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17 August 2021

Committee Secretary  
Community Support and Services Committee  
Parliament House  
George Street  
Brisbane Qld 4000

Via email: [CSSC@parliament.qld.gov.au](mailto:CSSC@parliament.qld.gov.au)

Dear Committee Secretary

Thank you for the opportunity to contribute to this much needed enquiry. QPP commends the Palaszczuk Government for its foresight in recognising that the advent of COVID 19 has created additional challenges in relation to social isolation and loneliness in Queensland.

Queensland Positive People (QPP) has been funded by the Queensland Government since 2004 to deliver state-wide peer led, community-based health service programs for people living with HIV (PLHIV) and people at risk of HIV/STIs. Since 2014 these services have included the delivery of peer led testing for HIV and other sexually transmissible infections; peer navigation for those newly diagnosed with HIV; case management for PLHIV experiencing more complex health and treatment challenges; as well as legal assistance for those experiencing stigma and discrimination.

Even prior to COVID 19, long standing stigmatising societal attitudes experienced by many PLHIV in Queensland have made social isolation and loneliness a pervasive challenge. As our submission will point out, these long-standing disadvantages have in recent years been paradoxically worsened by the very scientific advances that have improved the long-term medical outlook for PLHIV. For many years HIV programs were focused on peer support and education. However, in recent years advances in treatments, which reduce the viral load of a PLHIV to “undetectable” has seen these earlier approaches scaled back, to be replaced with bio-medical models of care aimed at maximising the number of people on treatment. The COVID-19 pandemic has further added to this challenge in a number of ways as outlined in the submission.

I commend our submission to you and look forward to the outcomes of your very welcome deliberations.

Warm regards



**Mark Counter**  
QPP President

QUEENSLAND POSITIVE PEOPLE SUBMISSION  
TO THE  
QUEENSLAND GOVERNMENT PARLIAMENTARY ENQUIRY  
INTO  
SOCIAL ISOLATION AND LONELINESS

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For and on behalf of the Queensland Positive People Board, staff and QPP membership.



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Melissa Warner – Chief Executive Officer

17 / 08 / 2021

## Executive Summary

QPP was established in 1989 in response to the growing AIDS epidemic and the increasing trend of decisions being made about our futures without consultation or the involvement of people living with HIV (PLHIV). For over 30 years it has offered community-based peer led health and community services/programs for PLHIV and people at risk of HIV/STIs including:

- Social and emotional support.
- Peer navigation to navigate the complex environment of HIV diagnosis, disclosure, health system for treatment and care and living well with HIV.
- Case management support and practical assistance for PLHIV with more complex needs to access medications, clinical services, food, housing and other essential support services.
- Information and case management support with stigma, discrimination, migration and the law.
- Emergency funding for PLHIV experiencing financial hardship.
- Peer led HIV/STIs point of care testing.

**TOR 1: The nature and extent of the impact of social isolation and loneliness in Queensland, including but not limited to:**

- I. **Identification of and consultation with vulnerable and disadvantage individual or groups at significant risk across the course of life**
- II. **The interplay of COVID with this issue.**

- *More than three decades after the first cases of AIDS were diagnosed in Australia people living with HIV still face unacceptable levels of discrimination and stigma. Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic.<sup>1</sup>*
- This can happen in a number of areas including employment, health care, immigration, privacy and insurance. The result of the above is people living with HIV (PLHIV) are more likely to engage in the protective behaviour of self-isolation, in many cases leading to increased loneliness.
- In the most recent QPP community consultation, the key themes identified by PLHIV in Queensland were:
  - Peer and social connection - PLHIV want more opportunities to come together collectively and contribute to a deeper sense of community.
  - Social connection and emotional support with peers empower you to reduce internal stigma and become more resilient.
  - The community continues to need support to navigate and engage with health systems and community services to support health, financial, housing and legal needs. Health needs were related to HIV clinical services, ageing, self-management of chronic illness, mental and sexual health, and dental care.
  - Support for our ageing community and management of chronic illness.
  - Greater involvement in mental health and addiction support such as counselling, psychological therapies and peer support.
  - Implementation of an HIV stigma campaign to increase HIV awareness more broadly across society.

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<sup>1</sup> <https://napwha.org.au/stigma-and-discrimination>

- Whilst early evidence has shown that PLHIV are at no greater risk than the general population of COVID-19 many PLHIV continue to remain concerned about the impact of a COVID infection on often weakened immune systems. Recently released data from the World Health Organisation confirms these fears reporting that HIV infection is a significant independent risk factor for both severe/ critical COVID-19 presentation at hospital admission and in-hospital mortality. Overall, nearly a quarter (23.1%) of all people living with HIV who were hospitalised with COVID-19 died<sup>2</sup>.
- Fear of COVID transmission and the possible above complications have led to many PLHIV reporting a disproportionate fear of contracting COVID, adding to the already present tendency to self-isolate and retreat from social settings and networks.
- *The many social consequences created or magnified by the pandemic are linked to disruptions in HIV care, which can lead to medication non-adherence, social isolation, poor mental health outcomes and increased substance use. Impacts on income and employment render treatment options less accessible, while also creating food and housing insecurity.*<sup>3</sup>
- The result is that already isolated PLHIV are feeling further isolated and disconnected. Since the COVID pandemic, QPP has experienced a 30% increase in demand for support services, with a significant number of PLHIV reaching out for the first time.

#### **TOR 2: The causes and drivers of social isolation and loneliness, including those unique to Queensland.**

- There are a number of factors that contribute to social isolation and loneliness for PLHIV in Queensland including:
  - Living in regional areas
  - Ageing population
  - Accelerated and accentuated ageing
  - Mental health
  - The bio-medicalisation of HIV.
- QPP believes the combination of these five features of the PLHIV population in Queensland add to increased risk factors for poorer physical and mental health and well-being, as well contributing to increased social isolation and loneliness.

#### **TOR 3: The protective factors known to mitigate social isolation and loneliness.**

- The key factors that can mitigate against social isolation and loneliness is connection and resilience. Social networks play an important role in supporting PLHIV across the lifespan, including reducing barriers to health service access, promoting health literacy, facilitating self-management and promoting a sense of solidarity and belonging. For PLHIV their social networks are often limited due to internalised, anticipated and/or experienced stigma. Fear of disclosure and stigma related to HIV impact marginalised and vulnerable people disproportionately. People from migrant and refugee communities and Aboriginal and Torres Strait Islander peoples are particularly vulnerable.
- Social and peer connection for people with HIV is a protective factor to disengagement from care and improves health outcomes including, adherence to treatment, mental and psychological wellbeing and quality of life. Peer connection ameliorates the impact of social isolation and loneliness caused by HIV. Connecting with other PLHIV and sharing stories facilitates PLHIV to have their experiences

<sup>2</sup> WHO 2021, <https://www.who.int/news/item/15-07-2021-who-warns-that-hiv-infection-increases-risk-of-severe-and-critical-covid-19>

<sup>3</sup> <https://link.springer.com/article/10.1007/s10461-021-03300-1>

validated, and to reduce the burden of worry or guilt. They are able to become part of something larger and stronger.

**TOR 4. The benefits of addressing social isolation and loneliness, examples of initiatives undertaken nationally and internationally and how to measure social isolation and loneliness in Queensland to determine if implemented strategies are effective.**

- The benefits to Queensland of being able to engage with a much broader cross section of the PLHIV population are significant in both economic and social terms:
  - Interventions aimed at reducing social isolation not only reduce the burden of loneliness but help to reduce morbidity and mortality, the number and complexity of hospital admissions, and identify those with mental health disorders that would benefit from peer support and/or professional referrals.
  - Interventions targeted to reduce social isolation will improve PLHIV engagement in HIV care and adherence to treatment. This will have the benefit of ensuring PLHIV maintain an undetectable viral load thereby preventing disease progression and onward transmission.
  - Programs aimed at outreaching to PLHIV to reduce social isolation and loneliness would have the additional benefit of providing an avenue for educating PLHIV about the preventable risks associated with ageing including diabetes, osteoporosis, coronary heart disease and high blood pressure.
  - PLHIV become more confident and self-resilient, increasing their ability to withstand the stigma and discrimination they may face and resume participation in local activities including cultural sporting activities, or work and/or local volunteer programs<sup>4</sup>.
- QPP would recommend the utilisation of the *PozQoL Scale* quality of life measure as the measurement tool to determine progress and successes of interventions aiming to address social isolation and loneliness.

**TOR 5. How current investment by the Queensland Government other levels of government, the non-government, corporate and other sectors may be leveraged to prevent, mitigate and loneliness across Queensland, including:**

- I. **Services and programs such as health and mental health, transport housing, education, employment and training, sports and recreation, community services and facilities, digital inclusion, volunteering, the arts and culture, community development, and planning for accessible, inclusive and connected communities**
  - II. **Targeted support to vulnerable and disadvantage groups and those most at risk**
- QPP has a 30 year history as a community based peer led organisation working with PLHIV in facilitating peer support networks and groups. More recently, we have championed the development and delivery of HIV Peer Navigation services.
  - We know that the benefits of existing peer support networks and groups are significant and include PLHIV experiencing:
    - acceptance and non-judgement
    - maintaining stability

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<sup>4</sup> [https://www.ohtn.on.ca/wp-content/uploads/2020/06/RR\\_MSM-social-isolation.pdf](https://www.ohtn.on.ca/wp-content/uploads/2020/06/RR_MSM-social-isolation.pdf)



- meaningful connections and solidarity
- promoting physical and mental health
- validating HIV positive status
- encouraging personal growth and development.
- Currently, QPP's Peer Navigation is funded to support newly diagnosed PLHIV or PLHIV re-engaging with care to engage with HIV treatment and clinical services. Peer Navigators (PNs) provide peer education to assist with developing HIV health literacy and practical assistance and support with navigating health systems. The program assists PLHIV to make informed choices about the often-complex array of doctors, specialists, testing, and pharmacies associated with HIV care. Peer Navigation plays a crucial support role by providing meaningful contact from a fellow PLHIV that helps bridge their clinical and everyday worlds.
- The benefits of leveraging off existing QPP programs with expanded scopes and a focus on supporting PLHIV at risk of or experiencing social isolation are enormous. Additional funding could provide facilitated therapeutic social support groups and sessions; vital home visits and other outreach; coordination of a volunteer program; and the development of technology based solutions for PLHIV to connect with each other and seek likeminded PLHIV across Queensland for companionship and social connection.

**TOR 6: The role, scope and priorities of a state-wide strategy to address social isolation and loneliness, considering interactions with existing Queensland and national strategies.**

- QPP is cognisant of the powerful role of state-wide and national strategies in ensuring coordinated strategic responses for funding, resource allocation and service delivery.
- QPP supports the further development of an overarching strategy that addresses social isolation and loneliness. It is essential that such strategies are based on peer models of care and whole of government approaches with identified roles for all relevant departments including health, communities, housing and education etc. It is also important to facilitate shared funding arrangements across departments to ensure the strategic alignment of priorities and resource allocations with integrated versus siloed interventions.
- QPP recommends that in relation to PLHIV such a strategy incorporate the goals of the current *Queensland HIV Action Plan 2019 -2022* (which is focused predominantly on preventing HIV infections), but be widened to include:
  - Strategies to address social isolation and loneliness including new and targeted funding to deliver on the recommendations above.
  - Interventions for mental health, and alcohol and other drug related interventions.
  - Education strategies to reduce/prevent co-morbidities in ageing PLHIV through improved screening and awareness protocols which would result in better overall health and wellness.
  - Improved education for staff of age care and disability facilities about HIV and ageing including the risk of social isolation and loneliness and associated risk of co-morbidities.
- *Ensuring that PLHIV are empowered to enact the support they need from networks of family, friends, providers, and peers is crucial. Interventions that facilitate PLHIV to build these networks for support must be incorporated into contemporary models of HIV care<sup>5</sup>*

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<sup>5</sup> Bringing the 'social' back into HIV care: A qualitative study of self-management experiences for recently diagnosed people living with HIV in Queensland, Australia. O Hollingdrake et al. 2021

QPP submits this report to the Parliamentary Enquiry and respectfully asks that PLHIV be considered a sub-population at high risk of social isolation and loneliness. QPP has a proud tradition of working and reporting its outcomes to government and would like to be considered for funding of the recommendations above or any other strategies recommended by the enquiry to address this growing crisis.

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## 1. Background

### 1.1 Queensland Positive People

QPP was established in 1989 in response to the growing AIDS epidemic and the increasing trend of decisions being made about our futures without consultation or the involvement of people living with HIV (PLHIV). For over 30 years it has offered community-based peer led health and community services/programs for PLHIV and people at risk of HIV/STIs including:

- Social and emotional support.
- Social connection.
- Peer navigation to navigate the complex environment of HIV diagnosis, disclosure, health system for treatment and care and living well with HIV.
- Case management support and practical assistance for PLHIV with more complex needs to access medications, clinical services, food, housing and other essential support services.
- Information and case management support with stigma, discrimination, migration and the law.
- Emergency funding for PLHIV experiencing financial hardship.
- Peer led HIV/STIs point of care testing.

During this time QPP has developed a respectful and trusted relationship with the Queensland PLHIV community. This connection has placed QPP in a unique position to reach out to and engage with people who are experiencing heightened levels of marginalisation and vulnerability, especially during the COVID 19 pandemic. This includes PLHIV who are:

- ineligible for Medicare;
- culturally and linguistically diverse;
- Aboriginal and Torres Strait Islander;
- living long term with HIV; and
- ageing and/or experiencing HIV related co-morbidities.

Please see our [Annual Report 2019-2020](#) for further details.

### 1.2 HIV in Queensland

The introduction of combination antiretroviral therapy (ART) in 1996 vastly improved survival of PLHIV by preventing HIV disease progression and death from AIDS. Consequently, the Australian PLHIV population is increasing. The Kirby Institute, University of New South Wales reports that in 2010, there were 17,960 Australian PLHIV. In 2018, this number had increased to 25,490, and estimates it will further increase to 31,170 in 2025 and 34,990 by 2030. Please refer to table 1.

**Table 1: PLHIV population in Australia by jurisdiction**

	2018		2025		2030	
State/Territory	Number of PLHIV	% All	Number of PLHIV	% All	Number of PLHIV	% All
National	25,490	100%	31,170	100%	34,990	100%
New South Wales	9,640	37.1%	11,250	35.7%	12,330	35.0%
Victoria	6,760	26.0%	8,630	27.4%	9,870	28.1%
Queensland	5,040	19.4%	6,230	19.8%	7,010	19.9%
Western Australia	2,200	8.5%	2,670	8.5%	2,990	8.5%
South Australia	1,320	5.1%	1,540	4.9%	1,690	4.8%
Australian Capital Territory	380	1.5%	420	1.3%	450	1.3%
Tasmania	360	1.4%	460	1.5%	520	1.5%
Northern Territory	260	1.0%	290	0.9%	320	0.9%

## 2. Social isolation and loneliness for People Living with HIV

TOR 1 – The nature and extent of the impact of social isolation and loneliness in Queensland, including but not limited to:

- i) Identification of and consultation with vulnerable and disadvantage individual or groups at significant risk across the course of life
- ii) The interplay of COVID with this issue.

The predominant factor affecting social isolation and loneliness for PLHIV in Queensland is HIV stigma and discrimination, which can impact on people's confidence to participate in the various formal and informal networks that may be available in their local areas. PLHIV experience more social isolation, on average, compared to the general population stemming (generally) from their complex social contexts.

<sup>6 7</sup>

***More than three decades after the first cases of AIDS were diagnosed in Australia, people living with HIV still face unacceptable levels of discrimination and stigma. Stigma has long been recognised as a serious and debilitating feature of the HIV epidemic.<sup>8</sup>***

HIV stigma can best be described as negative attitudes and beliefs towards and about PLHIV. They can include beliefs that only certain groups are at risk of HIV (such as gay and bisexual men); making moral judgements about certain actions (for example same-sex relationships, sex outside a monogamous relationship); and feeling that some people 'deserve' HIV because of their choices including injecting drug use etc. PLHIV often internalise these experiences or expected stigmas, which result in devalued self-esteem including feelings of shame, guilt and lower self-worth. PLHIV often fear they will be discriminated against or judged negatively if their HIV status is revealed.

6 Webel, A. R., Longnecker, C. T., Gripshover, B., Hanson, J. E., Schmotzer, B. J. & Salata, R. A. 2014. Age, stress, and isolation in older adults living with HIV. *AIDS Care*, 26, 523-31.

7 Shippy, R. A. & Karpiak, S. E. 2005. The ageing HIV/AIDS population: fragile social networks. *Ageing Mental Health*, 9, 246-54.

8 <https://napwha.org.au/stigma-and-discrimination>

PLHIV also experience high levels of HIV related discrimination. This can happen in a number of areas including employment, health care, immigration, privacy and insurance. QPP offers legal support services to PLHIV where discrimination is potentially in breach of legislation, however unfortunately most PLHIV experience stigma and discrimination in more subtle but equally distressing forms. The result of the above is PLHIV are more likely to engage in the protective behaviour of self-isolation, in many cases leading to increased loneliness.

Stigma and discrimination toward PLHIV can manifest in several ways including:

- Residual fear of members of the public contracting HIV, resulting in alienation and rejection in many settings including family settings, workplaces, sporting and recreation clubs etc.
- Conservative or religious values that condemn the many PLHIV who identify as gay or bisexual, or engage in sexually adventurous practices and/or injecting drug use.
- Cultural values and religious views which may carry strong views about HIV including associations with sexuality or relationship conducted outside the cultural norm.
- Language or cultural barriers that prevent PLHIV being able to access services or address inbuilt discrimination in service models available to them.

Whether real or perceived, the impact of these fears is that PLHIV opt to not reveal their full identities or avoid situations where their personal stories may become known. Often relationships with family may be tense or have been severed due to these differences. QPP continues to work with clients whose lives have been disrupted through confidence breaches that result in stigmatising and discriminatory behaviour from families, friends, workplaces and social networks. The withdrawal from these previous points of connection is frequently quoted as a reason for increasing isolation and loneliness.

In the case of ageing PLHIV who lived through the earlier days of the HIV epidemic these challenges can be exacerbated by:

- frailty linked to premature ageing that may limit their ability to participate in social events;
- the loss of friends and partners to AIDS;
- the fear of being left alone with no close family or friends to care for them or assist them as they age<sup>9</sup>;
- the fear of navigating complex and possibly discriminatory health; disability and aged care systems;
- the fear of early death due to associated co-morbidities <sup>10</sup>; and
- early memories of the openly discriminatory treatment provided in hospitals, dentists and GP surgeries in the early days of the epidemic.

Research studies have identified that social isolation may have a greater impact on human health than previously considered, with some studies suggesting it may be comparable in risk to better known risk factors such as smoking and high blood pressure<sup>11</sup>. Other research suggests isolation can lead to poor

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9 Community-Driven Health Priorities for Healthy Aging With HIV

Journal of the Association of Nurses in AIDS Care -January-February 2019 - Brandon Brown et al

<sup>10</sup> [https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(20\)30197-](https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(20)30197-)

<sup>11</sup> Pantell M, Rehkopf D, Jutte D, Syme SL, Balmes J, Adler N. Social isolation: a predictor of mortality comparable to traditional clinical risk factors. Am J Public Health. 2013;103(11):2056–62.

mental health outcomes<sup>12</sup>; chronic inflammation<sup>13</sup>; cardiovascular disease<sup>14</sup>; and an increase in likelihood of mortality<sup>15</sup>.

Studies have reported that almost a third of participants reported that living with HIV was burdensome. The burden was associated with the experience of other chronic conditions, recent diagnosis, and isolation from others living with HIV.

A national survey of more than 800 PLHIV reported in *HIV Futures 9* that (56.6%) reported at least one experience of HIV-related stigma or discrimination in the past 12 months, while 38% reported that they had been treated differently by a healthcare worker due to their HIV in the past 12 months<sup>16</sup>.

In the most recent QPP community consultation, the key themes identified by PLHIV in Queensland were:

- Peer and social connection - PLHIV want more opportunities to come together collectively and contribute to a deeper sense of community.
- Social connection and emotional support with peers empower you to reduce internal stigma and become more resilient.
- The community continues to need support to navigate and engage with health systems and community services to support health, financial, housing and legal needs. Health needs were related to HIV clinical services, ageing, self-management of chronic illness, mental and sexual health, and dental care.
- Support for our ageing community and management of chronic illness.
- Greater involvement in mental health and addiction support such as counselling, psychological therapies and peer support.
- Implementation of an HIV stigma campaign to increase HIV awareness more broadly across society.

## 2.1 The impact of the COVID-19 pandemic on people with HIV

The COVID-19 pandemic has added a layer of complexity to the above factors including:

- Whilst early evidence has shown that PLHIV are at no greater risk than the general population of COVID-19 many PLHIV continue to remain concerned about the impact of a COVID infection on often weakened immune systems. Recently released data from the World Health Organisation confirms these fears reporting that HIV infection is a significant independent risk factor for both severe/critical COVID-19 presentation at hospital admission and in-hospital

<sup>12</sup> Leigh-Hunt N, Bagguley D, Bash K, Turner V, Turnbull S, Val-torta N, et al. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017;152: 157–71.

<sup>13</sup> Shankar A, McMunn A, Banks J, Steptoe A. Loneliness, social isolation, and behavioral and biological health indicators in older adults. *Health Psychol*. 2011;30(4):377–85.

<sup>14</sup> Everson-Rose SA, Lewis TT. Psychosocial factors and cardiovascular diseases. *Annual Rev Public Health*. 2005;26: 469–500.

<sup>15</sup> Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspect Psychol Sci*. 2015;10(2):227–37.

<sup>16</sup> HIV Futures 9 Quality of life among People Living with HIV in Australia The Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia p6.



mortality. Overall, nearly a quarter (23.1%) of all people living with HIV who were hospitalised with COVID-19 died<sup>17</sup>.

- There is also a degree of anxiety about “long-term COVID” and its impact on HIV infection and how and whether the two conditions will intersect worsening prospective health outcomes after surviving an initial COVID infection. Many of the reported effects of “long-term COVID” mirror those of long-term HIV infection.
- Whilst shipments of medications have to date not been disrupted, many PLHIV expressed fears about production or shipping supply chain issues from medications produced exclusively overseas. This resulted in some early stockpiling of HIV medications.
- Early reports that HIV medications might be protective against COVID which subsequently proved to be unfounded.
- Fear of COVID transmission and the possible above complications have led to many PLHIV reporting a disproportionate fear of contracting COVID, adding to the already present tendency to self-isolate and retreat from social setting and networks.
- For older PLHIV who lived through the early days of the HIV epidemic and lost partners and friends to AIDS, this new epidemic has triggered post-traumatic stress responses as painful memories and losses are triggered.
- Support agencies, including QPP, have been required to move many of their services online and to cancel face-to-face interventions removing the personal contact and support previously on offer during lockdown periods.

A scoping review of available publications on the intersection between HIV and COVID 19 in relation to its social impacts concluded that:

*The many social consequences created or magnified by the pandemic are linked to disruptions in HIV care, which can lead to medication non-adherence, social isolation, poor mental health outcomes and increased substance use. Impacts on income and employment render treatment options less accessible, while also creating food insecurity.<sup>18</sup>*

The result is that already isolated PLHIV are feeling further isolated and disconnected. Since the COVID pandemic, QPP has experienced a 30% increase in demand for support services, with a significant number of PLHIV reaching out for the first time.

### 3. Drivers of social isolation and loneliness for People Living with HIV

**TOR 2. The causes and drivers of social isolation and loneliness, including those unique to Queensland.**

The following factors add to the complexity of the lives of PLHIV and can contribute to their greater propensity for social isolation and loneliness.

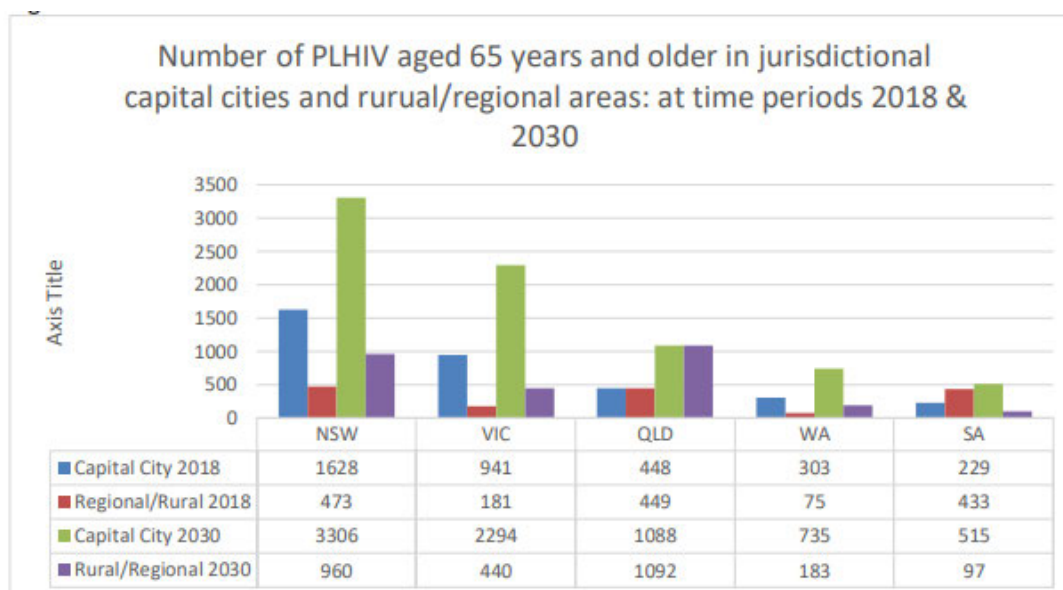
<sup>17</sup> WHO 2021, <https://www.who.int/news/item/15-07-2021-who-warns-that-hiv-infection-increases-risk-of-severe-and-critical-covid-19>

<sup>18</sup> <https://link.springer.com/article/10.1007/s10461-021-03300-1>

### 3.1 Regional Distribution

Queensland is similar to the rest of Australia in relation to most demographic factors- however, as the following graph shows, the proportion of PLHIV living in regional areas in Queensland is already higher and estimated to grow further than that of other Australian jurisdictions. This phenomenon presents a greater challenge in relation to all forms of service delivery including those addressing isolation and loneliness as the graph and commentary below explore.

**Graph 1: Number of PLHIV aged 65 years and older across Australia**



*The situation will be even more challenging in Queensland, where more than 1,000 PLHIV aged 65 years and older will live in a regional/rural area. The population will be spread thinly over an extensive geographical area, making the provision of appropriate aged care services extremely difficult - both for residential and home-based aged care service providers. Many older PLHIV will increasingly experience poorer physical and mental health, and will require transportation over long distances, to receive routine specialist treatment and care for HIV and other chronic health conditions*<sup>19</sup>.

Whilst this data refers specifically to access to aged care services, QPP submits that the same would hold true for services addressing social isolation and loneliness.

### 3.2 Ageing population

The PLHIV population in Australia and Queensland is ageing. Table 2 below predicts that by 2025, approximately 45% of the PLHIV population in Queensland will be over 55 years of age, and 25% over 65 years.

<sup>19</sup> Positive Life NSW 2019 PLHIV and Aged Care Submission to Royal Commission

<https://www.positivelife.org.au/wp-content/uploads/2020/10/plnsw-sb2020-aged-care-royalcommission.pdf>



**Table 2: Ageing PLHIV population across Australia**

State/Territory	2018		2025		2030	
	Number of PLHIV >55	Number of PLHIV >65 years	Number of PLHIV >55	Number of PLHIV >65	Number of PLHIV >55	Number of PLHIV >65
National	9,712	4,869	14,307	8,260	17,667	11,057
New South Wales	4,039	2,101	5,558	3,319	6,597	4,266
Victoria	2,319	1,122	3,599	1,976	4,590	2,734
Queensland	1,875	897	2,847	1,601	3,533	2,180
Western Australia	774	378	1,196	668	1,503	918
South Australia	531	272	776	462	948	612
Australian Capital Territory	140	68	197	118	234	154
Tasmania	149	74	235	141	294	191
Northern Territory	89	42	138	73	170	100

As explored below this phenomenon has significant implications for health and well-being programs.

### 3.3 Accelerated and Accentuated Ageing

Research reports that as PLHIV age they experience accelerated and accentuated ageing. This means they are much more likely to experience a range of health-related co-morbidities at an earlier age compared to their HIV negative counterparts. HIV related premature ageing is well documented and includes:

- cognitive difficulties;
- bone fragility;
- diabetes;
- cardiovascular disease; and
- kidney and liver disease.

*Many people with HIV have one or more of these conditions of premature aging - something known as polypathology. Although polypathology is also seen in older HIV negative adults, it occurs an average of 15 years earlier in people who are infected with HIV.<sup>20</sup>*

A separate report added blood cancers to the above list<sup>21</sup> whilst another noted that HIV anti-retroviral treatments in use in the early days of the HIV epidemic also have contributed to significant long term side effects<sup>22</sup>.

An Australian study found that PLHIV aged over 50 were significantly more likely than younger people to be dealing with at least one chronic health condition as well as HIV. Multiple comorbidities were associated with poorer quality of life. Among people aged over 50:

- 79.7% of people aged 50-64 reported living with at least one chronic condition as well as HIV.
- 88.1% of people aged 65+ had at least one other chronic condition.

<sup>20</sup> <https://www.verywellhealth.com/premature-aging-and-hiv-3132959>

<sup>21</sup> <https://www.agedcareinsite.com.au/2021/07/older-people-with-hiv-are-twice-as-likely-to-develop-ageing-related-genetic-changes/>

<sup>22</sup> <https://bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-020-05593-4>

The most common conditions were hypertension, cardiovascular problems, asthma and arthritis as well as mental health conditions.<sup>23</sup>

The combined impact of these additional health conditions is most acutely felt in the ability of PLHIV to participate in external social events often feeling exhausted, overwhelmed and/or in pain. They increase the likelihood of PLHIV sinking further into social isolation and depression.

### 3.4 Mental Health

Psychosocial factors such as multiple intersectional trauma, mental illness and addiction is strongly associated with being diagnosed with HIV. The prevalence of mental health illness among PLHIV is substantially higher than the general population with 40% of PLHIV reporting current mental health condition diagnosis and 65% report having a current or prior diagnosis - which is 20% higher than the general population. In a 2016 study of 895 PLHIV in Australia, more than half the participants (51.8%) indicated they had been diagnosed with a mental health condition at some point in their life, while 31.9% had taken medication for a mental health condition in the past six months<sup>24</sup>. PLHIV are twice as likely to be diagnosed with a depressive disorder than the general population and are five times more likely to die by suicide.

### 3.5 The Bio-medicalisation of HIV

Recent biomedical advances in HIV treatments have for the first time offered real hope of a normal life expectancy for PLHIV. Studies have shown that PLHIV can have a similar life expectancy to an HIV negative person – providing they are diagnosed and treated early and are able to adhere to lifelong HIV treatment.

Further, evidence has emergence since 2016 on *Undetectable=Untransmissible*. The Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) advises:

***“Undetectable equals untransmissible’, or U=U, refers to the fact that people who take antiretroviral therapy for HIV daily as prescribed, and who achieve and maintain an undetectable viral load, cannot sexually transmit the virus to an HIV-negative partner.”***

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HIV medication can also be taken by HIV negative people to prevent HIV, known as HIV pre-exposure prophylaxis (PrEP). Further, medication can be taken after possible exposure to HIV to prevent HIV establishing itself in the body, known as post exposure prophylaxis (PEP).

The combined effect meant that for the first time the end of the HIV epidemic was within reach, with slogans such as “End HIV by 2020” becoming prevalent.

<sup>23</sup> HIV Futures 9 – Quality of Life among People Living with HIV in Australia; Australian Centre in Sex Health and Society La Trobe University 2019 p 7.

<sup>24</sup> Power, J., Thorpe, R., Brown, G., Lyons, A., Dowsett, G.W., Lucke, J., 2016, HIV Futures 8: Health and Wellbeing of People Living with HIV, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne.

<sup>25</sup> <https://www.ashm.org.au/HIV/UequalsU/>:

These biomedical developments have allowed public health approaches to focus instead on clinicians, medications and access to testing.

In Queensland this approach was also adopted in the states *Queensland HIV Action plan 2016 – 2020* where the Health Minister's opening statement confirmed that:

***To achieve this, the Queensland Government is committing to a comprehensive approach to prevention, testing and treatment focused on meeting the United Nations 90-90-90 targets that: 90% of people living with HIV know their status, 90% of people diagnosed with HIV are on treatment and 90% of people on treatment have a suppressed viral load so their immune system remains strong and minimises the risk of transmitting HIV.***<sup>26</sup>

The net effect was to move funding away from earlier broad support and education mechanisms, to a tight focus on HIV testing and strategies aimed at getting all known PLHIV on treatment. Whilst this was undoubtedly a sound approach in purely epidemiological terms, many PLHIV began to voice their concerns that whilst HIV transmission might end in 2020, they would still be infected. For them, HIV was not coming to an end, and in fact as they aged the challenges would only become greater.

For QPP, our Service Agreements redirected our activity to more clinical interventions with many of our long-standing peer support and education programs having to be significantly scaled back, and with a much narrower focus on PLHIV engaging with clinical services and being on treatment.

*The loss of support networks over time can lead to social isolation among older PLHIV and impact long-term health and quality of life.*<sup>27</sup>

QPP was and still is acutely aware of the gap this change has left in the lives of many PLHIV and, paradoxically, whilst lowered infection rates are undoubtedly welcome, they come at the cost of increased social isolation and loneliness for many. They also assume PLHIV will maintain adherence to complex and often large medication regimens without external supports.

*Such understanding fails to capture the ways in which HIV self-management and care are enacted in complex social contexts, which include disclosure decisions, and efforts to seek support and navigate the significant societal stigma that continues to surround HIV*<sup>28</sup>

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<sup>26</sup> Queensland HIV Action Plan 2016 -2020 Queensland Health p 1

<sup>27</sup> Social Support Networks of People Recently Diagnosed with HIV in Queensland: A Qualitative Exploration O. Hollingdrake. 2020

<sup>28</sup> Flowers, P. (2010). HIV Transitions: Consequences for Self in an Era of Medicalisation. In M. Davis & C. Squire (Eds.), *HIV Treatment and Prevention Technologies in International Perspective* (1st ed., pp. 109-125). Palgrave Macmillan UK. <https://doi.org/10.1057/9780230297050>

Social isolation and loneliness have independently shown to be associated with:

- psychological distress<sup>29</sup>;
- greater immune suppression<sup>30</sup>;
- higher morbidity and mortality<sup>31</sup>;
- lower levels of support have been associated with increased HIV stigma<sup>32</sup>; and
- poorer mental health and quality of life among older gay and bisexual men living with HIV<sup>33</sup>.

There are also complex links to: *HIV-related stigma, discrimination and broader determinants of health, including employment, housing and social disadvantage*<sup>34</sup>.

In summary, QPP believes the combination of these features of the PLHIV population in Queensland add to increased risk factors for poorer physical and mental health and well-being, as well contributing to increased social isolation and loneliness.

#### 4. Protective factors

TOR 3 - The protective factors known to mitigate social isolation and loneliness.

The key factors that can mitigate against social isolation and loneliness is connection and resilience. Social networks play an important role in supporting PLHIV across the lifespan, including reducing barriers to health service access, promoting health literacy, facilitating self-management and promoting a sense of solidarity and belonging. For PLHIV their social networks are often limited due to internalised, anticipated and/or experienced stigma. Fear of disclosure and stigma related to HIV impact marginalised and vulnerable people disproportionately. People from migrant and refugee communities and Aboriginal and Torres Strait Islander peoples are particularly vulnerable.

29 KALICHMAN, S. C., HERNANDEZ, D., CHERRY, C., KALICHMAN, M. O., WASHINGTON, C. & GREBLER, T. 2014. Food insecurity and other poverty indicators among people living with HIV/AIDS: effects on treatment and health outcomes. *J Community Health*, 39, 1133-9

30 HECKMAN, T., KOCHMAN, A., SIKKEMA, K., KALICHMAN, S. C., MASTEN, J. & GOODKIN, K. 2000. Late middle-aged and older men living with HIV/AIDS: Race differences in coping, social support, and psychological distress. *J. Natl. Med. Assoc.*, 92, 436-444.

31 EMLET, C. A. 2006a. A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS Patient Care STDS*, 20, 350-8

32 EMLET, C. A., BRENNAN, D. J., BRENNENSTUHL, S., RUEDA, S., HART, T. A. & ROURKE, S. B. 2013a. Protective and risk factors associated with stigma in a population of older adults living with HIV in Ontario, Canada. *AIDS Care*, 25, 1330-9.

33 EMLET, C. A., FREDRIKSEN-GOLDSSEN, K. I. & KIM, H. J. 2013b. Risk and protective factors associated with health-related quality of life among older gay and bisexual men living with HIV disease. *Gerontologist*, 53, 963-72

34 PETTIGREW, S., DONOVAN, R., BOLDY, D. & NEWTON, R. 2014. Older people's perceived causes of and strategies for dealing with social isolation. *Aging and Mental Health*, 18, 914-920.



Peer connection - i.e. being socially connected with another person that has the same or similar lived experiences to you - is especially important for PLHIV. Peer connection for people with HIV creates a safe space where people can talk about a range of issues that impact them.

Social and peer connection for people with HIV is a protective factor to disengagement from care and improves health outcomes including, adherence to treatment, mental and psychological wellbeing and quality of life. Peer connection ameliorates the impact of social isolation and loneliness caused by HIV. Connecting with other PLHIV and sharing stories facilitates PLHIV to have their experiences validated, and to reduce the burden of worry or guilt. They are able to become part of something larger and stronger.

The strength of QPP as a community-based organisation has been through its ability to allow PLHIV in Queensland to feel that we are on their side and advocating for their needs at all levels of government. Our work allows our members to feel that we have their back and they are not fighting HIV completely alone.

Education about the trajectory of HIV and its impact on health and wellness are also vital. In the early days of the HIV epidemic there was very little knowledge about how HIV was transmitted and how it impacted on the body. As knowledge grew PLHIV became more confident in their trust of medications and safe sex practices. This knowledge became empowering and reduced the tendency of many PLHIV to avoid social situations where they may have feared spreading HIV to family and friends.

Today, this same up to date knowledge about treatment options, available services, the impact of COVID on HIV and the risks of receiving a COVID vaccination are all equally relevant and essential to PLHIV feeling in control.

## 5. Benefits of addressing social isolation and loneliness

**TOR 4.** The benefits of addressing social isolation and loneliness, examples of initiatives undertaken nationally and internationally and how to measure social isolation and loneliness in Queensland to determine if implemented strategies are effective.

The benefits of addressing social isolation and loneliness are improved mental and physical health, well-being and improved quality of life.

The benefits to Queensland of being able to engage with a much broader cross section of the PLHIV population are significant in both economic and social terms:

- Interventions aimed at reducing social isolation not only reduce the burden of loneliness but help to reduce morbidity and mortality, the number and complexity of hospital admissions,

and identify those with mental health disorders that would benefit from peer support and/or professional referrals.

- Interventions targeted to reduce social isolation will improve PLHIV engagement in HIV care and adherence to treatment. This will have the benefit of ensuring PLHIV maintain an undetectable viral load thereby preventing disease progression and onward transmission.
- Programs aimed at outreaching to PLHIV to reduce social isolation and loneliness would have the additional benefit of providing an avenue for educating PLHIV about the preventable risks associated with ageing including diabetes, osteoporosis, coronary heart disease and high blood pressure.
- PLHIV become more confident and self-resilient, increasing their ability to withstand the stigma and discrimination they may face and resume participation in local activities including cultural sporting activities, or work and/or local volunteer programs<sup>35</sup>.

Initiatives which have proven successful to address social isolation and loneliness amongst PLHIV are delivered by services which have an in depth understanding of the issues which have precipitated social isolation and loneliness. Peer based services like Opening Doors London deliver a friendly caller program titled 'Telefriending' and an in-person visiting service called 'Befriending.' These programs provide free telephone or in person visiting for people who identify as LGBT+, over 50 years and feel lonely and isolated. These programs aim to reduce loneliness and isolation, increase confidence and support people to maintain independence. These programs are adaptable to the HIV context.

To measure the benefits of its currently funded programs, QPP uses the *Poz Quality of Life* (PozQoL) survey tool <sup>36</sup> developed by a consortium of HIV services across Australia including the Australian Research Centre for Sex, Health and Society at La Trobe University and QPP. The scale measures quality of life across four domains including: functional, psychological, social and health concerns. PozQoL enables staff and programs to measure the short to long-term effectiveness of their interventions. PozQoL is widely used across Australia and in Canada, United States, New Zealand, Spain, South Korea and Romania.

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<sup>35</sup> [https://www.ohrn.on.ca/wp-content/uploads/2020/06/RR\\_MSM-social-isolation.pdf](https://www.ohrn.on.ca/wp-content/uploads/2020/06/RR_MSM-social-isolation.pdf)

<sup>36</sup> <https://www.pozqol.org>



**PozQoL Scale**

Optional = "This survey is intended for people living with HIV."

Essential = "We would like to ask you about your health, relationships, life satisfaction, and wellbeing. Please indicate how much the following statements apply to you on a scale from 1 (not at all) to 5 (extremely)."

Optional numeration for the response table = 1 – not at all 2 – slightly 3 – moderately 4 – very 5 – extremely.

	Not at all	Slightly	Moderately	Very	Extremely
1. I am enjoying life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I worry about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I lack a sense of belonging with people around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel that HIV prevents me from doing as much as I would like.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel good about myself as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Having HIV limits my opportunities in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I worry about the impact of HIV on my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel in control of my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am afraid that people may reject me when they learn I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Managing HIV wears me out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel that HIV limits my personal relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I fear the health effects of HIV as I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am optimistic about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The data from this tool helps QPP to conduct a program of continuous improvement in its service model and produce data on improvements to physical and mental health. QPP would recommend the utilisation of this now universally accepted tool to measure the progress and successes of any intervention.

## 6. Services to prevent social isolation and loneliness

**TOR 5.** How current investment by the Queensland Government other levels of government, the non-government, corporate and other sectors may be leveraged to prevent, mitigate and loneliness across Queensland, including:

- i) Services and programs such as health and mental health, transport housing, education, employment and training, sports and recreation, community services and facilities, digital inclusion, volunteering, the arts and culture, community development, and planning for accessible, inclusive and connected communities
- ii) Targeted support to vulnerable and disadvantage groups and those most at risk

QPP has been delivering a range of social support programs during its 30-year history and understands well the challenge of supporting such a diverse population of PLHIV including;

- Older people who identify as men who have sex with men who are best described as "long term survivors" and may well now be dealing with multiple complex health issues and issues of frailty and ageing;
- People who have been diagnosed since advanced treatment became an option and who may be living outwardly "normal" lives;

- People only recently diagnosed for whom the challenge is coming to terms with their diagnosis, understanding its implications and how to tell family and friends;
- People from Aboriginal and Torres Strait Islander backgrounds living in community where knowledge and the degree of shame around HIV and sex generally raises the need for secrecy;
- People from non-English speaking backgrounds where HIV may be misunderstood, and where cultural and religious factors may impact on a person's ability to gain the support of family and friends;
- Heterosexual men and women who form a minority within the PLHIV population and suffer even greater isolation because of their fewer number and fewer opportunities to form meaningful connections.

QPP currently uses a range of mechanisms to reach PLHIV that could be further expanded to reduce social isolation and loneliness amongst these and all other PLHIV including:

### 6.1 Peer Support Networks

Hosting peer-led targeted support groups and networks aimed broadly at the sub-populations of PLHIV above have been a mainstay of the QPP service model since its inception. As contemporary understanding of health promotion increased in the early 2000s, Queensland Health directed funding to QPP to conduct support groups and HIV related education outreach to assist PLHIV. While these programs were primarily aimed at reducing the rates of HIV transmission, they had the indirect benefit of improving networks and bringing PLHIV together in safe settings where their fears of being "outed" or suffering stigma or discrimination were removed.

Unfortunately, with the bio-medicalisation of HIV, such strategies became redundant for the more certain outcome of an undetectable viral load. To be clear, QPP is not against strategies that achieve this outcome, because there are long term health benefits of viral replication being controlled for PLHIV and the prevention of onward transmission. However, in the context of this submission, it is this change of approach and the subsequent shift in service agreement deliverables, that have seen these important social interventions dramatically reduced. Social isolation and loneliness have increased proportionately.

The University of Queensland *HIV Testing to Treatment Trajectory in Queensland Study* found the benefits of peer-led support groups to be:

- acceptance and non-judgement
- maintaining stability
- meaningful connections and solidarity
- promoting physical and mental health
- validating HIV positive status
- encouraging personal growth and development<sup>37</sup>

QPP fully understands the pragmatic reality that available funding from Queensland Health must be aimed at the best strategies for reducing new infections. Instead, this submission highlights that PLHIV support networks focused on reducing social isolation have a valid place in the Queensland response

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<sup>37</sup> O Hollingdrake RN University of Queensland From diagnosis to living well with HIV: The pivotal role of peer support. *The HIV Testing to Treatment Trajectory in Queensland Study*



and need to be funded elsewhere in Government. While QPP has maintained some peer-led support groups through small amounts of self-generated funding and volunteers, this funding is extremely limited and does not have the resources to adequately train and support facilitators as they should and need to be. Further, it does not allow the opportunity to provide much required additional therapeutic interventions into these settings. QPP believes that there would be many (particularly older) PLHIV who would volunteer for such a role to give back to their community.

Whilst QPP also understands that one of likely outcome of this enquiry may to be introduce a range of broadened social opportunities for supports at the local level, for all the reasons raised above, it is QPPs view that they would likely be poorly subscribed by PLHIV.

It is important to recognise that many people living with HIV are from marginalised and vulnerable communities including gay men, men who have sex with men, culturally and linguistically diverse people. Intersectionality of stigma due to HIV status and other identities will present as a barrier for people engaging with mainstream initiatives to address social isolation and loneliness.

As a peer community organisation, QPP is best placed to provide a safe environment, hosted by trained QPP staff and volunteers.

**Recommendation 1:** Funding to enhance and expand QPP's existing peer support networks and groups to reach a broader range of PLHIV for the purposes of reducing the impacts of social isolation and loneliness. Funding should include resources to coordinate volunteer peer support group coordinators with training and support.

## 6.2 Peer Navigation

The HIV peer navigation program is a more recent addition to the QPP range of programs and has been funded by the Queensland Department of Health since 2016. The program has proven so successful it has now been replicated and funded by Government in Victoria and New South Wales. The programs are successful contenders for academic research and the QPP Peer Navigation Program features regularly in published papers.

The peer navigation program is targeted towards people newly diagnosed with HIV, people re-engaging with care or at risk of disengaging with care. Peer navigators (PNs) who deliver the program are PLHIV with demonstrated lived experience of personal empowerment. PNs are professionally trained and supervised and matched to another PLHIV in need of support. They are located around the state, from geographically diverse regions and represent different gender, ethnic and cultural backgrounds.

In its currently funded form, the focus of Peer Navigation is on supporting newly diagnosed PLHIV to engage with HIV treatment. PNs provide peer education to assist with developing HIV health literacy. PNs also provide practical assistance and support with navigating health systems. For example, the program aims to assist those newly diagnosed to make informed choices about the often-complex array of doctors, specialists, testing, and pharmacies associated with HIV care. Peer Navigation plays a



crucial support role by providing meaningful contact from a fellow PLHIV that helps bridge their clinical and everyday worlds.

The goal is for PLHIV to be stable on HIV treatment that delivers them an undetectable viral load to improve their physical health and wellbeing and prevent the onward transmission of HIV. Over time peer navigators have consistently demonstrated their ability to provide protective factors to good mental health, and act as a bridge to engagement and retention in HIV care<sup>38</sup>. QPP's peer navigation program is almost always oversubscribed with waiting lists, pointing to an urgent need for the program to be expanded.

*Peer Navigators normalise HIV, alleviating fear and stigma, educating and translating clinical information for patients..... Peer navigation has clear potential in supporting the care of PLHIV, to alleviate constraints in GP settings and expand HIV care beyond the clinic.*<sup>39</sup>

QPP believes the above success points add to the value and need of peer navigation being expanded to those PLHIV experiencing social isolation and loneliness (but who may be stable on treatment) in the form of a home visiting and/or outreach program. Such a program would easily compliment the QPP existing training standards and procedures, however would require funding for salaries, training costs, professional supervision costs, and travel reimbursements etc.

An expanded Peer Navigation Home Visiting/Outreach Program would have the joint benefit of linking local PLHIV to their local communities as well as helping them to access non-discriminatory local services. Already QPP possesses a comprehensive statewide service and resource list, and PN's could link their clients into these programs.

Peer support and peer navigation also provide entry points into other QPP programs e.g. case management support for all social determinants of health including legal support and referral. QPP is also currently exploring becoming a *My Aged Care* and NDIS service provider. An expansion of such a home visiting/outreach program would be a logical bridge to educating ageing PLHIV or those with disability about this complimentary range of safe services on offer at QPP.

**Recommendation 2: Funding to provide an expanded peer navigation home visiting/outreach program to provide needed connections for PLHIV experiencing social isolation and loneliness.**

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<sup>38</sup> Hollingdrake et al. 2019 From diagnosis to living well with HIV: The pivotal role of peer support networks University of Queensland and Queensland Positive People

<sup>39</sup> *Peer navigators' role in supporting people living with human immunodeficiency virus in Australia: Qualitative exploration of general practitioners' perspectives*. Health and Social Care in the Community. DOI: 10.1111/hsc.13465 Apr 2021.



### 6.3 Technology based solutions

As highlighted, the PLHIV community is diverse in characteristics including age, gender, sexual orientation, ethnicity and lifestyle preferences. Whilst the above strategies offer meaningful options, the geography of Queensland mean it will never be possible or cost effective to always offer these predominantly face-to-face solutions to all socially isolated PLHIV.

The QPP Constitution requires that 'Ordinary Members' are PLHIV and they are required to demonstrate, through signed documentation by a health professional that they are HIV positive. This requirement provides a unique opportunity to provide a peer online platform for HIV+ members to search the database via a search engine to find likeminded PLHIV. QPP is the *only* service that could offer this function, and its true value is that *the most difficult topic* in meeting new people would be nullified, as all members are guaranteed by the QPP Board to be HIV+.

Members could enter the desired attributes they are seeking to connect with (age, sexual orientation, gender, hobbies and interests etc.) and then define the geographic radius (e.g. 20km, 50km, 100 km, statewide etc.) to find a match. Then, via a secure email, text, or online chat function they could reach out to another PLHIV with a view to meeting up in person or via phone/text, email, online etc.

QPP would never be in a position to support or fund such links but a well facilitated member data base would allow socially isolated PLHIV to connect and develop common interests. The specifications and protocols for the operation of this program have been written for some years, however the service has been on hold due to lack of funding to further develop the existing database and then employ a webmaster/member services officer to manage and safeguard contact through the site.

Peer Navigators would also have access to the database to consider their local PLHIV populations and tailor support groups/outings by age, sexuality, interest etc.

Recommendation 3: QPP recommends the introduction of innovative uses of technology to improve opportunities for PLHIV to contact each other. Included would be a closed member database search engine function that would allow PLHIV to seek likeminded PLHIV across Queensland for friendship and social outings.

## 7. The role of state-wide strategies.

TOR 6. The role, scope and priorities of a state-wide strategy to address social isolation and loneliness, considering interactions with existing Queensland and national strategies.

QPP is cognisant of the powerful role of state-wide and national strategies to help guide services across a state the size of Queensland, and indeed Australia. They ensure coordinated strategic responses for

funding, resource allocation and service delivery. Often community-based agencies utilise such documents to hold service providers to account in regional centres when service delivery is inconsistent, or being unduly influenced by local factors to the detriment of smaller population groups such as PLHIV.

The Australian approach to managing HIV is an example in point where HIV National Strategies have guided service models since the outbreak of HIV in the 1980s. These nationally endorsed roadmaps have helped in turn to guide the development of jurisdictional based strategies, which in turn influence local government area service providers in the practice and principles they expound on the ground. On many occasions during its 30-year history QPP has been able to quote the current National HIV Strategy to reinforce the role of PLHIV being included in decision making.

QPP would therefore support the further development of an overarching strategy that addressed social isolation and loneliness. It is essential that such strategies are based on whole of government approaches with identified roles for all relevant departments including Queensland Health, the Department of Communities and Housing and the Office of the Attorney General. It is also important to facilitate shared funding arrangements across departments to ensure the strategic alignment of priorities and resource allocations with integrated versus siloed interventions.

As highlighted throughout this submission, the intersection between overall physical and mental health, and isolation, loneliness and depression in the case of PLHIV are closely intertwined and interventions addressing only parts of the solution are likely to fail or be sub optimal.

This position is restated in the *8th National HIV Strategy 2019 -2022* which states that stigma and discrimination is a central concern for many people ageing with HIV who may require health and social services outside of their regular HIV care and support providers with whom they have an established relationship.<sup>40</sup>

QPP recommends that in relation to PLHIV such a strategy incorporate the goals of the current *Queensland HIV Action Plan 2019 -2022* (which is focused predominantly on preventing HIV infections), but be widened to include:

- Strategies to address social isolation and loneliness including new and targeted funding to deliver on the recommendations above.
- Interventions for mental health, and alcohol and other drug related interventions.
- Education strategies to reduce prevent co-morbidities in ageing PLHIV through improved screening and awareness protocols which would result in better overall health and wellness.
- Improved education for staff of age care facilities about HIV and ageing including the risk of social isolation and loneliness and associated risk of co-morbidities.

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<sup>40</sup> 8<sup>th</sup> National HIV Strategy Department of Health Commonwealth of Australia p 28



## 8. Conclusion:

The HIV epidemic is changing and QPP believes it is incumbent on governments to change with it.

For over 30 years in Queensland, the primary response to HIV has been funded and managed by the Queensland Department of Health. As treatment regimens have become the go-to method for prevention and bureaucrats discuss the “End of HIV”, the human cost of HIV and its impact on individuals is being increasingly overlooked.

As pointed out in this submission, levels of social isolation and loneliness interplay with the above and yet availability of interventions to address these social conditions continue to decrease over time as funding is diverted.

*Ensuring that PLHIV are empowered to enact the support they need from networks of family, friends, providers, and peers is crucial. Interventions that facilitate PLHIV to build these networks for support must be incorporated into contemporary models of HIV care<sup>41</sup>*

QPP submits this report to the Parliamentary Enquiry and respectfully asks that PLHIV be considered a sub-population at high risk of social isolation and loneliness. QPP has a proud tradition of working and reporting its outcomes to Government and would like to be considered for funding of the recommendations above or any other strategies recommended by the enquiry to address this growing crisis.

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<sup>41</sup> Bringing the ‘social’ back into HIV care: A qualitative study of self-management experiences for recently diagnosed people living with HIV in Queensland, Australia. O Hollingdrake et al. 2021



17 August 2021

Committee Secretary  
Community Support and Services Committee  
Parliament House  
George Street  
Brisbane Qld 4000

**Ref: Queensland Government Parliamentary Enquiry into Social Isolation and Loneliness**

Dear Committee Secretary

The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV). NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia. NAPWHA provides advocacy, policy, health promotion, effective representation, and outreach on a national level. Its work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people. NAPWHA's vision is of a world in which HIV positive people can live their lives to their full potential and free from stigma and discrimination.

NAPWHA has had the opportunity to review the submission of our member organisation in Queensland, Queensland Positive People (QPP) and we wish to register our strong support. As the national peak representing PLHIV, we are acutely aware of the destructive role that a lack of meaningful connection plays in reducing quality of life, health, and well-being within the HIV positive population.

In addition to our support of QPP's submission we would like to take this opportunity to add the following comments:

In Australia HIV is a virus that continues to disproportionately affect Gay and Bisexual Men. Epidemiological modelling by the Kirby Institute shows over half of this population is now over fifty years of age. For this cohort the effects of social isolation are particularly acute. This is due to several reasons.

Firstly, the process of 'coming out' in previous decades often resulted in the permanent severing of important family and friendship ties that, for the rest of the population, serve to reduce social isolation in old age.

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**National Association of People With HIV Australia (NAPWHA)**

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Secondly, the formation of long-term homosexual relationships that could have provided support in old age were actively prohibited by the coercive apparatus of the State; through a hostile legal environment that did not recognise same sex partnerships, and by discriminatory surveillance and targeted policing. This, along with generalised societal homophobia, has left older gay and bisexual men with fewer (and shorter) supportive relationships and smaller support networks than their heterosexual peers.

Thirdly, prior to the development of effective HIV treatments people with HIV routinely accessed their superannuation early in contemplation of significantly shortened lives. With the development of the first anti-retroviral medications came debilitating side effects which, in addition to severe illness caused by the virus itself, left many people in this group permanently debilitated and unable to work. This, combined with no familial inheritance, has left this group poorer than their heterosexual counterparts and unable to afford to buy-in the care that their heterosexual counterparts would typically receive from family and friends.

Finally, rates of mortality among gay men in the early days of the epidemic were so significant that entire groups of friends were lost.

This has left this cohort poorer, more isolated and more alone than most other groups in Australia.

Accordingly, NAPWHA is strongly supportive of additional government investment into initiatives that reduce social isolation and loneliness of all Australians and in particular people with HIV.

We commend QPP's report you and thank you for the opportunity to submit our additional comments.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'A. Cogle', with a stylized flourish underneath.

Aaron Cogle  
Executive Director