia (classified as major cities, inner regional and outer region/ remote or no postcode recorded) is well aligned to the distribution of the Australian population. Services that are potentially over-represented in their provision to major city clients may benefit from reviewing their promotional strategies to facilitate a re-balancing towards other regions. Of course, this needs to be understood in the context of where people with the targeted health conditions live.

From our understanding none of the targeted conditions are associated with a particular cultural group who have a higher proportion of the population impacted (e.g. as is observed in sickle cell disease with Mediterranean and African populations). Accordingly, we were not expecting to identify any of those condition and cultural background relationships. Our main observation would be that the program is reaching a greater proportion of Caucasian/white participants (91.5%) than is seen in the Australian population. Only two NPOs had less than 85% Caucasian/white participants. Additionally, only two NPOs had greater than 2% of their participants identifying as Aboriginal and/or Torres Strait Islander.

Each of the NPOs should consider the cultural reach of their PPP program and consider strategies for engaging a profile of participants that more closely aligns to the Australian population and certainly where relevant aligned to any particular cultural groups who are more highly represented with their targeted condition. NPOs could consider (as relevant) whether there are opportunities for making their services more accessible to people from different cultural backgrounds through ensuring they are culturally safe, have translated information and can access translator services. Strategies could also be thought about as a collective group across all NPOs.

Given the part-time nature of the service, access across the day and after-hours for some services was also a positive outcome.

Unfortunately, without access to raw data, we were unable to draw any reliable correlations between the factors of program reach. NPOs reviewing the correlation between these factors (such as SEIFA, cultural background, geographical location, and gender identity) for their own client group would be very informative as to the extent to which they consider their service is equitable and whether additional strategies should be developed to ensure more equitable reach. This also presents an opportunity for where NPOs might work together and/or potentially engage technical assistance to develop common strategies for addressing issues of equity (e.g. engaging cultural groups, achieving geographic reach).

Implementation against intent and lessons learnt

Standardisation: A key goal outlined by CC-DR in their proposal for a patient pathways pilot was to set standards and a baseline in the way that patient organisations offer support. Their previous navigation program in pancreatic cancer would support the development of protocols and guidelines for the participating NPOs and for future uptake of the model across any disease area.

A protocol was to be developed and made publicly available and CC-DR reporting states that this has occurred. The CC-DR website notes that this is provided to patient organisations when they register to participate. Subsequently, we are not able to determine what it includes and what might have been provided to participating NPOs and would be available for future patient organisations who might take up a telehealth navigation program.

Similarly, a set of guidelines were under development from 2019 but were not published until early 2022 (we have assumed this is what is in the CC-DR 'pathwaysportal' website for the proposed roll out). Based on the very limited information and context we have in relation to the guidelines (and protocol), we would consider that the time taken to complete these guidelines given their importance to standardised implementation has been very extended. We would, however, note that this was not an issue raised by the NPOs we consulted.

While it appears that there are a comprehensive set of guidelines available to support implementation of the pathways program, including for any new entrants wishing to establish such a program including independently, our only caution is that the availability of the protocol and the guidelines for use by any patient organisation should be clarified by the Department.

A Database was specifically built for the pilot and was available online so that NPOs could directly input their data. Given this was a pilot and some of the participating organisations had no existing systems for collecting such data this was an efficient and effective solution for the time.

A comprehensive set of data fields to measure implementation, support reporting and inform any evaluation processes was developed by CC-DR. It is evident from the CC-DR annual reports and the way we have been able to use the data in our evaluation that this process of having a consistent minimum dataset and a supportive system has been highly beneficial in describing the pilot. As discussed in the section on program reach, there is significant potential to further detail and analyse program delivery through correlation of data fields, particularly at the NPO level.

Issues were identified by NPOs in relation to the data base through the course of the pilot, such as; 'taking the data' when exiting, ownership and restrictive permissions for access. It is our understanding that NPOs have communicated these issues with CC-DR and we note that the proposal for any future program is that each NPO have their own database. This will likely address the issues described above, however, ideally a minimum dataset is maintained so that comprehensive, consistent reporting is possible. In any program going forward the primary objectives of the program need to be specified and data fields included in the database (as relevant) to enable systematic collection as discussed further below.

Centralised support to nurses by CC-DR for clinical supervision, networking and professional development was very important given some of these nurses were working in isolation from any other nurses or clinical staff in very small organisations. Nurses we interviewed valued the support provided although some noted that this was not consistently provided in the latter period of the program. All nurses interviewed consider a mechanism to enable a comprehensive range of supports (including linkage to clinical advice and supervision, case review) into the future needs to be maintained. This is a key factor to be considered should a model of direct funding of NPOs be put in place rather than through an auspicing organisation with responsibility for this function.

2.2 Effectiveness

The following section presents key findings in relation to the effectiveness of the PPP program.

Contribution to better patient health outcomes

Based on the program data and limited consultations undertaken, it is reasonable to conclude that the PPP program is contributing to better patient health outcomes. As a new service for most disease groups, it opened up access for patients, families and carers to receive reliable information, advice and support. While 72% already had an established chronic condition when they contacted the telehealth nurse, the program did engage 18% of clients at the point of diagnosis and 2% pre-treatment, which is a positive outcome in terms of achieving early intervention that is likely to result in better health outcomes.

The service has been able to facilitate referrals to other services and navigate through to other support mechanisms such as the NDIS. Given the emphasis in the program proposal for linkages to clinical trials

this hasn't occurred to the extent that might have been expected, however, there may be very plausible reasons for this that our limited consultations have not been able to uncover.

Unfortunately, we were unable to find evidence of a PPP program wide standardised or systematic process for collecting patient feedback whether that be their satisfaction, experience or short term outcomes including reducing interactions with other parts of the health system. Additionally, this has negated the opportunity for reporting on cost effectiveness. Whilst the data collected infers how the program has been effective, and we have a small number of positive patient testimonials, there is an opportunity lost for systematic collection of evidence. This should be a requirement of any future funded program and include an ability to measure cost effectiveness as discussed in the efficiency section below.

Creating a system of support, referral, connection and engagement

The evaluation has been very limited in assessing the extent to which the PPP program created a system that supports the uptake of existing and new services, systems and technologies, and enables effective and meaningful patient and community engagement in decisions about health and research.

The data supports the fact that referrals were made, clinical trials were discussed and support was provided to access the NDIS. However, we do not have sufficiently detailed quantitative data to describe the extent to which this has occurred at program or NPO level nor could we gather qualitative data (from NPOs or patient experience feedback) that demonstrates the real impact of this for clients.

A Register of Community Engagement Opportunities and Initiatives was to be developed and updated quarterly by CC-DR. In the 2021 annual report it was noted that 156 opportunities had been listed. CC-DR report that these opportunities are communicated through a newsletter and are available on the Australian Patient Organisation Network web page. At the time of writing this report we cannot locate the register on the CC-DR or related websites. Whilst consultations with NPOs has been limited, none we interviewed had any familiarity with the register and consequently used it to give their patients advice.

Building capacity within the NPO sector

Across all of the NPOs who participated in the PPP, there was wide variation in their history of providing none or some form of information and advice, and/or referral, and/or case management directly to clients. However, all NPOs had a greater capacity to provide services as a result of the funding and for most their capacity and capability was built as a result of establishment and implementation support provided by the CC-DR. NPOs we consulted, including a couple with no history of providing a service, expressed confidence in being able to continue providing a telehealth nurse case management program independently. In fact, a couple of NPOs who were not included in the collaborative Treasury bid for future funding are either; (i) now operating on jurisdiction funding alone or (ii) are using fundraising resources to maintain the program in the interim while they try to secure other sources of funds (philanthropic, sponsorship, state government) in order to continue the program.

It is apparent that participation in the PPP program has built capacity within NPOs to implement a pathways service and been the catalyst for some to proceed independently and potentially sustainably.

2.3 Efficiency

As noted in the methodology section above, the cost consequence analysis was not undertaken given the limited qualitative and quantitative evidence of impact and the unavailability of income and expenditure statements. Accordingly, other measures of efficiency herein need to be interpreted with caution given they are based on CC-DR reporting of budget allocation. However, we do have a degree of confidence around the funding which has been reported to have flowed to NPOs as the ones we consulted with confirmed the budget allocations reported.

What we are also unable to report on is how decisions were made as to the amount of funding allocated to each NPO. In fact, the amount of funding reportedly provided to NPOs is almost the inverse of the activity undertaken.

Cost per NPO and client

It is important to note from the outset the unit cost per client of around \$70 that has been consistently promoted in annual reports is based solely on the average direct time spent with the client. This methodology does not report the full cost of providing the service, that is, all of the additional time that the nurse spends on associated client activity and other program requirements which is the real cost of providing the service to patients.

Our analysis found a significant range in funding provided per client from \$143 to \$1821. Even with the two outliers removed the range is still large at between \$343 to \$959. Some factors that could explain the variation include; some NPOs were partially funding their program, variations in intensity and duration of the model of care, the pre-existing experience of some NPOs, and higher volumes producing some efficiencies. Unfortunately, we are unable to be certain as to why this variance in funding per client exists.

Critically, without robust and comparable measures of benefit or effectiveness, it is not possible to conclude whether the cost per client is justified by the benefit. It might be the case that an NPO has a much higher cost per client but delivers a more comprehensive package of services that at least makes it less likely for clients to continue accessing more expensive services such as outpatient departments at hospitals. Hence, although this organisation looks relatively more inefficient when looking at cost per client or cost per client contact than other organisations, the more comprehensive package of services, and the better client outcomes might show that it is providing more value for money. There is a risk then that those with lower costs per client are considered to be cost efficient and therefore warrant ongoing funding.

Notwithstanding the unique constraints in this project for undertaking a CCA, it does illustrate the need for a more systematic approach to identify program performance metrics that allow stakeholders to examine: (a) whether or not resources invested are commensurate with the services provided and outcomes delivered; and (b) the specific programmatic areas or elements of the various models of care that are having an impact on the efficient use of resources.

For further iterations of government-funded navigation programs, the cost effectiveness assessment needs to be built into the design from the beginning and relevant data collected accordingly. It is likely that technical expertise would need to be engaged to ensure this was integrated.

A proposed approach is for the Department and the key stakeholders to consider/review the performance metrics of the program and identify specific metrics related to outcomes and efficient delivery of services. The latter includes not only costs, but specific measures of service delivery or program design that are likely to impact how resources are spent and what sort of outcomes are achieved. This would require first a determination or strategic review of the program theory of change to identify how the program intends to deliver expected outcomes and how it intends to achieve any efficiency gains. Once these elements of the theory of change have been identified, associated key performance indicators, including outcomes and specifics of the model of care should be identified and routinely measured. As above, technical assistance may be required to facilitate this process.

2.4 Appropriateness

This section addresses the question of how appropriate the program design is.

Program Objectives

The overarching aim of the PPP program is quite clear; providing a mechanism through NPOs for patients to navigate through a complex health system and get access to treatment and management that they

might not otherwise be aware of or referred to. However, we could not identify specific, high level and measurable program objectives that are essential to assessing effectiveness including cost effectiveness. We consider this to be a critical part of program design and should be identified for any future telehealth pathways program. From the literature, we would expect those common objectives to include but not be limited to; improved quality of life, improved patient experience, improved patient self-management, reduced visits to the emergency department and reduced unplanned hospital admissions.

Target Disease Groups

Our observation in relation to target groups relates to that which government might consider as a priority for funding. For the pilot, they were a 'reactive' funder of a broad range of NPOs, subsequently waiting to be informed by the outcomes of the pilot in relation to future funding decisions. However, moving forward and more broadly than just the PPP program, the Department may want to have a more proactive and strategic approach to determining which disease groups are the highest priority for navigation funding and the most appropriate mechanisms through which the service is provided (including NPOs).

PPP program components

The design of the PPP program is based around four key components including; (i) NPOs as providers with CC-DR as an auspicing program manager, (ii) Delivered by nurses, (iii) a navigation/case management model, and (iv) delivered through telehealth.

Utilisation of NPOs appears to be an appropriate and positive innovation. The first point of call for many patients when they are diagnosed with a condition is to go to local NPOs. Generally, they already have some form of information, advice and support service (e.g. support group, helpline) and are closely tracking developments in their area of interest. They can be well connected to leading specialists (Board members etc) and clinics/research bodies in the disease area which we would consider critical in ensuring a high quality, contemporary, disease specific case management service including support for the nurse.

Telehealth Nurses: Patient navigation models can be delivered by a variety of personnel including both lay and professional staff. If the model is one of case management, the literature supports this being supported by professional staff with social workers, allied health and nurses most noted. Interviews with the NPO managers and also with associated referrers (note this was highly limited) is that the clinical nature of the PPP program warrants the use of clinical staff and the consensus was that this should be nurses. This is in line with other Australian navigator services for chronic and complex conditions.

The PPP program was proposed to be a telehealth nurse **case management service**, that is, more than just information, advice and navigation. Based on a synthesis of several studies, researchers at The Commonwealth Fund suggest a range of components that a patient navigator model should include and noting our limited methodology, it is reasonable to conclude that these components are characteristic of that provided by the NPOs through the PPP program. However, what is also clear is that the extent of case management differs from NPO to NPO and this likely lies in the extent of ongoing patient contact, management and dependence post the care planning process. We would suggest that this is contributed to by not having clear objectives. It may well be that variable response levels are required that is influenced by the other resources available to that disease group and more intensity and higher dose may in fact be highly cost effective.

The use of telehealth appears to be appropriate and more efficient given the program design. The numbers of clients are always likely to be small and geographically distributed, premised on this model having been developed for disease groups that are rare / less represented in the population. In our consultations with NPOs there was a strong consensus for telehealth being more than adequate and since COVID, a more routine method for patients to engage with health professionals (including NPO services).

Selection of NPOs

The selection of the NPOs was a competitive process (at least initially) and was managed by an Independent Review Committee who reviewed applications based on defined criteria under the categories of 'need', 'adherence' (to the PPP), 'impact', and 'alignment with PPP'. This appears to have been a robust process. However, in the latter stages of the pilot (post June 2021), additional disease groups with what appeared to be a limited status as an NPO were added to the program without the same level of robust governance process provided in the initial selection stage. Reportedly there was not enough time to conduct such a process within the context of the Pilot, so given this and the fact that well over the required 10 patient organisations had been participating, we question the necessity for such 'NPOs' to be added at such a late stage.

Effort is made under the selection criteria ('adherence') to identify NPOs of adequate institutional capacity. Notwithstanding this effort, the design is limited by the maturity or available institutional capacity of the patient organisation sector itself in providing such services (including an available experienced nursing workforce) in a robust and accountable manner. This is evidenced by NPOs needing to withdraw or hand the nursing service back to CCDD post commencement. If the program was continued, consideration should be given to redesigning the model so that it can continue to leverage NPOs but not become reliant on or constrained by individual NPO organisational capacity, as is discussed below.

Need for an auspicing organisation

CC-DR as proponents of the model have as an auspicing body supported NPOs in the establishment and implementation of the PPP program. A very positive outcome has been that both NPOs who had some form of service and those for which this was a new venture have been able to consolidate the program within their organisational structures and a few have become self-funding. However, it is highly likely that there will always be disease groups either those with an established NPO or only a support group that would want to or would benefit from having an auspicing organisation. A potential future model is discussed below.

Fit with other programs

The PPP was intended to be complementary to existing services and programs and further reduce overlap and inefficiencies in the current system. There isn't sufficient evidence to determine whether or not this is actually the case. There is the potential for PPP to overlap with existing initiatives (particularly if robust selection is not maintained), however it appears to be largely complementary based on the pilot.

Whilst it appears to fit with existing Australian government programs, caution would need to be taken if it was to be continued, in defining the bounds of the service to ensure it remains complementary – in relation to disease priorities/conditions as well as the parts of the health system. It would also be important to further consider how the PPP program interacts with the broader NPO sector and enables and improves the broader role of these organisations and overall governance.

2.5 Future navigation program(s)

In funding any future navigation and case management programs, the design should take account of the following key issues:

- There is a purposeful and strategic approach to determining which disease groups are the highest priority for funding
- At the outset, specific, high level and measurable program objectives that are essential to assessing effectiveness including cost effectiveness are determined and documented

- Service providers have strong existing links to relevant lead clinics and clinicians, research bodies and patient organisations ensuring a high quality, contemporary, disease specific case management service including support for the nurse.
- Institutional capacity of the accountable organisations is strong.

The broad steps we consider a re-design could follow include:

(A) DETERMINE HIGH PRIORITY DISEASES AND CATEGORISE

Strategically determine what ‘disease groups’ would most likely benefit from a telehealth navigation and case management program. It would be anticipated that these are conditions with limited existing service supports and the provision of the service is likely to be cost effective. These may include, for example, rare disease, rare cancers, genetic conditions, or mental health related disorders. These could be prioritised into 2-3 categories.

(B) ADVISORY GROUP

An advisory group is determined or established for that category of diseases. For example, Rare Voices Australia could be asked to represent rare diseases and a Mental Health Peak Body represent less well supported mental health related conditions. Alternatively, an independent group may be established.

This advisory group could be tasked and resourced to undertake relevant research that would inform the program design and may in the longer term play the role of auspicing body for the program.

(C) PROGRAM DESIGN

With a primary aim of providing a complementary service and avoiding duplication, under the guidance of the advisory group, research is undertaken to determine existing supports for the disease category and the major gaps. This could include specific gaps for certain patient cohorts within a disease group (e.g. location, culture, gender).

A navigation and case management program is subsequently designed to address the key needs of the patient group taking into account the funding envelope. It likely picks up the four program components of; Telehealth, Nurse (or clinician) led, Navigation/Case management and leverages NPOs. The design establishes clear Program Objectives that inform:

- Model of Care (including the parameters of any case management component)
- Performance metrics / cost effectiveness measures
- Database system and a minimum data set.

(D) CONTRACT PROVIDERS

An auspicing body is identified to fund and potentially is the service provider for each disease category. This may be the advisory group, a related body to the advisory group or an appropriate patient organisation. Critically, the auspicing body must have institutional capacity that we consider needs to include:

- Strong existing links to relevant lead clinics and clinicians, research bodies and patient organisations to ensure a high quality, contemporary and sustainable service
- A capacity to support clinicians (likely nurses) in delivering a clinical service
- Establishing or ensuring there is a sustainable service, that is, one that is not dependent on one individual person (manager or clinician)
- Governance, Clinical Governance and Service Management capabilities including, financial, legal, grants, data governance, monitoring and evaluation (M&E).

The auspicing body would subsequently determine whether they are the service provider and link to related NPOs or whether they contract NPOs who have also been assessed to have the institutional capacity described above to deliver the service.

The broad steps for consideration regarding a re-design

