**Peer support for the Huntington's community... by the Huntington's community, 'Huntington's Community Connect'**

**Part 1: Gap Analysis Report**

National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC) Individual Capacity Building (ICB) Program Grant Round: 2020

December 2020

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## Abbreviations

| Abbreviation | Full terminology |
| --- | --- |
| HCC | Huntington's Community Connect |
| HD | Huntington's Disease |
| HV | Huntington's Victoria |

## Plain Language Summary

The NDIS have funded a large project called '*Huntington's Community Connect*'. The project investigates online peer support for the Huntington's community...by the Huntington's community, through three parts. These are 1) a gap analysis, 2) an implementation project and 3) an evaluation. This document is the Gap Analysis Report.

### What did we do?

1. We performed a **rapid evidence review** to find out about the current national prevalence of Huntington's Disease (HD), that is, how many people are diagnosed with HD in Australia. We looked at published evidence and we asked genetics services within Australia,

2. We looked at how impacts of HD are described, and the relevance of the **Huntington's Victoria Social Impact Domains** to describe the things that matter to the Huntington's community,

3. We asked members of the Huntington's community and health professionals supporting people with HD about what services and supports they use, and what services and supports they need. We asked what **gaps** exist and we asked how peer connection might help,

4. We developed some **implementation recommendations** to help the Huntington's Community Connect peer support program be effective in its impact and its national uptake.

### What did we find?

1.The rapid evidence review

- *How many Australians have Huntington's disease?* The best available published evidence of relevance to Australia suggests a prevalence rate of 8.4 per 100,000 people. This indicates that with a current population of 25.7 million people in Australia[1], there is currently around 2,160 people with a diagnosis of HD. Even though the Australian Bureau of Statistics collects national data, information about HD is hidden within the 'progressive neurological' category.

- *How many Australians with Huntington's disease are using the NDIS?* 833 people with HD listed as a diagnosis were receiving an NDIS package on 31 December 2019.

- *How many people with Huntington's Disease live in Residential Aged Care (RAC)*? About 38 people per year over the last 5 years move into RAC permanently. In total, 331 people with HD resided in RAC as at June 2019.

- *How many people are tested and diagnosed with HD across Australia?* We asked 17 Genetic clinics and services about their numbers in the last year, and the last ten years. The clinics and services told us it was difficult to count accurately, and also described very different

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[1] https://www.abs.gov.au/AUSSTATS/abs@.nsf/Web+Pages/Population+Clock?opendocument&ref=HPKI (accessed December 2020)

services across the country. Some clinics suggested a national database is required. Some clinics were involved with other research around prevalence. Three clinics provided information about their service numbers, and showed that small numbers of people are tested and diagnosed each year.
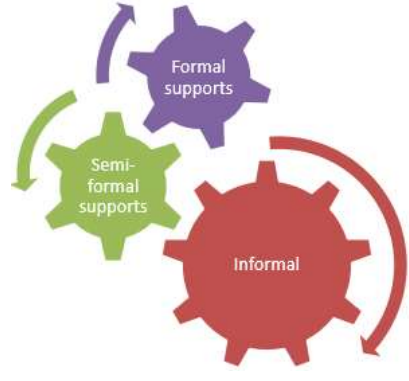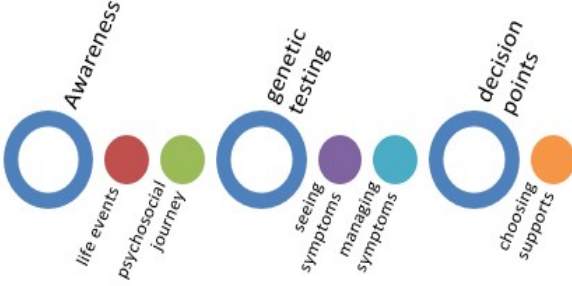
o   Work is underway to find out about prevalence rates in each State/Territory of Australia. We have shared our data with Professor Stout, Principal Investigator with the Huntington's Disease Network of Australia.

2.This research confirmed the relevance of the Huntington's Victoria Social Impact Domains and explored the relationships of these domains. Participants responded to all the domains as being relevant. Domains were described as either being about **risks and safety** or about **social inclusion**. Risks and safety topics included housing stability, and economic sustainability). Social inclusion included health and symptom management, physical well being, emotional wellbeing, and building resilient relationships (see Figure 2 in Main Report).



See Main Report Figure 2 Thematic clusters for HV Social Impact Domains

3.We ran three Focus Groups. The first was with six health professionals, the second was with two people who are gene positive, and the third was with three people who are gene negative and supporters of people with HD. We have summarised what participants said in the three themes and diagrams below. Appendix 4.1 contains a full plain language summary of each theme.

| | |
|---|---|
| **Sources of Support**<br><br>People draw support from a range of sources. Different supports are useful at specific times and for specific tasks. Peer support is one of those supports. |  |
| **Gap analysis**<br><br>Peer support is a type of informal support. Peer support is one of the creative way we might work together to wrap supports around the person, across regions and across services. |  |
| **Right time right touch supports**<br><br>Supports need to be responsive to the trajectory of Huntington's Disease. |  |

4.How should a digital national peer support program for HD be implemented to maximise uptake and impact? Here are some implementation recommendations:

- Huntington's Victoria should construct a peer support model with clear role boundaries and support structures
- The communications / marketing approach needs to signal an understanding of the relationship between peer support and other forms of support (formal / semi-formal / informal)
- Huntington's Victoria need to design peer support to cluster resources around key points
- Huntington's Victoria need to design peer support to identify resources at regional levels, where appropriate
- The online peer support model needs to be endorsed by data (that is, the findings of this gap analysis)
- During the early project stages, Huntington's Community Connect should be monitored closely to ensure processes are being followed. This monitoring should continue ongoing.
- Huntington's Victoria should offer flexible service with opt-in capacity. This will enable community to step in /step out according to individual support needs over the HD journey
- Huntington's Victoria need to structure the peer support offering to run independently of individual volunteers

What comes next?:

- We learned that a range of other Huntington's Disease research is underway and we recommend that the next phases of this project occur in close collaborations with the Huntington Disease Network of Australia.
- We have provided the useful data we gained, to Professor Julie Stout who is the principal investigator of the National Health and Medical Research Council grant which will build a national registry as part of the work of the Huntington Disease Network of Australia.
- We will write a journal article summarising some of our findings.
- Huntington's Victoria will now implement Part 2) an implementation project and Part 3) an evaluation. This involves rolling out the 'Huntington's Community Connect' peer support program for the Huntington's community. Part 2) and Part 3) will occur in parallel. That is, the evaluation will occur alongside implementation of the 'Huntington's Community Connect'.
- We propose the HCC Steering Committee for Part 2 include the key stakeholders identified in the Gap Analysis, this includes state-based HD associations, and the Huntington Disease Network of Australia. The findings of this Gap Analysis, and of the full 'Huntington's Community Connect' project, will be made available to the Huntington's Disease community nationally.

## Background to the project

Huntington's Disease (HD) is a rare neurodegenerative disorder of the central nervous system characterised by unwanted choreatic movements, behavioural and psychiatric disturbances and dementia (Roos, 2010). HD results in brain cell death and affects the regions of the brain that are responsible for motor movement control and coordination, cognition, personality and emotions. Deterioration in these regions of the brain results in significant impairments in one's ability to think, feel and move. HD onset predominantly occurs in young-middle adulthood (Huntington's Victoria, 2019).

In Western countries it is estimated that about five to seven people per 100,000 are affected by HD. In Australia it is estimated that over 1,800 people have Huntington's Disease and approximately 9,000 are at risk (Huntington's NSW ACT website, 2019) with a reported prevalence rate in Australia which ranges from 4.5 per 100,000 to 6.5 per 100,000 (Pringsheim et al., 2012). However, these estimates are based on incomplete and old data indicating that the current HD prevalence in Australia is unknown. Being a genetic disease, each child of a parent with HD has a 50% chance of inheriting the defective Huntington's gene (Huntington's Victoria website 2019). There is also evidence that in Australia, North America and in Western Europe (including the United Kingdom), prevalence has increased over the past 50 plus years (Rawlins et al., 2016).

In Australia, there is no national body for HD, however there are a number of state-based organisations, such as Huntington's Victoria. Huntington's Victoria works with individuals of all ages and has an array of support services accessible to those impacted by HD. A Client Support Services team provides information and links to vital services as well as education. Huntington's Victoria's specialist Client Support Services team connects those impacted by HD with services and support, including support for families and carers (Huntington's Victoria, 2019).

Access to accurate information and support services is vital for people impacted by HD (Walker, 2007). A study in the UK examined the content of an online Huntington's disease peer support group and the most frequent exchange was in the provision of information to one another (n=730, 56%), demonstrating that this community is actively seeking access to up to date, relevant and quality information (Coulson et al., 2007). Support groups are a valuable source of information (Walker, 2007) however knowledge on their existence and how to access them is limited.

Gaps exist within the Australian Huntington's community which relates to access to up to date, relevant and quality information, including peer support, and this directly impacts an individual's ability to exercise choice and control. Gaps also exist for a current and accurate national HD prevalence. In response to these gaps, Huntington's Victoria has developed a project where the overarching aims are to enable nation-wide access to up to date, relevant and quality information, including peer support, for people impacted by HD, as well as establish the current HD prevalence in Australia. This project is called the 'Huntington's Community Connect' (HCC) peer support program. However, to achieve this overarching aim, there are two smaller projects and a combined program evaluation which need to occur (Figure 1). This project is funded by National Disability Insurance

Scheme (NDIS) Information, Linkages and Capacity Building (ILC) Individual Capacity Building (ICB) Program Grant Round: 2020.

The over-arching project comprises three stages (figure 1) with the overall aims as follows:

- To enable nation-wide access to peer support and mentoring for people impacted by HD
- Provide a mechanism to deliver up to date, high quality information for people impacted by HD
- Enable the individual to exercise choice and control

Current Project

**Project 1: Gap Analysis**

- Complete a rapid evidence review to determine the Australian prevalence of HD
- Complete a formal and informal support needs analysis for the Huntington's community and report where gap exists between the support available and the support needed.
- Develop implementation recommendations to maximise the National uptake and impact of HCC

**Project 2: HCC Implementation**

- Trial of the HCC peer support program for the Huntington's community
- Evaluate the impact of the HCC peer support program reporting the National uptake and impact
- Develop of a model for sustainability

**Evaluation of Project 1 and 2 Combined**

- Evaluate the implementation of the HCC (Project 2) against the implementation recommendations (Project 1)
- Report if implementation of the HCC (Project 2) addressed any of the gaps identified in the formal and informal support needs analysis for the Huntington's community (Project 1)

Figure 1: Project stages for the 'Huntington's Community Connect' peer support program

"Project 1: Gap Analysis" is the first project and addresses following research questions;

- What is the current prevalence of HD in Australia?
- What are the formal and informal support needs of the Huntington's community, and are these needs being met?
- How should a digital national peer support program for HD be implemented to maximise uptake and impact?

Project 1 has three parts and used a mixed method approach inclusive of both qualitative and quantitative methodology, specifically a formal and informal support gap analysis for the

Huntington's community, verification of the Huntington's Victoria social impact domains, as well as a rapid evidence review to determine the Australian prevalence of HD. This project worked together with the people impacted by Huntington's as well as the health, support and disability professionals who support those impacted, to understand the current formal and informal support needs of the Huntington's community and report where gaps exist between the support available and the support needed. Through the gap analysis, combined with the rapid evidence review, this project developed implementation recommendations to maximise the national uptake and impact of the planned HCC peer support program.

"Project 2: HCC Implementation" is the second project and this includes implementation of the HCC peer support program for the Huntington's community. Project 2 will evaluate the implementation process and the early impact of the HCC peer support program / web-based interface, and develop of a model for sustainability.  Project 2 will commence after Project 1 is completed and is out of scope for this current report.

## Our Findings

We firstly present our Rapid Evidence Review findings on the current prevalence of HD in Australia. We then present two aspects of our Gap Analysis. Firstly, the work that was done to verify the Huntington's Victoria social impact domains, and secondly, focus group findings regarding the formal and informal support needs of the Huntington's community, using social impact domains as the question set and analysis framework. Finally, we present our implementation suggestions regarding how a digital national peer support program for HD should be implemented to maximise uptake and impact.

### Rapid Evidence Review

The rapid evidence review aimed to identify prevalence of HD in Australia with the best available data. Prevalence studies address the prevalence or incidence of conditions. They inform health policies and explain or predict healthcare utilisation. It is important that health policy decisions are based on high quality research. Prevalence and risk factors for conditions such as chronic diseases are evaluated using observational studies. The methods that are used to assess the validity of prevalence studies therefore differ from those that might be used to assess studies of the effects of interventions. Rapid reviews assess what is already known about an issue by using systematic review methods to search and critically appraise existing research. The completeness of searching is determined by time constraints and a time-limited formal quality assessment is conducted. Analysis focusses on quantities of literature and overall quality / 'direction of effect' of literature (Grant and Booth, 2009).

## Method

A rapid evidence review of data sources regarding Australian prevalence of Huntington's Disease, triangulated with a comparative analysis of available datasets including government data and genetic facilities in Australia.

## Results

*Literature review*: a systematic database search using an adapted search protocol from Rawlins et al 2016 (including incidence plus 2010 date range plus Australia). It is important to note whether studies call upon data prior to 1985 as, before this date, the MRI was not routinely in clinical use. A search strategy was run on the 31st July 2020 on two databases resulting in the following yields: Embase n=20, Medline n=8. Three duplicates were removed and two reviewers utilized Covidence to review n=25 abstracts. From this, full text review occurred for n=9 articles and 4 articles underwent quality appraisal to assess for risk of bias in prevalence studies (Hoy et al., 2012) and data extraction.

The most recent prevalence studies were published in 2016. Most elected not to do meta analysis due to study heterogeneity, and many cited the same source data. Rawlins (Rawlins et al., 2016) published The Prevalence of Huntington's Disease in Neuroepidemiology, providing detailed rationale regarding method and data extraction, but no formal quality appraisal. Prevalence for Australia, Western Europe including the United Kingdom and North America, was calculated at 9.71 (95% CI 9.32–10.12) per 100,000 head of population. Wexler et al conducted a systematic review of the incidence of adult Huntington's disease in the UK but did not attempt a quantitative assessment of the quality of the included studies. Australia was thought to be comparable with UK studies with rate of 7-8 per million patient years (Wexler et al., 2016). Baig and colleagues (Baig et al., 2016) provide a systematic review and discussion of the global prevalence of Huntington's disease, published in Neurodegenerative Disease Management. No formal quality appraisal measures were noted, but the authors clearly specified the drawbacks of study heterogeneity in reporting their findings, estimating prevalence of HD in North America, North Western Europe and Australia ranges from 5.96 to 13.7 cases per 100,000 population. The final study reviewed was from 2012, where Pringsheim and colleagues (2012) estimated a prevalence of 5.70 per 100,000people in North America, Europe, and Australia as well as 0.40 per 100,000 people in Asia: a strength of this study was the inclusion of two formal publication bias tools (see Table 1).

Table 1 Rapid Evidence Review yield and quality appraisal

| Record | Prevalence results | Quality appraisal |
|---|---|---|
| Rawlins it al (2016) | Average prevalence (Australia, Western Europe including the United Kingdom and North America, was 9.71 (95% CI 9.32–10.12) per 100,000. | Explicit actions re rigor; Annexes of detailed method and data extraction, no formal qual appraisal detailed |
| Wexler et al (2016) | Australia thought to be comparable with UK studies (including current study) with rate of 7-8 per million patient years | The systematic review does not attempt a quantitative assessment of the quality of the included studies |
| Baig et al (2016) | The estimated prevalence of HD in North America, North Western Europe and Australia ranges from 5.96 to 13.7 cases per 100,000 population | No formal quality appraisal noted, elected not to do meta analysis due to study heterogeneity |
| Pringsheim et al (2012) | prevalence of 5.70 per 100,000 people in North America, Europe, and Australia as well as 0.40 per 100,000 people in Asia | Used two formal publication bias tools in determining yield |
| BOTTOM LINE | Averaged Rawlins and Pringsheim, with mean point of Baig to reach 8.4 per 100,000 <br><br> This indicates that with a current population of 25.7 million people in Australia (https://www.abs.gov.au/AUSSTATS/abs@.nsf/Web+Pages/Population+Clock?opendocument&ref=HPKI; accessed December 2020), there is currently around 2,160 people with a diagnosis of HD. | |

*Scan of government data sets* (Appendix 2)

Australian Bureau of Statistics and AIHW Reporting: Granular data on HD is hidden within progressive neurological datasets at the ABS level.

NDIS: A Freedom of Information request (Huntington's Victoria) identified that 833 people with Huntington's Disease listed as a diagnosis were receiving an NDIS package on 31 Dec 2019.

Residential Aged Care: An AIHW data request identified that about 38 people per year over the last 5 years move into RAC permanently. In total, 331 people resided in RAC as at June 2019.

*Environmental scan to identify any registry or data in existence for HD*

In terms of primary clinic-based data in Australia, 17 clinics and services nationally were invited to provide broad estimates of numbers diagnosed, and numbers tested, in the last financial year or over the last 10 years.

Responses were mixed. Four clinics provided data, three clinics indicated they were involved with similar studies[2], and two clinics queried data overlap issues (that is, how to separate diagnostic and predictive testing, the risks of double counting when collecting both diagnostics and service usage). There was strong agreement across respondents that a systematic approach to data collection was needed, and that plans in this regard are underway nationally. It was also interesting to note that Victoria has had a registry in the past.

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[2] Eg through the Huntington Disease Network of Australia collaboration

Table 2 identified the question set mailed to 17 genetics clinics within Australia[3]

| Environmental scan to identify any registry or data in existence for HD |
| --- |
| **Questions sent to the 17 State-based neurological services registries**<br><br>QUESTION SET please identify:<br>Number of people diagnosed in the 2019- 2020 financial year, that is, gene positive<br><br>Number of people tested in the 2019- 2020 financial year, that is, combined gene positive and negative<br><br>Over the last 10 years, average annual number of people diagnosed (prior to the 2019- 2020 financial year), that is, gene positive<br><br>Over the last 10 years, average annual number of people tested (prior to the 2019- 2020 financial year), that is, combined gene positive and negative<br><br>Over the last 10 years, how many individuals impacted by Huntington's Disease have presented to your service (via data available or your best estimate)?<br><br>•　　Please include a total for all individuals presenting to your service who have been impacted by Huntington's Disease. Impacted may include: Gene status unknown; Gene status positive; Gene status negative; Family planning; Person in a carer role<br><br>•　　If you have the data available, please break down the total number of individuals into these sub-groups, or sub-groups of your determination.<br><br>Please provide any comments about changes to your service, or about the individuals impacted by Huntington's Disease who are presenting to your service, over the last 10 years. For example, changes in demographics, services requested, referral patterns, etc. |
| **Responses:**<br><br>-　RMH Neurogenetics<br>-　RBWH Queensland<br>-　Monash Health Genetics<br>-　Tasmanian Clinical Genetics Service |

Data clusters emerged for Victoria and Tasmania, with a small amount of data for Queensland. These snapshots of data point to the imperative to access data from one primary source for each state or region to ensure it is counted appropriately.

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[3] Tasmanian Clinical Services; Neurology Clinic Royal Hobart Hospital; Genetic Services WA; Specialist Clinic/ Neuroscience Unit Graylands Hospital WA;; SA Huntingtons Disease Service; Genetic Health Qld; Royal Brisbane and Women's Hospital; The Huntington's Disease Service @ Westmead and John Hunter Hospitals NSW; Victorian Clinical Genetics Services; Monash Health Genetics; Royal Melbourne Neurogenetics; Victorian Clinical Genetic Services; Royal Melbourne Hospital; Calvary Healthcare Bethlehem

VICTORIA

Royal Melbourne Neurogenetics Victoria provided the following information: Clients may self-refer or arrive from different health professions, experiencing a 1-6 week wait depending on urgency and preference, and are sourced from Melbourne metro as well as some regional/rural including the Geelong area.

- Number of people diagnosed in the 2019- 2020 financial year, that is, gene positive: **Approximately 13**
- Number of people tested in the 2019- 2020 financial year, that is, combined gene positive and negative: **Approximately 38**
- Over the last 10 years, average annual number of people diagnosed (prior to the 2019- 2020 financial year), that is, gene positive: **Approximately 4**
- Over the last 10 years, average annual number of people tested (prior to the 2019- 2020 financial year), that is, combined gene positive and negative: **Approximately 12**
- Over the last 10 years, how many individuals impacted by Huntington's Disease have presented to your service (via data available or your best estimate)? **50 families (approximately 150 individuals)**

Monash Health Genetics suggest the Victorian Clinical Genetics Service is the most suitable source of testing data for the State. Monash Health Genetics provide genetic counselling for at risk individuals. Referral is via GPs, neurologists (Calvery) and coverage is South East Metro Melbourne and regional Vic (Gippsland; Mornington Peninsula) with a 2-3 month wait list. Monash Health Genetics commenced services to the Huntington's community in 2014 with the commencement of a regular neurogenetics clinic. Between 2014 to 2019, 168 people attended the service for HD related issues. These individuals are patients at risk of HD themselves, already affected, and carers/supporters. Patients attending for prenatal/reproductive planning were n= 22; with a further n= 11 being patients attending for paediatric indication (including carers). An update on numbers for the last year (July 2019 to May 2020) was a further 31 individuals attending.

TASMANIA

Members of Tasmania's medical community noted they have a similar study undergoing ethical review. Nevertheless, complementary data was received from the Tasmanian Clinical Genetics Service and via Huntington's Case Management: Older Person's Mental Health at the Repatriation Centre, Hobart.

- Number of people diagnosed in the 2019- 2020 financial year, that is, gene positive: **Approximately 11**
- Number of people tested in the 2019- 2020 financial year, that is, combined gene positive and negative: **Approximately 18**
- Over the last 10 years, average annual number of people diagnosed (prior to the 2019- 2020 financial year), that is, gene positive: **44 over 10 years = average 4 per year, but testing may have also been offered through the Adult Mental Health Unit in Launceston for part of this period**

- Over the last 10 years, <u>average annual number</u> of people tested (prior to the 2019- 2020 financial year), that is, combined gene positive and negative: **98 over 10 years = average 10 per year**
- Over the last 10 years, how many individuals impacted by Huntington's Disease have presented to your service (via data available or your best estimate)? **Approximately 170 individuals including 71 gene status unknown; 44 gene positive; 55 gene negative; at least 4 family planning.**

The biggest changes in Tasmania's services included the NDIS; research and trials; IT advances (communication, education, information, telehealth, support groups and services). There was a noted decrease in stigma resulting in a willingness to engage with services to access support for younger adults impacted by HD.

QUEENSLAND

This included the Royal Brisbane and Women's Hospital Queensland. Since 2017, an estimated 321 patients attended the clinic. Approximately 5% gene status is unknown; 95% gene positive with 1 patient gene negative who was discharged from the clinic. Approximately 10% of patients have a carer role. Wait times average 3-4 months, and a full treating team is offered to clients from metro, rural regional Queensland, and northern NSW. Data collection is limited to the last 4 years due to health systems administration filing changes. These services reported that Genetic Health Queensland **holds the data on** numbers diagnosed**.**

## Gap Analysis - Formal and informal support needs of the Huntington's community

### A framework to measure impacts and outcomes

The impacts and outcomes of any service or support can be viewed and reported in many different ways. It is critically important to 'measure what matters' and to select frameworks which capture the interrelationships of, for example, formal and informal supports, as well as the dynamic and complex needs of service users such as the Huntington's Disease community. Huntington's Victoria has developed a structure to report the different domains of social impact (Appendix 1.1) based on years of experience and a number of published frameworks (Marino et al., 2016, Lee et al., 2013, Pan et al., 2007, World Health Organization, 2020).

### Findings regarding measurement of impacts and outcomes

The Huntington's Victoria Social Impact domains structure was used as a starting point and triangulated with other relevant frameworks in order to validate the content and provide a sound

basis for an analysis framework.  Other relevant frameworks included the COAG intersect domains[4] (Appendix 1.2) and the National Disability Insurance Scheme Outcome Framework (Appendix 1.3).

These frameworks were mapped (Appendix 1.4) to inform both questions set the analysis matrix, and the implementation work. Through a co-design process, the Gap Analysis Steering Committee reviewed these frameworks and advised regarding the mapping to triangulate and confirm the content validity of the various social impact dimensions, to gain consensus on terminology, and to confirm relevance to the HV population. This work informed the Focus Group Schedule (Appendix 1.5).

During the Focus Groups, individual domains were introduced and discussed. During discourse, participants 'clustered' various impact domains together.  Broadly, participants grouped domains according to the 'safetynet' cluster of risks and safety (including housing stability, economic sustainability), or the 'social inclusion' cluster (including health and symptom management, physical wellbeing, emotional wellbeing, building resilient relationships), see Figure 2.



Figure 2 Thematic clusters for HV Social Impact Domains

## Gap Analysis method and ethical approval

A co-design approach was taken in identifying the sampling method and data analysis approach. The intent was to conduct qualitative data collection of formal and informal support needs. Ethical

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[4] https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

approval was received (Monash University Project ID: 24641) to conduct a national online survey and follow up focus groups (HD health professionals, gene positive individuals, gene negative individuals and supporters).  Regular meetings with Gap Analysis Steering Committee were held via Zoom[5] and advised on and confirmed these steps. Initially a survey tool was produced and piloted, capturing nearly 60 questions and including the HV social impact domains. This was piloted by members of the Gap Analysis Steering Committee and the burden of completion was found to be high. Further, a concurrent survey was being piloted as part of National Health and Medical Research Council funded research through the Monash University Stout Lab. A series of collaborative meetings with Stout Lab resulted in the determination to move straight into Focus Groups. An ethical amendment was subsequently approved and Focus Groups were conducted in November 2020. A final adjustment to method involved a verification of results phase undertaken when opportunity presented at the Huntington's Community Conference 5-6 December, 2020.

## Focus Groups: sample and data

Focus Group 1 comprised health professionals and included 6 participants (physician, counselor, advocate, speech pathologist, OT manager, genetic counselor). This purposeful sample was drawn from Huntington's Victoria existing networks.

Focus Group 2 included two gene positive individuals who were members in the Gap Analysis Steering Committee, one of whom was symptomatic.

Focus Group 3 included three family members involved with supporting relatives (children, parents, spouses) with Huntington's disease, one of whom identified as gene negative. Two were members of the Gap Analysis Steering Committee and one additional informant who responded to information through the Huntington's Victoria network.

### *Data collection*

Each Focus Group was held online via Monash University's access to the Zoom.us platform, for between 75- 90 minutes in the first two weeks of November. A representative of Huntington's Victoria, Tammy Gardner, was invited online for the first 5 minutes to provide context to the focus group, then left the session. Dr Natasha Layton facilitated each Focus Group, and Dr Natasha Brusco acted as notetaker. The sessions were recorded with permission.

### *Data management and analysis*

The audio files were securely lodged along with raw notes from both researchers. The focus group narratives (from researcher notes and recordings) were synthesized into a tabulated summary of

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[5] NOTE COVID-19 pandemic restrictions in place

themes. From this, a core set of summary notes was created.  The data collected was analysed by the researchers according to different domains of social impact and expressed met and unmet support needs from the perspective of a) the person and b) a sector perspective of the Australian service system[6].

While the focus group numbers are small (n=11), a rich set of indicative findings were generated. To increase the robustness of these findings, a verification phase was run and the thematic results were checked with delegates at the Huntington's Community Conference, made available to over 200 delegates, with 50 delegates in attendance at the research presentation, and with responses received from 17 delegates.

## Gap Analysis Verification Phase

A one hour workshop was held during the virtual Huntington's Community Conference 5-6 December, 2020. This workshop presented the results of the research to date (see Appendix 3 Plain Language Summary) and invited live responses to three question sets across the workshop. The results below are drawn from the Zoom poll run within the Zoom workshop presentation, open to approximately 200 Community Conference delegates and attended by 50 delegates. These findings are included in the results section below.

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[6] WHO ICF; COAG principles; HV social impact framework

## Results

Three broad themes with a range of subthemes emerged from the data. These are provided below.

### Theme 1: Sources of Support

Sources of support

SUMMARY people draw support from a range of sources. Different supports are useful at specific times and for specific tasks. Peer support is one of those supports.



**Subthemes**

- *Support* is drawn from many sources: from family and friends (informal supports), and from sources of semi-formal, and formal supports.
- *Support* might be emotional (people to stand with you), educational (advice about options), physical (actual help to physically manage), and support related to advocacy (making systems better).
- *Support makes a difference*: 'issues are worse for people without a support person (health professionals). Having people 'on your team' was important to all Huntington's community members we spoke to.
- *Quality of support makes a difference*: there are challenges with getting the right information, approach, and reactions at the right times. Being **knowledgeable** and **insightful** were the top attributes of informal and semi-formal supports (such as family members, online peer support groups and support workers) and of formal services which are not HD specific (such as local medical services, community health services, prenatal screening services).
- *Quantity and availability of support makes a difference*: Trustworthiness, availability and geographic coverage were the top attributes of formal support services which are specific to HD (such as genetics counselors, medical staff, health professionals).
- *Knowledge exchange can be empowering*: the power of collaborating and sharing knowledge and experiences was described as valuable and energising. The Huntington's community described a feeling of 'strength in numbers'.
- *Knowledge exchange can build better outcomes:* intelligence-sharing in a community can make things better for individuals. This type of knowledge exchange can also enable

'systemic advocacy', where systems and services are changed and improved. It is challenging to change government policy and to speak up, but it can be rewarding and can help with making meaning out of the difficulties and challenges.

**Data from the Verification Phase:**

Delegates to the Huntington's Victoria Community Conference (n=50) were asked if there was a gap between the services they need and the services they receive. Responses were received from 17 of the delegates in attendance. For formal services (medical and health care professionals 59% (10 individuals) stated there were gaps, and 41% (7 individuals) stated they did not experience a gap. In terms of semi-formal supports and services (community services), 67% (8 individuals) stated there were gaps, and 33% (4 individuals) stated they did not experience a gap. Regarding informal supports (carer and peer support), 65% (11 individuals) stated there were gaps, and 35% (6 individuals) stated they did not experience a gap. See Figure 3.
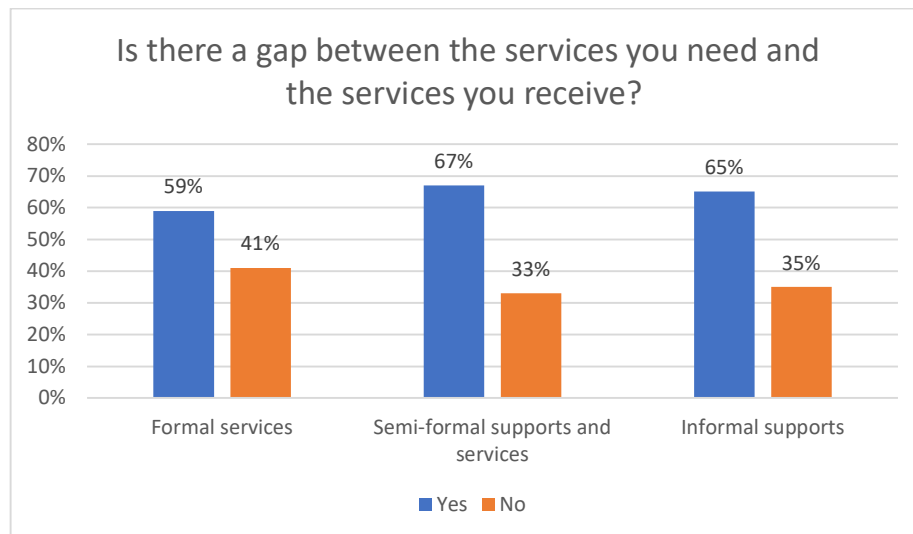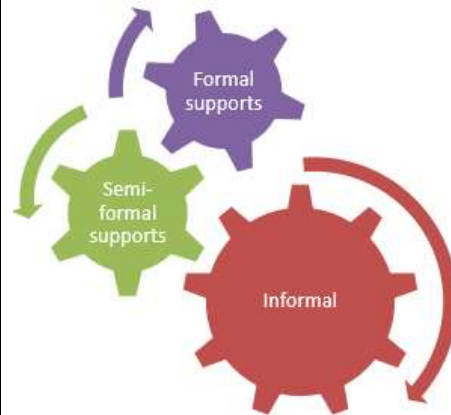
Figure 3 Gaps in sources of support

Theme 2: Gaps and the role of peer support

| | |
|---|---|
| Gap analysis<br><br>Peer support is one of the creative way we might work together to wrap supports around the person, across regions and across services. | |

**Subthemes**

- *Geographic gaps*: There is a lack of equity of access in Australia: some great services which do not cover all geographic areas
- '*Wrapping around the person' gaps:* some desired supports are just not available to the person. For example, the smart technologies and concierge style supports in new Specialist Disability Accommodation settings, cannot be delivered at home or in other forms of residential care.
- *Intersectionality gaps:* absence of for example indigenous-focussed services
- *System complexity:* The system of formal, semi-formal and informal supports is complex: it is extremely important to access experienced people who can advise how systems work. Any support network needs to build skills and knowledge around the following system interface issues (in priority order based on focus group input): aged care, NDIS, mental health services, community health services, justice, child protection, employment.
- *Dynamic systems:* The system of formal, semi-formal and informal supports keeps changing. For example family know-how about helpful council-based supports is no longer accurate due to rollout of NDIS.
- *Innovation gaps and opportunities:* the Huntington's community and supporters have expert insights into needs and opportunities, and demonstrated a critical eye for what might 'really work'. For example: could an Airtasker network model work for accessing 24/7 support.

**Data from the Verification Phase:**

Delegates provided data on reasons why they may not receive needed services, with the possible reasons presented in percentage order of magnitude in Figure 4. Actual data is as follows: Preferred to manage myself (n=4), Didn't know where to get help (n=3), Couldn't afford the money (n=3), Asked but didn't get help (n=3), There were no services available (n=2), Didn't think anything would help (n=2), and Afraid to ask for help or what others would think (n=2).
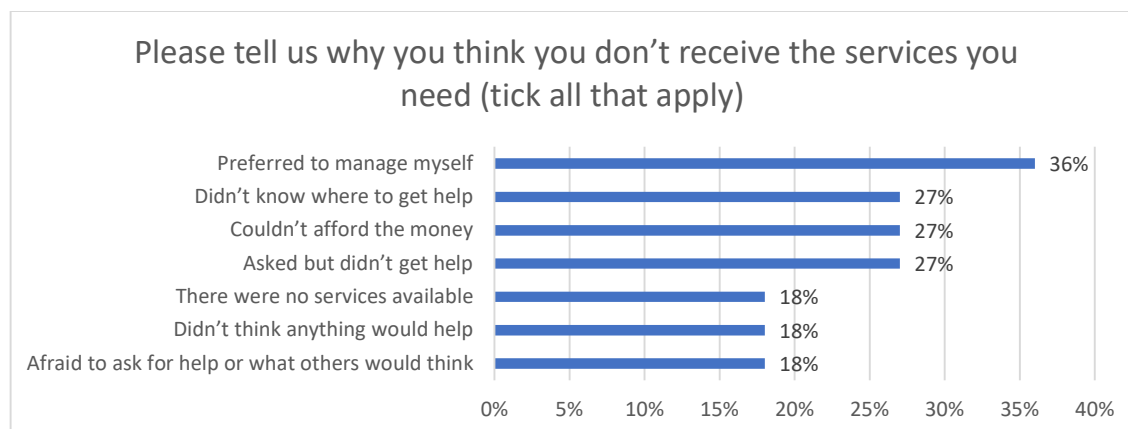
Figure 4 Reasons for lack of services

## Theme 3: Right Time Right Touch Supports



Right time right touch supports

Supports need to be responsive to the trajectory of Huntington's Disease.
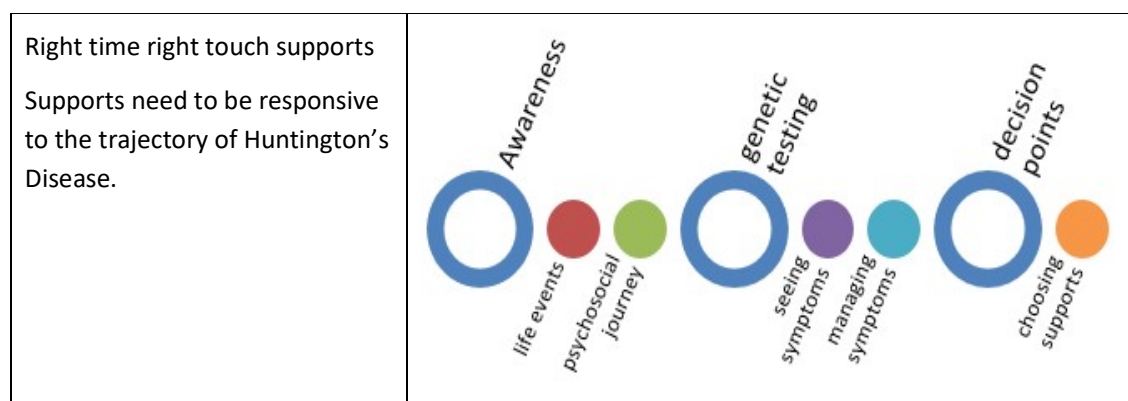
**Subthemes**

- **The HD trajectory** presents many points at which certain supports are needed. Different people need different types of supports at different times. People from the Huntington's community were very clear that there is a right and wrong time for certain types of information. The HD professional community agreed, suggesting '*Lived experience needs to be mapped around stage of illness'.* There are some key moments where skilled peer support can be very helpful. These include : i) negotiating family support boundaries (for example whether to support someone at home, and when to use formal supports…); ii) when you are being 'given bad news', iii) when you are deciding how to handle disclosure of HD status in daily life – being around peers can help to 'model' ways to manage this issue.
- **Supports at key transition points** for example across housing situations or into aged care, can represent a break in the continuum of care from professionals and formal services, and teams need to '*start again'* at point of admission. A role for a peer support network could anticipate and guide people through these system entry problems

- **Matching, screening and readiness**: a peer support needs to be able to:
  - demonstrate capability to be able to think beyond their own situation
  - manage the fact that progression of HD may be a factor for both peer and person being supported and *'ensure that the person giving peer support does not get overwhelmed with someone else's stories'*
  - manage the fact that confidentiality can become an issue eg. extended families;
  - understand and cope with the risk-based decisions which are central to management of a person with HD.
- *How might HD peer support be accessed?* Access styles may be very different (online, face to face, telephone) and all might be needed.
- *Thinking about local and national support:* its challenging to locate helpful professionals with the skillset and then the knowledge of HD. Huntington's community members utilized systems and services which might be international (online support groups) national (NDIS, My Aged Care), state/ territory based (HD associations), regional (health networks) or local (local councils and community facilities). Some aspects of support could be delivered 'anywhere'. Others related to knowing what is in the local area. People wished for local support, but recognized given the rarity of the condition that regional networks were more likely. The 'strength in numbers' argument also suggests that a national approach would create a pool of supporters, and ensure that, when individuals need to step out and care for themselves, the network can still continue.

**Data from the Verification Phase:**

Seventeen respondents responded to the question: when would you prefer to speak to a community member. Seven individuals (78%) prioritized 'When I choose, on my HD journey', followed by 44 % (4 individuals) selecting 'At key decision points eg. moving home'. Then, 33% (3 individuals) identified 'When first aware of HD' and 'When choosing supports' and 'when deciding how to talk about HD in your daily life'. Equal numbers (2 persons each, or 22 %) agreed with 'During genetic testing', 'When symptoms come along', when 'Deciding how much support a family can manage' or 'When being 'given bad news'.

## Implementation recommendations for the Huntington's Community Connect peer support program

Implementation recommendations will take a systems view in order to specify the duty holders and actors in regard to HV in Australia. Specific consideration will be given to the COAG principles to determine the responsibilities of the NDIS and other service systems[7].   The implementation recommendations are structured according to Proctor's implementation framework which considers acceptability, adoption, appropriateness, feasibility, fidelity, penetration, sustainability and the cost of implementation.

Recommendations developed based on themes that have emerged from the RER and Gap Analysis are found in Table 3. In summary they include the following recommendations:

- Huntington's Victoria should construct a peer support model with clear role boundaries and support structures
- The communications / marketing approach needs to signal an understanding of the relationship between peer support and other forms of support (formal / semi-formal / informal)
- Huntington's Victoria need to design peer support to cluster resources around key points
- Huntington's Victoria need to design peer support to identify resources at regional levels, where appropriate
- The online peer support model needs to be endorsed by data (that is, the findings of this gap analysis)
- During the early project stages, Huntington's Community Connect should be monitored closely to ensure processes are being followed. This monitoring should continue ongoing.
- Huntington's Victoria should offer flexible service with opt-in capacity. This will enable community to step in /step out according to individual support needs over the HD journey
- Huntington's Victoria need to structure the peer support offering to run independently of individual volunteers

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[7]https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

Table 3: Recommendations based on themes from the RER and Gap Analysis

| PROCTOR | Findings from data collection | Recommendations |
|---|---|---|
| **Acceptability**<br><br>**Stakeholder responses on palatability / satisfaction/ content (multi-stakeholders)** | Data supports role for / interest in peer support models across stakeholders (Huntington's community members and health professionals).<br><br>Agreement that capability, competence, trustworthiness, knowledge, insight and the capacity to refer on / be supported will be key factors in a successful peer support model.<br><br>Tailored principles needed for working with the Huntington's community (lots of examples of friends, professionals, support staff 'getting it wrong') | Huntington's Victoria should construct a peer support model with clear role boundaries and support structures |
| **Adoption**<br><br>**Take up rates within services/ demonstrated willingness and 'intention to try'** | Adoption most likely when the offering is appropriate:<br><br>- Emotional support<br>- Resources and advice (professional referral – is this needed?)<br>- Physical support | The communications / marketing approach needs to signal an understanding of the relationship between peer support and other forms of support (formal / semi-formal / informal) |
| **Appropriateness**<br><br>**Perceived compatibility across settings and for consumers at different stages** | There are time points where peer support is perceived to be particularly helpful, for example testing, diagnosis, and symptom onset. One person noted that peer support is appropriate when traversing life change: 'when you decide to start the testing process, through the process of appointments, and then when you get the results, and in the days following that…'<br><br>It was noted that for peer support being in the same state may be helpful if you need some practical supports, but otherwise Australia | Huntington's Victoria need to design peer support to cluster resources around key points<br><br>Huntington's Victoria need to design peer support to identify resources at regional levels, where appropriate |

| | wide peer support is fine, as it would be good to have the most people involved as possible | |
|---|---|---|
| **Feasibility**<br><br>**The extent to which initiatives can be utilised across various settings (states/ territories etc)** | - *Peer support does not need to be totally local*<br>- *We need to take Huntington's Community Connect nationally, as long as its in Australia*<br>- *Peer support does not necessarily need to be face to face. There are a number of options such as phone calls, messages, email, online anything.* | The online peer support model needs to be endorsed by data (that is, the findings of the gap analysis) |
| **Fidelity**<br><br>**The extent to which the uptake adheres to protocols / operating principles established** | | During the early project stages, Huntington's Community Connect should be monitored closely to ensure processes are being followed. This monitoring should continue ongoing. |
| **Penetration**<br><br>**All people impacted? Including those indirectly (family / carers) and directly impacted (+ve, -ve, not yet tested).** With consideration for "**youth**" impacted. | Different needs across the community at different phases and depending on different roles and relationships to HD | Huntington's Victoria should offer flexible service with opt-in capacity. This will enable community to step in /step out according to individual support needs over the HD journey |
| **Sustainability** | Power in peers and engagement can be energizing, yet people need to step out to sustain themselves… need strength in numbers to be able to sustain a network / community / enable input to wax and wane | Huntington's Victoria need to structure the peer support offering to run independently of individual volunteers |

| | | |
|---|---|---|
| **Cost of implementation Resources required for implementation** | The *Huntington's Community Connect* evaluation will establish the cost of implementation and the cost of running the *Huntington's Community Connect* as business as usual. | |

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# APPENDIX 1 Domains of Impact

## 1.1 Domains of social impact (Huntington's Victoria)

| Social Impacts of HD | Formal (F) or informal (IF) support | Definition of a positive outcome | • Examples | • Evidence points |
|---|---|---|---|---|
| Health and Symptom Management | F | Achievement of HD symptom stability and overall ongoing maintenance of these symptoms. Achievement of overall health separate from HD that when not attained can negatively impact on the individual | • Ongoing active participation in Allied Health intervention (diet or physical activity)<br>• Link in to HD specialist for symptom management<br>• Continue the management of the health care plan (GP, HD SPEC)<br>• Managing client progression throughout various stages of disease.<br>• Maintaining physical and cognitive stimulation | • Routine scheduled review appointments from HD specialist<br>• Information/education provision about HD and health<br>• Physically and cognitively active<br>• Strong allied health presence in care plan |

| Social Impacts of HD | Formal (F) or informal (IF) support | Definition of a positive outcome | • Examples | • Evidence points |
|---|---|---|---|---|
| Physical well being | F & IF | Achievement and maintenance of the highest possible level of physical independence for stage of disease | • Mobility appropriate at the stage of HD<br>• Safety in home and community (environment)<br>• Physically capable of completing ADL's | • Equipment accessed to support the individual at home and in the community<br>• Allied Health review imbedded in care plan |
| Emotional wellbeing | F & IF | To achieve emotional wellbeing and a quality of life when living with HD | • Improved mental health<br>• Mental health maintenance Improved coping skills and resilience.<br>• Confidence building<br>• Maintenance of self-identity<br>• Increased hope<br>• Life satisfaction | • Access to therapeutic (non-medical) intervention<br>• Access to therapeutic (medical) intervention<br>• Engagement in activities/routine that promote self-worth and identity |
| Social Inclusion | IF | To identify as a valued member of their local community. To maintain social connections and networks throughout disease progression | • Strengthening social skills (awareness of HD, self in the HD context)<br>• Reduced social isolation/contact/community connections<br>• Inclusive and accessible communities<br>• Access to venues (dining, entertainment, sporting etc) without discrimination | • Engages in age appropriate social activities<br>• Engages in regular community access<br>• Capacity building of local venues to enhance community access experiences |

| Social Impacts of HD | Formal (F) or informal (IF) support | Definition of a positive outcome | • Examples | • Evidence points |
|---|---|---|---|---|
| Housing stability | F & IF | To either obtain and/or maintain stable housing that meets the support needs at any given point during disease progression | • Housing security/safety<br>• Housing that is accessible and structured to maximise ongoing support needs (minimise risks of falls, capacity for in-home mods if needed)<br>• Cost of rent or mortgage can be sustained long term<br>• Cost of utilities and other household related expenses are affordable<br>• Staff are skilled to meet the care needs of the individual | • Secured permanent disability accommodation<br>• Access to in-home modifications<br>• Centre-pay, other financial institutions implemented to pay bills and manage funds<br>• Services and supports implemented |
| Economic sustainability | F & IF | To achieve and/or maintain financial security. To live without financial hardship and be able to afford basic needs. | • Maintaining appropriate employment/supporting opportunities for appropriate employment<br>• Education/ Skills development<br>• Obtainment of appropriate income stream (Centrelink pension, Superannuation, paid employment) | • In receipt of DSP, Superannuation, TPD<br>• Capacity building of workplace for reduced/modified employment<br>• Completed training/skill development |

| Social Impacts of HD | Formal (F) or informal (IF) support | Definition of a positive outcome | • Examples | • Evidence points |
|---|---|---|---|---|
| Building Resilient relationships | IF | To build and/or maintain resilient relationships with family members, partners etc. | • Family Resilience<br>• Reconnecting families/siblings<br>• Preventing carer burnout | • Regular respite opportunities<br>• Participated in meaningful activities/quality time together<br>• Capacity building of family members |
| Risks and safety | F & IF | The absence of 'behaviour' by the individual or towards the individual that places them at risk of not achieving the above measures. | • Reduced incidents of risks (vulnerable to financial, emotional, sexual, physical abuse)<br>• Maintaining service delivery through funded packages<br>• Competent and supported decision making<br>• Reduced incidences of 'challenging behaviour' that places the individual at risk of: losing current accommodation, criminal/civil law proceedings, removal/ceasing of critical care need supports<br>• Reduced incidences of industrial relation issues and other acts of discrimination | • EPOA financial, guardianship appointed<br>• Behaviour Management Plan implemented<br>• Behavioural Management services engaged<br>• Advocacy within justice system<br>• Advocacy within the legal setting (court, VCAT, tenancy) |

## 1.2: Australian service sector intersects (COAG DOMAINS)

| |
|---|
| 1. Health |
| Health systems are responsible for funding time limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person's health and improving the person's functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically. 4. The NDIS will be responsible for supports required due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes "maintenance" supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment. |
| 2. Mental health |
| The designation of mental health system responsibility here refers chiefly to public funding through the state and territory public mental health system and/or private mental health services receiving Commonwealth funding through the Medicare Benefits Schedule, together with non-government organisations in receipt of state, territory or Commonwealth funding where these continue to undertake roles outside the NDIS. |
| 3. Early childhood development |
| 4. Child protection and family support |
| In recognising the statutory role of the child protection system and in line with the National Framework for Protecting Australia's Children 2009-2020: |
| a. other parties will be responsible for promoting the safety of children from abuse and neglect, including public education on child safety, and management of the statutory child protection system including reports of child protection. |
| b. the NDIS will ensure its rules and processes are consistent with jurisdictional child protection legislation, including reporting requirements |
| 5. Education |
| The NDIS and the school education system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both school education and disability services recognising that both inputs may be required at the same time or through a smooth transition from one to the other or across service systems. |
| 6. Higher education & VET |
| The NDIS and the higher education and VET system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both further education/vocational education and disability services recognising that both inputs may be |

required at the same time or through a smooth transition from one to the other or across service systems.

## 7. Employment

The NDIS will be responsible for reasonable and necessary supports additional to those required by reasonable adjustment, that assist people with disability to take part in work where the person's impairment has an impact on their functional capacity and/or productivity and the person is unlikely to be able to find or retain work in the open market, including with the assistance of employment services. The NDIS will be responsible for funding individualised assistance to support a person with disability to take part in work where the person's impairment has an impact on their functional capacity and/or productivity and where these supports are additional to the needs of all Australians and additional to what is required by reasonable adjustment, such as training on dress, workplace relationships, communication skills, punctuality and attendance, and travelling to and from work.

The NDIS and the employment system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both employment services and disability services recognising that both inputs may be required at the same time or through a smooth transition from one to the other or across service systems.

## 8. Housing and community infrastructure

The NDIS will be responsible for support to assist individuals with disability to live independently in the community, including by building individual capacity to maintain tenancy and support for appropriate behaviour management where this support need is related to the impact of their impairment/s on their functional capacity.

The NDIS will be responsible for home modifications required due to the impact of a participant's impairment/s on their functional capacity in private dwellings, in social housing dwellings on a case-by-case basis and not to the extent that it would compromise the responsibility of housing authorities to make reasonable adjustments.

The NDIS is also responsible for user costs of capital in some situations where a person requires an integrated housing and support model and the cost of the accommodation component exceeds a reasonable contribution from individuals.

The NDIS and the housing system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both housing and disability services recognising that both inputs may be required at the same time or through a smooth transition from one to the other.

## 9. Transport

The public transport system will be responsible for ensuring that transport options are accessible to people with disability, including through concessions to people with disability to use public transport (including parties choosing to provide concessions for the total cost of transport) and compliance with relevant non-discrimination legislation including the Disability Standards for Accessible Public Transport.

Others parties will continue to be responsible for transport infrastructure, including road and footpath infrastructure, where this is part of a universal service obligation or reasonable adjustment, including managing disability parking and related initiatives.

The NDIS will be responsible for funding supports for individuals that enable independent travel, including through personal transport-related aids and equipment, training to use public transport and modifications to private vehicles (i.e. not modifications to public transport or taxis).

The NDIS will be responsible for reasonable and necessary costs associated with the use of taxis or other private transport options for those not able to travel independently.

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10. Justice

The NDIS and the justice system will work closely together at the local level to plan and coordinate streamlined services for individuals requiring both justice and disability services recognising that both inputs may be required at the same time or through a smooth transition from one to the other.

** Pathway for transition from Corrections Facility back into NDIS important to consider

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11. Aged care

The aged care system will continue to be responsible for access to quality and affordable aged care and carer support services, including through subsidies and grants, industry assistance, training and regulation of the aged care sector, information assessment and referral mechanisms, needs-based planning arrangements and support for specific needs groups and carers.

A participant can choose to continue to receive supports from the NDIS after age 65, or can choose to take up an aged care place.

## 1.3 NDIS 8 Outcome Domains

| 1. Daily Living |
| --- |
| 2. Home |
| 3. Health and Wellbeing |
| 4. Lifelong Learning |
| 5. Work |
| 6. Social & Community Participation |
| 7. Relationships |
| 8. Choice and Control |

(NOTE: no operational definitions published by NDIS)

## 1.4 Mapping HV, NDIS, WHO ICF and COAG Domains

| Social Impacts of HD | NDIS Outcome Domains[8] | WHO ICF[9] | COAG Domains |
|---|---|---|---|
| Health and Symptom Management<br><br>Physical well being | Health and Wellbeing | Body structures and functions<br>Selfcare<br>Learning and applying knowledge | Health<br>Aged Care |
| Emotional wellbeing | Choice and control | General tasks and demands<br>Communication<br>Mobility<br>Products and technology (also belongs in social inclusion) | Mental Health |
| Social Inclusion | Daily Living<br>Lifelong learning<br>Social, community and civic participation | Community, social and civic life (culture, recreation, spiritual, political)<br>Attitudes | Transport |
| Housing stability | Home | Natural environment and human-made changes to environment | Housing and community infrastructure |
| Economic sustainability | Work | Domestic life<br>Major life areas (education, economic) | Education<br>Higher education and VET<br>Employment |
| Building Resilient relationships | Relationships | Interpersonal interactions and relationships<br>Support and relationships | Early childhood development |
| Risks and safety | | Services, systems and policies | Justice<br>Child protection and family support |

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[8] **Domain 1:** Choice and control; **Domain 2:** Daily living; **Domain 3:** Relationships; **Domain 4:** Home; **Domain 5:** Health and wellbeing

**Domain 6:** Lifelong learning ; **Domain 7:** Work ; **Domain 8:** Social, community and civic participation

[9] https://www.who.int/classifications/icf/en/

## 1.5 Focus Group Schedule based on impact areas

| Gap Analysis Focus Group Guide 2020 | |
|---|---|
| Theme | Prompts |
| 1. Introductions | - Researcher introductions & about the Project <br> - Tell us your name and a little bit about yourself <br> - How are you involved with the Huntington's community? How long have you been involved? |
| 2. The idea of a gap analysis | We want to find out about formal and informal support needs. We will be asking questions for each area of life that the Huntington's community, and NDIS, identify as important. We invite you to add any other areas at the end |
| Supports and gaps across areas of life from a human perspective: <br> We will ask the following questions for areas 3-10 <br> - What is an enabler or a support (*what helps*) in this area? <br> - What is missing in this area? <br> - What is needed in this area (what would 'good' look like?) | |
| 3. HEALTH AND WELLBEING | - Health and symptom management <br> - Physical wellbeing |
| 4. EMOTIONAL WELLBEING | - Choice and control |
| 5. SOCIAL INCLUSION | - Lifelong learning <br> - Community participation (political, cultural, spiritual, recreational) |
| 6. HOUSING STABILITY | - Civic participation |
| 7. ECONOMIC SUSTAINABILITY | - Daily living |
| 8. RELATIONSHIPS | - Building resilient relationships <br> - Social participation |
| 9. RISKS AND SAFETY | |
| Supports and gaps across areas of life from a government perspective: <br> The Commonwealth Government (COAG) describe 11 areas where their policies 'intersect' and where there can be service gaps. Tell us what you think about supports and gaps in the following areas: | |
| 10. FORMAL SUPPORTS AND GAPS | - Aged care <br> - Justice <br> - Transport <br> - Housing and community infrastructure <br> - Employment <br> - Higher education and VET <br> - Education <br> - Child protection and family support |

| | |
|---|---|
| | - Early childhood development<br>- Mental health<br>- Health |
| **11.** OTHER? | |
| **12.** Thank you… | |

## Appendix 2 Prevalence Data

### 2.1 AIHW

Residential Aged Care (RAC).

In the year 2019, 331 people with HD as one of their primary medical conditions were recipients of permanent RAC. This includes 149 people under 65, and 182 people over 65. Admission rates in 2018-2019 were 30 for under 65 years, and 44 for over 65 years.

| Table 1: Recipients of permanent residential aged care who had Huntington's disease[a] as one of their medical conditions, based on their ACFI assessment[b], by age group[c], State/Territory and Australia, at 30 June 2018 and 30 June 2019 | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Reference date | NSW | Vic | Qld | WA | SA | Tas | ACT | NT | Australia |
| Under 65 years | | | | | | | | | |
| 2018 | 60 | 39 | 35 | 9 | 12 | 8 | — | — | 163 |
| 2019 | 57 | 42 | 25 | 8 | 10 | 7 | — | — | 149 |
| 65 years and over | | | | | | | | | |
| 2018 | 54 | 50 | 41 | 15 | 18 | 3 | 3 | — | 184 |
| 2019 | 43 | 55 | 44 | 15 | 17 | 5 | 2 | 1 | 182 |

Table 1 AIHW National Aged Care Data Clearinghouse: Data Request R1920_3860_Robinson

Data from the previous 5 years (2014-2018) averaged 173 RAC recipients under 65, and 181 RAC recipients over 65 [10]. This is approximately 38 admissions per year.

| Table 1. Recipients of permanent residential aged care who were under 65 years old (a) and had Huntington's disease as one of their medical conditions at their latest valid ACFI assessment (b), by State/Territory (c) and Australia, at 30 June 2014 to 30 June 2018 | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Reference date | NSW | Vic | Qld | WA | SA | Tas | ACT | Australia |
| 30 June 2014 | 65 | 37 | 34 | 9 | 9 | 9 | 4 | 167 |
| 30 June 2015 | 75 | 41 | 32 | 9 | 11 | 8 | 3 | 179 |
| 30 June 2016 | 76 | 44 | 35 | 9 | 11 | 8 | 2 | 185 |
| 30 June 2017 | 61 | 45 | 36 | 10 | 11 | 8 | 1 | 172 |
| 30 June 2018 | 58 | 36 | 38 | 10 | 12 | 8 | — | 162 |

| Table 4. Admissions into permanent residential aged care (a) of persons over 65 years old (b) and had Huntington's disease as one of their medical conditions at their latest valid ACFI assessment (c), by State/Territory (d) and Australia, 2013-14 to 2017-2018 | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| Reference year | NSW | Vic | Qld | WA | SA | Tas | ACT | Australia |
| 2013-14 | 8 | 9 | 5 | 3 | 4 | — | 1 | 30 |
| 2014-15 | 11 | 14 | 9 | 2 | 3 | 1 | 1 | 41 |
| 2015-16 | 15 | 10 | 6 | 3 | 6 | 2 | 1 | 43 |
| 2016-17 | 8 | 9 | 8 | 6 | 2 | 2 | — | 35 |
| 2017-18 | 12 | 13 | 7 | 1 | 5 | 2 | — | 40 |

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[10] Sourced from AIHW Data Request R1920_3478 via HD NSW

## 2.2 NDIS[11]

AS at 31 December 2019, 833 people with HD received NDIS Plans.

**Table 1. Number of participants with Huntington's disease (HD) as their primary or secondary disability who have an approved plan, split by jurisdiction and age groups as at 31 December 2019**

|  | 0 to 18 | 19 to 24 | 25 to 34 | 35 to 44 | 45 to 54 | 55 to 64 | 65+ | Total |
|---|---|---|---|---|---|---|---|---|
| NSW | <11 | <11 | 15 | 28 | 80 | 106 | 25 | 267 |
| VIC | <11 | 0 | 21 | 26 | 75 | 82 | 20 | 232 |
| QLD | <11 | <11 | <11 | 30 | 55 | 50 | <11 | 151 |
| WA | 0 | <11 | <11 | <11 | 19 | 24 | <11 | 63 |
| SA | <11 | 0 | <11 | <11 | 23 | 18 | <11 | 59 |
| TAS | <11 | 0 | <11 | <11 | 13 | <11 | <11 | 36 |
| ACT | 0 | 0 | <11 | <11 | <11 | <11 | <11 | <11 |
| NT | <11 | 0 | 0 | <11 | <11 | 0 | 0 | <11 |
| Total | 22 | <11 | 50 | 117 | 269 | 292 | 65 | 822 |

2. The number of people with HD and an approved plan by gender.

**Table 2. Number of participants with HD as their primary or secondary disability who have an approved plan, split by gender as at 31 December 2019**

| Gender | Male | Female | Total |
|---|---|---|---|
| Number | 369 | 446 | 822 |

Note: Gender specified as other or missing for a small number of participants.

**Table 3. Average annualised committed supports of participants with HD as their primary or secondary disability who have an approved plan, split by support type as at 31 December 2019**

| Support Type | Core | Capacity Building | Capital | Total |
|---|---|---|---|---|
| Average annualised committed supports ($) | $141,041 | $20,567 | $9,009 | $170,617 |

For NDIS participants with Huntington's disease (HD) as their primary or secondary disability, the average time from Access Met to receipt of an approved plan during the quarter Oct-Dec 2019 was 79 calendar days. During this period, there were 53 plans approved for participants with HD (52 participants for whom HD was their primary disability).

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[11] Data from FOI Request 19/20-0923

Table 4. Number of participants with HD as their primary or secondary disability who have an approved plan and have SIL and/or SDA in their plans as at 31 December 2019

|  | SIL and/or SDA |
|---|---|
| Number | 112 |

## Appendix 3 Focus Group Summaries

huntington's victoria    MONASH University

## 3.1 Gap Analysis Focus Group 1 HD Professional Community Summary Notes

DATE 1 October 2020 via Zoom – 75 minutes

**Researchers:** Natasha Layton (facilitator) and Natasha Brusco (note taker).

6 participants (physician, counselor, advocate, speech pathologist, OT manager, genetic counselor)

All participants lodged consent.

Data Management and Analysis

1. The meeting was recorded with permission and the audio files securely lodged along with raw notes from both researchers.
2. Themes and Data table created: a tabulated summary of themes linked to the focus group narratives, drawing on researcher notes and recordings.
3. Summary Notes by Theme: this record is a synthesis of written notes from both researchers, triangulated with the focus group recording.

Theme 1 Roles and Gaps of professionals

**This Focus group included d**iverse professions (genetics testing / counselling), social work, speech pathology, occupational therapy/ management, physician policy and advocacy. Professionals occupied diverse roles (private and public systems, progressive neuro or specific HD, acute, community, residential care), and had often progressed through a range of roles.

Professions are diverse, with a common appreciation of the need for multiple disciplines to be involved in the complexity of HD over its trajectory.

The nature of the service will influence the service approach, for example progressive neurological versus psychiatric, or acute hospital. It is challenging to wrap services around a person or family with HD when the service systems we work in, don't allow it (eg travel to facilities, people admitted to nursing homes cannot be followed up by units based in acute hospitals) '*we can't see people admitted to nursing homes .. this is a gap they are no longer under wing of specialist centre*'

Theme 2 The HD journey/ trajectory

People with HD have a '*long diagnostic odyssey*', strongly influenced by the nature of the service which is accessible to them.

**Self-protection:** Social work perspective of self protection (otherwise known as denial) preventing people accessing services. Sometimes knowledge and readiness plays out in accessing counselling, for example the following gap was identified by genetic counselors in the group: '*there's a knowledge gap to understand the difference between genetic testing and a genetic counsellor…this often stops people from talking to genetic counsellor'*

Gaps include early and late stage supports. Research (HEROs Project[12]) indicates strong value from active supports (exercise, self management) at the early state of symptom management to slow progression. Also, advanced care planning to identify decision around for example PEG feeds, dignity of risk in mobilizing, use of helmets…

Transition points for example across housing situations or into aged care, can represent a break in the continuum of care from professionals and formal services, and teams need to '*start again'* at point of admission to for example APRC.

Theme 3 Supports and gaps across social impact domains

Participants were presented with nine domains [13]: health and wellbeing; emotional wellbeing; social inclusion; housing stability; economic sustainability; relationships; and risks and safety. The discussion dealt with a number of these concepts together, demonstrating their interlinked nature.

Overall the group described the landscape as follows: Many supports exist, but also gaps exist and are influenced by geography, type of service offering nearby, whether the person is alone or has a family or community, and how well general services understand the needs of the Huntington's community. People in the Huntington's community have '*a lot of stress and anxiety' in accessing services*'. It was noted *'If the person is on their own, these issues are far worse. They are a little easier if the person has a support person'* (physician), and this may be a good reason to look to peer support networks.

The concepts are grouped as per the discussion below:

**Health and wellbeing**: The group asked: what is health and wellbeing? Physician asked if it covers more than symptom management and physical health. People felt managing health and wellbeing includes health and symptom management, as well as physical wellbeing. Overall, there are centres of excellence but many geographic gaps '*services are patchy'*

Exclusion can occur eg asking community teams to pick up when HD is reason for mental health issue (organic disease versus mental health). Denial or self-protection issues were seen to block people from accepting programs even where they are available. A related service is that of advocacy, which is often missing eg in NDIS packages.

The discourse around **emotional wellbeing** included **relationships, social inclusion**, and **civic participation** mapped across to the twin concerns of cognitive impairment and risk management: '*cognitive decline is responsible for social isolation'* .Emotional wellbeing, maintaining relationships and being included in any community activities, and managing daily life were all at risk if people cannot cognitively manage an 'ordered lifestyle'. **Housing stability** and **economic stability are**

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[12] https://www.huntingtonswa.org.au/resources/G0002718_HEROs-Project-Report-FINAL-Feb-2013.pdf

[13] Drawn from HV social impact domains and WHO ICF see project protocol

**foundations for these aspects of emotional wellbeing, and** examples were given of living in toilet blocks or cars, struggling with finances, disturbing neighbours, and requiring emergency accommodation.

Protective factors include the presence of family. Anecdotally people thought that living in rural areas may prevent some of these outcomes.

Managing risk is central to HD, e.g. mobility, eating. Make the risk-based decisions with the person. Support the person to have choice and control, even with risks. Within the NDIS context this is described as *' really hard to understand (although it is) part and parcel of general service delivery so important to map out journey with person eg walking, swallowing, choices about wearing a helmet, going into hospital… '(service manager and OT)*

Theme 4 Formal supports and gaps across government services

Participants were asked about the following formal service systems: Aged care; Justice; Transport; Housing and community infrastructure; Employment; Higher education and VET; Education; Child protection and family support; Early childhood development; Mental health; Health. Gaps and challenges are presented below in order of magnitude, that is, with the systems that were most problematic:

**Aged Care and NDIS** Participants discussed that some systems are complex in themselves such as My Aged Care *'MAC is not easy for anyone' (social worker)* and others seem a poor fit for the specific needs of the Huntington's community  such as NDIS and its ability to manage issues of risk in choice and control. Participants discussed multiple experiences in each of these service structures where the needs of people with HD were poorly understood or where service offerings were not fit for purpose, that is, did not understand the nuances of suitable resources (how much, where to find them), approaches to risk, or disease trajectory. In facilities (ie residential) with multiple people with HD, networks are likely to be there, but it is provider-dependent and quite risky that there will be no connection to either informal or formal support or management *'The person can be invisible and mis-managed. Hard for RACF to access specialist and disability services' (advocate)*

**Mental Health:** Discussion of the many layers evident in the mental health suite of services: with the sense that no model works well apart from acute ED in that usually people are not denied psychiatric help in acute need. However, subacute care is done differently in different places. **'***Big gap in Victoria for the community members impacted by HD. Often due to poor understanding***.'**

**Justice** was seen as a negative system to be part of  **'***you don't want have HD and end up in justice system – either no treatment or you languish' (physician).* Some evidence was discussed from the speech pathology literature regarding projects working with those at risk of offending and taking a literacy / advocacy / communication approach to managing in the justice system.

**Employment**: big issues were noted in relation to employment

**Child-related:** Child Protection issues were experienced '*less than expected'* (social work), but the genetic counselor raised access to family planning and access to IVF is important issues for the community. These are being addressed currently by HV.

**Participants were asked what is missing from the above list.** Aboriginal services were raised, particularly in WA, and it was suggested appropriate services for this population would require information by the ATSI community for the ATSI community

Theme 5 roles and gaps for community members  - and the concept of peer support

**Peer support** '*does not happen enough in this space' (social work perspective).* There may be roles for peers supporters in HD journey / trajectory, but people discussed, and decided, that a matching process would likely be needed: (there is )'*Apprehension to contact other families with lived experience. Lived experience needs to be mapped around stage of illness' (*Social work perspective*).*

**What might connecting with peers look like**? Participants asked what the peer support options were, beyond 'support groups'. Examples shared by the researchers included spinal peer support (SPIRE: Austin); amputee self help (Limbs for Life) and AT Chat online community (AT users). Examples shared by the participants included:

- HDWA peer support groups which turn into longstanding consistent friendship groups
- Dementia / early memory loss groups (structured to get people at the same stages and provide structural information, but with the outcome of establishing their own peer support network; many mental health support groups very successful.
- DSO Consortium research on peer support (2020) contains current evidence about resourcing for peer networks and note they require an investment in leadership, Peer support leaders need  to  be selected carefully and need support and training**.**

**The nature of good peer support?**  General features include informality, genuinely run by and for the community, create friendships and trust, advocacy often follows. Some models are facilitated by health professional then become standalone. Access styles may be very different (online, face to face, telephone) and all might be needed.

**Screening and readiness:**  Specific to HD, the participants felt that **c**onnecting with peers would be influenced by a) the capability / training of the peer to be able to think beyond their own situation b) the progression of HD may be a factor for both peer and person being supported, c) confidentiality can become an issue eg extended families

 **'**The person joining a group would need screening about being confronted. Need to have trained peers supporters to 'set aside their own stuff' eg the genetic support network of Victoria could help here… (people) need to think outside themselves. (genetic counsellor)

**Checks and balances: '***Need to ensure that the person receiving peer support does not get overwhelmed with someone else's stories'* (genetic counsellor). Need to consider confidentiality in peer support, due to so much cross over in the Huntington's community

**Environments that foster peer connection:** One participant described her observations that historically 'overnurturing care environments' where professional staff were heavily involved, had the impact that  ' *clients in general had little to do with eachother'.* A change in service model and facilitation of peer to peer contact has led to a situation where residents in a HD facility are now *' better connected, sat by eachothers bed whilst dying, advocate for one another, supportive of eachother, working together*…' It was felt this is product of supporting people to take control of own lives and related to the discourse of choice and control. Other participants listened and concurred.

## 3.2 Gap Analysis Focus Group 2 Gene Positive Summary Notes

DATE 9 October 2020 via Zoom – 75 minutes

**Researchers:** Natasha Layton (facilitator) and Natasha Brusco (note taker).

- P1 is a 61 retired schoolteacher who has moved from Vic to NSW and is supported by HV. P1 was tested at 30 and is gene positive, and has been symptomatic for 5 years, utilizes NDIS
- P2 is gene positive and her mum resides in a nursing home aged 54. Two 2 other siblings are gene positive, and not symptomatic currently

All participants lodged consent.

Data Management and Analysis

4. The meeting was recorded with permission and the audio files securely lodged along with raw notes from both researchers.
5. Themes and Data table created: a tabulated summary of themes linked to the focus group narratives, drawing on researcher notes and recordings.
6. Summary Notes by Theme: this record is a synthesis of written notes from both researchers, triangulated with the focus group recording.

The Focus Group guide and analysis framework is organised according to:

- HV Social Impact Framework
- COAG principles to determine the responsibilities of the NDIS and other service systems[14]

Data from Focus Group 2

| Domain | Summary notes (quotes in italics) |
|---|---|
| Peer support?<br><br>- Relationships | PROMPT How would you order the support you get?<br><br>- First comes from family, then HV and medical support. It feels more authentic coming from someone who has been through it. Health professions are showing from their point of view. |

[14]https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

| | |
|---|---|
| | - Systemic advocacy: more people who can gather to generate awareness on these situations is always going to be beneficial.<br>- strength in numbers,… the more people who can work on something is better, so that if someone needs time out to focus on their own health, there are many other who can step up and take over, and things won't come to a halt…<br>- peer may not be a friend but may bring friendship<br>- There are time points that are particularly helpful: testing, diagnosis, symptom onset, when traversing life change 'when you decide to start the testing process, through the process of appointments, and then when you get the results, and in the days following that…'<br>- Being in the same state may be helpful if you need some practical supports, but otherwise Australia wide is fine, it would be good to have the most people involved as is possible<br>- Peer support does not need to be<br>- We need to take HV nationally<br>- As long as its in Australia…<br>- Does not necessarily need to be face to face. Phonecall, messages, email, anything…then you can make a face to face (post COVID) can come as needed |
| - Health and symptom management<br>- Physical wellbeing<br>- Emotional wellbeing | PROMPT What help? What is missing? What is needed in these areas?<br><br>- HV support services, HV counsellor, allied health<br>- Massage, yoga, meditation, aromatherapy (mood lifter to help with depression), crystal healing, reflexology or pressure point therapy, reiki, positive affirmations |
| - social inclusion | - Op shopping, having coffee, hang in cafes and sit and read the paper, hang out, do a bit of people watching, walking on the beach with my fur babies 'pet therapy is really awesome'<br>- My own ways to find comfort and support |
| - housing, risks, stability, economic stability.<br>- Housing and security<br>- Economic stability / | - Little to no public housing available for people with disabilities<br>- Wait lists<br>- Risks in a shared house or house with people with psychiatric impairment<br>- Where can my relative live? too young for aged care, but too impaired to live at home…<br>Mum tried to purchase a caravan and this was not a safe option<br>Dad needed to go into a home, there were no places available, there were generational differences, he was in his |

| | |
|---|---|
| managing daily living<br>- Risks and safety | 50's but they were 30, 40 years older than him… it was terrible for him, he tried to suicide twice.<br>- Where can I live? I feel by myself I could live by myself… There is no safe place for time out or for me to have respite care |
| - Any others? | Nil |
| Other? | - Assisted dying / euthanasia: one participant motivated<br>- Giving bad news: how to educate health professionals and others Those professionals that lack of compassion, understanding, commonsense… irresponsible. I went through the same thing when I got my results as well… I had a three month screening process there… there was no leadup, she just ripped it open, you've got HD and this is your count "I said what do I do now? She said: come back when you are symptomatic' |
| COAG DOMAINS<br><br>• Aged care<br>• Justice<br>• Transport<br>• Housing and community infrastructure<br>• Employment<br>• Higher education and VET<br>• Education<br>• Child protection and family support<br>• Early childhood development<br>• Mental health<br>• Health<br>• Any others you can think of? | Aged care: discussed above, generational lack of fit into aged care, lack of specific knowledge of HD management in aged care<br><br>Transport: lack of accessible public transport is an issue<br><br>Child protection:<br><br>- Once mum became unable to look after herself she was no longer able to look after me. But I fell through the gaps as I was 14, I wasn't technically homeless, she wasn't abusing me, but she wasn't able to take care of me. I had to go to many child protection appointments and represent myself, and say this is the situation. I was able to find somewhere who could take me on as an independent, so I put myself in care, but it was a really really hard process and absolutely lacking.<br><br>Education and employment:<br><br>- Learning how to present with HD? "I kind of just made it up as I went'<br>- Either up front about family history, or passing<br>- Another approach is to educate (about HD) as it comes up<br>- I don't shout that from the rooftops |

**huntington's victoria**    **MONASH University**

### 3.3 Gap Analysis Focus Group 3 Gene Positive Summary Notes

DATE 9 October 2020 via Zoom – 75 minutes

**Researchers:** Natasha Layton (facilitator) and Natasha Brusco (note taker).

Participants:

VP husband lived with DF and passed away in 2017. Two of Val's three children are gene positive, one elected not to be tested,

JX has a toddler, and her mum is gene positive, as was her grandfather

B caring for wife who has HD and a gene positive son, 2 granddaughters not yet tested

All participants lodged consent.

Data Management and Analysis

7. The meeting was recorded with permission and the audio files securely lodged along with raw notes from both researchers.
8. Themes and Data table created: a tabulated summary of themes linked to the focus group narratives, drawing on researcher notes and recordings.
9. Summary Notes by Theme: this record is a synthesis of written notes from both researchers, triangulated with the focus group recording.

The Focus Group guide and analysis framework is organised according to:

- HV Social Impact Framework
- COAG principles to determine the responsibilities of the NDIS and other service systems[15]

Data from Focus Group 3

| Domain | Summary notes (quotes in italics) |
|---|---|
| Peer support? | PROMPT How would you order the support you get? |

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[15]https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf

| Relationships? | • Emotional support: Family and friends but *lost many friends as they don't know how to manage it. So they drop away.* Therefore peer supports may offer friendship but from a place of knowledge.<br>jokes about alcohol, finding humour in things *light heartedness helps me*.<br>• Professional Support: We wouldn't be where we are today without Huntington's Victoria.<br>- Getting connected to this information (finding the right hospital, OTs who understand HD, NDIS package): needs to be local (2) could be regions, if we could have knowledge in regions, *Obviously I'm not going to have one in Craigieburn, or one in Gisbourne, Barry, but Western or Eastern..) does not necessarily need to be local but needs to have information on hand, that is local to you*<br>- Could be a mixed bag (via zoom, face to face), a knowledge bank, *almost a database*<br><br>Making systems better for everyone<br><br>  - Educating (security guards, police, shops that are welcoming,<br>  - Challenging to raise awareness for brain impairment eg raising awareness for pre-genetic testing via IVF<br>  - I find it empowering actually, to have a voice and help other people vs it can be a bit exhausting getting people to listen<br><br>Great support?<br><br>  - able to access people 24/7 (for the physical side)<br>  - having that information r that understanding for what is actually going on for that person<br>  - SDA apartments are so well serviced… this is amazing for SDA, if only that support were available for people who live at home<br>  - Intelligence-sharing via a community… noted air-task for 24/7 support (other agreed) *might not be possible, but what about Airtasker, but somehow that's a network..* |
|---|---|
| • Health and symptom management<br>• Physical wellbeing | - EMOTIONAL WELLBEING Friends may be a good distraction, but they understand what you are going through on a day to day basis, someone who understands may offer a better form of advice, more compassionate |

| | |
|---|---|
| • Emotional wellbeing | and more understanding, with someone who has been there on a day to day basis.<br>- Using the NDIS package to fund carers who know the person to visit the residential respite facility and work with person<br>- Professional support: challenging to locate helpful professionals with the skillset and then the knowledge of HD. remember feeling quite frustrated and sometimes paid a lot privately and they weren't up to scratch … we would live for them to come that day and they were not informed really<br>Even specialist services RMH) the registrars change every year, they may not have allied health<br>NDIS case manager working very well<br>- when I was caring for (husband) I reached out a lot for professional peer support and I did find that lacking, to be honest<br>- Physical support: physical support as I could not physically lift him… that's a tricky one, how would you reconcile that, how do you know when someone needs to go to the toilet. |
| • social inclusion | - |
| • housing, risks, stability, economic stability.<br>• Housing and security<br>• Economic stability / managing daily living<br>• Risks and safety | - Risk: shifting of supports eg pre NDIS, local councils may support with for example wheelchairs. With NDIS, this source of local and timely support *has fallen away* |
| Any others? | Knowing how to support children, relatives, people not yet tested.<br><br>Handling testing: the recommendations of p |
| Other? | - Having a team you can trust, in comparison with Disability / Aged Care Royal Commission findings, noting adverse outcomes of poorly trained support workers *had a carer who didn't really understand HD, who came from an agency. And the carer planted the seed about maybe you should leave dad. So that was the start of the downward spiral. So trust is really important…* |

| | |
|---|---|
| | - Support beyond the person themselves:  my dad felt he didn't have any support for him<br><br>INTERNET:<br><br>- its very broad, when you look up HD, because it has to be, because there are so many differing situations<br>- I'm on a couple of support groups on FB, HD specific that nobody who is gene positive can be on, so its just for carers (gene -ve) and have been really supportive, people post about things like the drugs that they have been on, very helpful |
| COAG DOMAINS<br><br>• Aged care<br>• Justice<br>• Transport<br>• Housing and community infrastructure<br>• Employment<br>• Higher education and VET<br>• Education<br>• Child protection and family support<br>• Early childhood development<br>• Mental health<br>• Health<br>• Any others you can think of? | Aged care – above (lack of expertise on HD)<br><br>Risk / Justice – need relationship with police as alarms.<br><br>Being excluded from the community **I've** been out after the HV ball with people who are gene +ve, **my mum, Kylie, and** had to explain to security guards that they have involuntary movements, they are not drunk. **There have been a few times where its been very difficult to get into places**<br><br>V: I work in retail and never assume, give them the benefit of the doubt, it may be a medical condition<br><br><br>Transport: transport, it was tricky for us, I still drive now with my hand on the gearstick, because going down the freeway at 100 he had a hand spasm and knocked my car into neutral…. Couldn't have him in the car for the last 6 months, I was lucky in my package I was able to get taxi vouchers<br><br><br>Employment: a colleague at husbands work wrote a letter to management about being drunk at work. saying they she believed he was drinking and coming to work drunk. I took that to heart, probably more than he did due to the apathy, it hurts the family.<br><br>This was really destructive to the whole family. |

## Appendix 4 Gap Analysis Verification

### 4.1 Gap Analysis Plain Language Summary for community consultation

A link to the following plain language summary was uploaded to the Community Conference page of the Huntington's Victoria website on 4 Dec, enabling delegates to read prior to the Gap Analysis verification session on 6 December, 2020.

Peer support for the Huntington's community... by the Huntington's community, 'Huntington's Community Connect'

Project 1 Gap Analysis

Monash University conducted a gap analysis regarding services and supports in the second half of 2020.

Our research included a rapid evidence review to find out about the current national prevalence of Huntington's Disease, that is, how many people are diagnosed with HD in Australia. We also looked at how impacts of Huntington's Disease are described and asked about the things that matter to the Huntington's community.

We ran Focus Groups with members of the Huntington's community, and with health professionals supporting people with HD. We asked what services and supports people use, and what services and supports they need. We asked about gaps and we asked how peer connection might help.

This Summary contains the Peer Support Findings from our Focus Groups. We will be running a final consultation regarding these findings at the Huntington's Victoria Community [Conference](#).

All are welcome to contribute to the Peer Support session there to shape our final Project recommendations.

The final results will be published as a Report and a journal article.

Sources of support

SUMMARY people draw support from a range of sources. Different supports are useful at specific times and for specific tasks. Peer support is one of those supports.
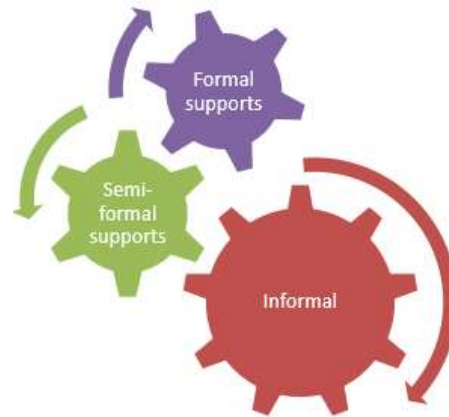


Key Messages

People get **support** in different ways. People who you happen to know, including family and friends are called **informal supports**. Other useful supports include community services like personal care workers, house cleaning, lawn services. These are called **semi-formal supports**. A third source of support is medical and health care professionals such as occupational therapists, physiotherapists, doctors, genetic counselors, Aboriginal and Torres Strait Islander health practitioners or complementary medicine practitioners. These are called **formal supports**.

Support can mean different things. Support might be **emotional** support, for example someone being with you at appointments. Support might be **educational** support**,** for example giving advice about your options. Support might be **physical** support such as actually help to phyically manage. And support might be related to **advocacy**, in other words talking to services and government to make systems work better.

Support can make a **difference** because things can feel worse for people without a support person.  It is best if support comes at the **right time**, and if the people providing support take the **right approach** for you.  People want their supports to be **knowledgeable** and **insightful** and **trustworthy**.  People who give support, like peer educators, get **a lot out of sharing** their knowledge and experiences.

COMMENTS BOX Is there a gap between the services you need and the services you receive?

- ☐ Formal services  (medical and health care professionals) (gap YES/NO)
- ☐ Semi-formal supports and services  (community services)?  (gap YES/NO)
- ☐ Informal supports  (carer and peer support)?  (gap YES/NO)

Any other comments?

Gap analysis

Peer support is one of the creative way we might work together to wrap supports around the person, across regions and across services.



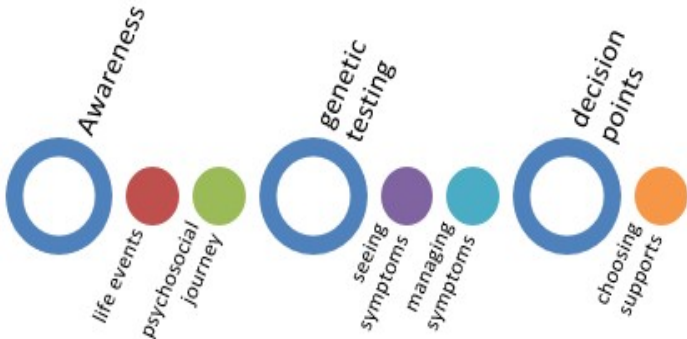Semi-formal supports     Formal supports

Key Messages

Australia has some great services but **not everyone can use them.** This might be because they do not cover all geographic areas. Or because different services fund different things. Sometimes services don't include all the **important things** about a person, for example their sexual orientation or their indigenous identity. This is called **intersectionality**.

There are lots of formal, semi-formal and informal supports available. It is **complicated** to understand them all. It is hard to find people who are **experienced** in all these supports. It is also hard to **keep up to date** as services frequently change. These support areas include aged care, NDIS, mental health services, community healh services, justice, child protection, and employment. The Huntington's community and supporters have lots of experience in thinking about supports, and thinking about future ideas for what might 'really work'.

COMMENTS BOX Please tell us (tick all that apply)

- ☐ Preferred to manage myself
- ☐ Didn't think anything would help
- ☐ Didn't know where to get help
- ☐ Afraid to ask for help or what others would think
- ☐ Couldn't afford the money
- ☐ Asked but didn't get help
- ☐ There were no services available

Any other comments?

| | |
|---|---|
| Right time right touch supports<br><br>Supports need to be responsive to the trajectory of Huntington's Disease. |  |

Key Messages

There are different **moments** in the Huntington's Disease journey where supports are needed. Different people need different types of supports at different times. People from the Huntington's community were very clear that there is a right and wrong time for certain types of information.

Skilled peer support can be very helpful at **particular** moments like:

- Deciding how much support a family can manage
- when you are being 'given bad news'
- when you are deciding how to talk about HD in your daily life

People tell us they don't have enough supports at **transition points**. A transition point is when you move from one situation to another, for example moving into aged care. It can feel like you need to '*start again*' telling your story to new professionals. A peer support network can help with this. People giving peer support need to **take care of themselves** too, and not feel sad or overwhelmed. People giving peer support should get regular **education** and be supported in their roles. Support can be useful in different ways including over the telephone, on line or face to face. Some supports are needed in a local region, but other supports can be helpful if delivered nationally.

COMMENTS BOX Please tell us when would you prefer to speak to a community member? (tick all that apply)

- ☐ When first aware of HD
- ☐ When I choose, on my HD journey
- ☐ During genetic testing
- ☐ When symptoms come along
- ☐ At key decision points eg moving home
- ☐ When choosing supports
- ☐ Deciding how much support a family can manage
- ☐ When being 'given bad news'
- ☐ when you are deciding how to to talk about HD in your daily life

Any other comments?

## 4.2 Live Poll results from Workshop at HV Community Conference

A one hour workshop incorporated a Zoom poll within a Zoom presentation, attended by 17 Community Conference delegates.

**Zoom Poll Results**

Is there a gap between the services you need and the services you receive?

- Formal services  (medical and health care professionals) (YES/NO):
  Yes 59% (10),  No 41% (7)
- Semi-formal supports and services  (community services)?  (YES/NO):
   Yes 67% (8),  No 33% (4)
- Informal supports  (carer and peer support)?  (YES/NO):
   Yes 65% (11),  No 35% (6)

Please tell us *why you think you don't receive the services you need* (tick all that apply)

- Preferred to manage myself - 36% (4)
- Didn't know where to get help – 27% (3)
- Couldn't afford the money – 27% (3)
- Asked but didn't get help – 27% (3)
- There were no services available  - 18% (2)
- Didn't think anything would help – 18% (2)
- Afraid to ask for help or what others would think  - 18% (2)

Please tell us when would you prefer to speak to a community member? (tick all that apply)

- When first aware of HD – 33% (3)
- When I choose, on my HD journey – 78% (7)
- During genetic testing – 22% (2)
- When symptoms come along – 22% (2)
- At key decision points eg moving home – 44% (4)
- When choosing supports  - 33% (3)
- Deciding how much support a family can manage  - 22% (2)
- When being 'given bad news' – 22% (2)
- when you are deciding how to talk about HD in your daily life – 33% (3)

Free text  comments:

*Comment*: Not yes or no as services not required at this time.

*Comment*: in terms of our professional health team, we have a great team in place.  Our team takes the time to learn about HD, and work with us to make the necessary changes that works best for my husband.  The biggest issue with community services support workers, this is an area where more education on a statewide basis would be advantages.  Especially as it is in the area that people get confused with HD. We have had many instances where my husband;s condition has been referred to as MND.

*Comment*: None of these are relevant as we receive support as we don't need them yet

*Comment*: 100% agree with that comment about gp's not knowing enough about hd to help efficiently