



# **My Home Hospital**

## **Outcomes of Community Consultations**

### **Report**

August 2020



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## Executive Summary

The My Home Hospital initiative was universally supported by those with Lived Experience of similar programs and by the general community in the Workshops.

In general terms participants felt that having hospital services provided in the home offered an excellent opportunity to build on the current service offerings in hospitals and provide a service that would better suit many patients' needs.

Participants in the process developed a strong set of 9 principles that they felt were essential for the successful implementation of My Home Hospital.

However, participants also identified a significant challenge to the program – the tension between eligibility vs accessibility/equity. Participants in the workshops identified that ensuring the scheme's success either relied on heavily restricted eligibility to those in the community who were best placed already to 'host' the service OR a very well-resourced program which supports South Australians irrespective of their circumstances. The principles developed are provided on the premise that the Department's intent is to provide a service which is accessible to all – and as a consequence, resourced appropriately to support patients irrespective of their personal circumstances.

Participants in the workshop also identified a number of risks associated with the proposal which we detail in this report.

Participants were mainly keen to continue working with Wellbeing SA on this important project and have identified some engagement considerations for Wellbeing SA to consider as they move forward.

# Introduction / Background

The Department for Health and Wellbeing is in the process of extending their provision of hospital in the home services.

*"My Home Hospital is a Hospital in The Home (HITH) service. Most of the Local Health Networks currently provide HITH services. HITH services in South Australia provide the spectrum of admission criteria types to children and adults outside of a hospital setting, in the patient's permanent or temporary residence as a substitution for in-hospital care."*

Patient receiving care through a HITH program would otherwise normally require hospitalisation.

The Department of Health and Wellbeing, through Wellbeing SA, is looking to grow the provision of Hospital in the Home services through the development of the My Home Hospital Program. Wellbeing SA is currently undergoing a tender process to procure service providers for My Home Hospital.

- In doing so they are engaging in work with the community to co-design principles which will be used to assist Wellbeing SA and service providers to understand what is important to people in having their hospital services provided at home.

My Home Hospital will be targeting particular diagnostic groups over the next two years, including;

- Year 1 - Cellulitis, respiratory infections / inflammation, , kidney and urinary tract infections, chronic obstructive airways disease and venous thrombosis (DVT)
- Year 2: Lymphoma and non-acute leukaemia, cystic fibrosis, heart failure and shock, chest pain, major procedures for breast conditions, pulmonary embolism, inflammation of bone and joint, and osteomyelitis.

It is expected that My Home Hospital will be integrated into the health system as an additional hospital in the home service. Existing HiTH services will continue to be managed by the Local Health Networks

**Being at home was a real shot in the arm for me!**

**Lived Experience Interviewee**

# Engagement process

Three groups were identified as being important for providing insights to government on the design of the My Home Hospital program and hence for involvement in this engagement process:

Group	Rationale/ Purpose
1. <b>General Community</b> - Diverse cross section of the metro and close metro community – that may or may not have experienced the hospital system	To gain an understanding of different at home environments and the perspectives / needs of different groups from in home hospital care.
2. <b>Lived Experience - of hospital care</b> - Recent or current patients who have received care in hospital for the diagnostic conditions identified for service provision in the home (for years 1 and 2)	To gain the understanding of patients which know what the care looks like in the hospital and hence the sort of care they may expect is required in the home. They will be able to apply what they know about the care required and their respective home environments and provide important intelligence from their lived experience
3. <b>Lived Experience - of hospital in the home care</b> - Current or previous patients that have received hospital in the home.	Will be able to provide insights into their experience of in-home hospital services in light of their home environment – what worked, what didn't – in general terms (not specific to their condition)

For all three groups democracyCo sought a broad cross section of people with diversity of:

- Culture / Ethnicity
- Location – different parts of metro South Australia and close regional centres
- Age
- Socio economic / home environments

For those with Lived Experience we also sought to talk to individuals with the different diagnostic groups targeted for the My Home Hospital program over the next two years.

democracyCo used tailored engagement techniques to engage those with lived experience (either of hospital or the hospital in the home programs) and the general community. We identified that current or recent patients could well have issues they want to discuss which are quite personal or private in nature or indeed conditions which make it harder for them to engage as part of groups. Their condition may also impact on their comfort and ability to participate – especially in a setting with others.

We recruited and involved the different groups as follows-

### **Lived Experience Participants – 16 participants**

#### **Recruitment**

- To occur through Local Health Networks, Department of Health and Wellbeing broader networks and supported by democracyCo's own database (although it is acknowledged that not many would likely be found through demCo)
- Invites were sent and interested people asked to respond to a democracyCo registration of interest page

### **General Community – 23**

#### **Recruitment**

- o A diverse range of avenues and networks were used to recruit a diverse group of participants – including –
  - o Government social media – particularly Dept. of Health and Wellbeing and Your Say Facebook, The Office for Ageing Well, SA Seniors Card, the Local Health Networks, Wellbeing SA and the Department of Human Services.
  - o democracyCo – own database of South Australians interested in working with Government on policy
  - o Through networks who run programs with targeted audiences including –
    - Aboriginal Family Support Service
    - Carers SA
    - Welcoming Australia
    - United Communities
    - Local Government
- o We also tried to promote this initiative through Health Consumers Alliance – but we are unclear whether they promoted the opportunity to their database.
- o Invitations were distributed through these groups / avenues and participants were asked to respond to a democracyCo registration of interest page.

## Review and Selection

DemocracyCo reviewed registrations of interest to check for diversity and selected participants.

### Individual meetings

- DemocracyCo organised individual meetings with people
- Participants were provided a reflection sheet in advance so that they could take their time to consider and reflect on their own lived experience prior to the session.
- We held 16 one on one interviews of between 30min-1 hour each mainly over the phone
- A series of structured questions were asked to each participant about their experience with home care

### Small Group Zoom Sessions

- democracyCo ran 2 small group sessions via Zoom for 23 people (Grp 1-13 & Grp 2-10) over 4 hours to find out what was important to community members in having hospital services delivered in the home.

DemocracyCo then worked with interested representatives from the Lived Experience and Community workshops to analyse all the information provided through the interviews and the workshops and agree on a suite of design principles.

This group was made up of 6 participants with 3 from the community workshops and 3 from lived experience interviews.

The substance of the design principles were developed by the community participants in the Design Principles Workshop.

The Principles are in the words of the community, clearly drawing on their diverse personal experiences.



# Engagement Limitations and next steps

The original intent was to interview approximately 25 people with lived experience. In the end this was not possible and we interviewed only 16 people. The insights gained from this group were exceptional, however we are concerned that we only spoke to people who had experienced the current program/s who were positive about the experience. Different avenues (through the Local Health Networks and Safety and Quality Teams) were pursued to access people who hadn't enjoyed their experience of a Hospital in the Home Service but were unsuccessful in finding these patients. It would have been helpful to understand the experiences with the current program that were not positive as this may have given us substantial insights into areas of concern.

We also would have liked a more diverse group at the workshops in terms of age, otherwise we were pleased with the diversity of the group. However, we note that the age group engaged was probably reasonably representative of the age group that most regularly accesses hospital services.

It was identified early that it would also be useful to obtain greater insights into the needs of particular priority care groups that can be hard to access, such as CALD, those experiencing mental health issues, those with disabilities and the LGBTQI community. As a consequence, we will be running a combination of lived experience interviews and further workshops to check in with this group about the Design Principles developed to date and make sure that they meet their needs (and adjust accordingly).

# Design principles

Participants in the Design Principles Workshop developed the following suite of Principles for the extended My Home Hospital initiative.

- 1. Clear / Transparent Eligibility** - Apply a robust method for determining suitability which uses a combination of diagnostic condition, home environment and home location.
- 2. Enable patient choice.** Patients need to be able to opt-in and opt-out of the program seamlessly and at any time
- 3. Be patient centred.** At all times, patients, their families and carers must be treated with dignity and respect and they all must have a voice in the care which is being provided to them. Cultural appropriateness must inform in-home services.
- 4. Be holistic.** Apply a common-sense flexible approach to service delivery which balances clinical needs with patient needs.
- 5. Quality care.** Pursue outcomes which are at least equivalent to those which are achieved in hospital. Great assessment up front will support the pursuit of great patient outcomes.
- 6. Coordinated team** - Be supported by a multi-disciplinary management system with a single point of coordination for the patient. Information and communication must be clear, complete and timely.
- 7. Accessible** - Be available to and inclusive of all South Australians who are eligible to access the program
- 8. Safe** - Be safe for everyone – for patients, their families, carers and clinical staff
- 9. Adequately resourced** -
  - Medical staff should have the right skills coupled with a high EQ and empathetic nature
  - The appropriate equipment, technology and 'hardware' should be provided for home care
- 10. Quality management systems and monitoring** – Continuous self-improvement systems must be foundational in the design of the My Home Hospital Program. The Program must continuously seek not only to identify faults and problems within its delivery but also seek to identify better and more efficient ways of delivering its patient services.

## A Lived experience...

Bob recently underwent surgery to review his previous hip replacement. He was unable to walk or drive post op and required ongoing antibiotics via pic line daily. With a 25minute drive to the closest hospital for treatment, Bob and his wife were in a difficult situation, where his elderly mother who lived with them was in the last months of her life and required 24 hr care and someone to be with her at all times. The offer of hospital at home care came at a desperate time for his family removed the challenges of managing Bob's care and their personal family situation. Bob received treatment from a visiting RN in his home 7 days a week for 8 weeks and reflected that he *'doesn't know what they would have done without this service'*. Removing the worry of getting to the hospital every day for critical care was a relief to Bob and his wife. They found that the nurses were extremely supportive and a pleasure to have in their home. He reflected that his recovery benefited from receiving care in his home and made things easier for his wife. He believes that the consideration of each person's personal circumstances is a key factor in the design of MyHH as is communication and record keeping between nurses and the hospital.

*\*names changed to protect privacy*

# Design Considerations – Common themes

The following key themes emerged from the workshops and lived experience workshops on elements that are important to consider when developing the My Home Hospital program -

- Quality care / Emotional intelligence of staff
- Contingency planning
- Patient centred
- Information and home readiness
- Quality of service
- Transition supports
- Appropriately resourced
- Culturally appropriate
- Accessibility and Transparency
- Regional service provision

This section explores each of these themes, however an important issue that emerged during the sessions concerned the conflict across the themes.

Participants in the workshops in particular talked about the importance of the program being accessible and open to all South Australians, irrespective of socio-economic status, disability, household make-up, employment etc with the diagnostic conditions, however there was also extensive conversation about the challenges of achieving this outcome. It was identified that the Hospital in the Home service could be challenging to provide in certain circumstances – ie where someone is single, the home doesn't provide adequate space / privacy or conditions.

The workshop groups identified that this could either be dealt with by

- 1) Refining the accessibility / eligibility requirements – narrowing the criteria of accessibility. Having a rigorous assessment of household circumstances to determine eligibility and only providing the service where it would easily work, OR
- 2) Providing appropriate supports – ensuring that ALL South Australians can access the scheme (providing they have the appropriate diagnostic conditions and are within the service area<sup>1</sup>)

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<sup>1</sup> NOTE – the workshops also discussed provision of the service in the Regions, more information can be found about this on Page 12

There was a general view that the provision of this service could be of great benefit to people in varied circumstances and that hence there was a preference for option 2 – that the services be widely available but that appropriate supports be in place to ensure its success. This thinking was central to the development of the Principles -

- Patient centred
- Accessibility
- Transparent
- Appropriately resourced.

They were really, really supportive, very uplifting and great to have around. I really don't know what we would have done without this service given our situation.

**Lived Experience Interviewee**

## Quality of Care / Emotional intelligence of the staff

This was the most significant theme emerging from the Lived Experience interviews in particular, although it was also raised in the community workshops.

**The nurse was very compassionate, not judgmental and kind, it really was fantastic. I felt as though I knew my husband was getting the help that he needed.**

**Lived Experience Interviewee**

Participants felt that it was absolutely essential that the medical practitioners/ providers of care going into homes need to have high levels of empathy and human connection.

The strongest theme, coming out of the feedback was that hospital in the home could easily work as long as the people providing the service have high degrees of empathy and strong communication skills – and that they realise that they are working not only with the patients, but the families and carers and that they work to make everyone feel comfortable. This was considered essential as these traits help the provider of the service to bend/ flex to the needs of the individual, their family and their individual environments. People with these skills can sense issues or needs of the patient and or their

family and then respond accordingly. As providers of care aren't in an environment they can control, they need to be able to work with and respond to the environments they are in. Whilst empathy is always important / helpful in the provision of medical services, it was felt that this importance is heightened when providing the services in a home environment.

## Contingency Planning

Those with Lived Experience identified the need for a clear /easy process for management of complications to be in place before hospital in the home services were provided. When deterioration has occurred, nimble decisions are required to ensure safe care.

There is a need to make sure that there is a clear, simple, and agreed plan as to what happens when something goes wrong – e.g. that an ambulance can be called, and the patient taken to hospital.

Feedback provided, outlined that it wasn't always clear what should happen if there were problems with their medical condition, if they didn't feel well or were deteriorating, i.e. who to contact. Some recipients of care at home depending on their condition, may have a nurse visit once per week or every 2 -3 days and the steps to take in the interim should something go wrong wasn't always clear. (NB: My Home Hospital patients will receive at least one face-to-face visit every day of their admission).

This was also discussed in the Workshops; the following suggestions were made regarding how this could be achieved:

1. Ensuring there are transport vehicles to attend
2. Resources to return to the most appropriate care location (which may be hospital)
3. There need to be good connections between My Home Hospital and the acute hospitals to ensure escalation can occur.

Each individual's circumstances need to be taken into consideration at all times

Workshop Participant

## Patient Centred

Participants in the interviews and the workshops identified the importance of ensuring that the model of care is patient and family centred.

Participants identified a number of areas that could be addressed/ looked at to assist the achievement of this outcome, including;

- **Scheduling** – being clear about when service providers are coming and keep patients up to date if changes are necessary
- **Communication** – tailored to the individual, particularly the need to speak the language or bring someone who can (if there is no one in the home to translate effectively)
- **Clear referral pathways and co-ordination of services** – the team providing care to be in communication with each other regarding the patient
- **Clear Contact arrangements** - Clear and easy communication mechanisms between providers of care and the patient
- **A go-to person / coordinator** – having someone to help you navigate the system that is not your family member or carer. Someone who is responsible for your care arrangements that you can call to ask questions or fix problems.
- **Choice** – people have the option of staying in hospital for their care. It should be their choice if they meet the eligibility criteria. This preference may be for a wide range of reasons, generally based on their home situation (lives alone, with partner/family) and their level of personal safety / comfort.

## Information and home readiness

The patient needs to be informed and clear about the service and have the option of in hospital care.

It is important that adequate information is provided about the service and how it works before the patient enters the program.

To ensure the patient is ready and their home environment is ready, it will be important to ensure patients are informed about:

- what the My Home Hospital suitability parameters are,
- who they communicate with
- needs for home set up (if any)
- what to expect on a daily basis
- how to exit / raise concerns / issues

This is about education regarding the service - for people / patients - and how it affects the day to day running of their household.

Could not speak highly enough of the care at home. They were brilliant! The people that came to attend to me were brilliant!

Lived Experience Interviewee

Workshop participants identified the need to ensure a holistic approach is taken to ensure that people do not fall through the gaps.

## Quality of Service

It is vital that a quality of service is provided and maintained in terms of the clinical care, the continuity of care and the emotional support (general care). This will be essential to recovery for the patient.

It is vital that patients being provided the hospital at home service don't get forgotten/ fall through the gaps.<sup>2</sup> Transparency will be integral to ensuring a quality service.

## Transition supports

The Transition to home care needs to be well supported, informed and how the service will be provided in the home needs to be clear.

## Appropriately resourced – Resources / Equipment / Tech

It is vital that providers of care/ medical staff / clinicians come equipped with everything they need (equipment and technology).

Service provision needs to be adequately resourced/ supported with the right equipment.

Hospital service provision in the home needs to be appropriate given the home environment. This connects to the theme on being "patient centred". Each household's needs to ensure the successful provision of this service may be different and this needs to be considered in the resourcing of individual patients.

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<sup>2</sup> The engagement on My Home Hospital took place in the context of the death of Ann Marie Smith. As a consequence, participants in this engagement were reflective about the gaps in the system that they perceived may have led to her death and many of the suggestions made by them about what needed to be considered in the context of the My Home Hospital program reflected concern about these issues. The identification of potential gaps -was raised in this context.



## Culturally appropriate

It is important that the service is provided in a way that is culturally appropriate. The design of the program needs to be culturally sensitive and deal with language barriers. This will require that staff are appropriately trained/ and have the necessary language skills.

The workshops discussed how this could be achieved and suggestions were raised such as, dedicated translation service, CALD workforce, and cultural training for practitioners.

### A Lived Experience ...

Kate's 5 year old daughter has cystic fibrosis and requires a daily IV treatment for 2 weeks 3 -4 times each year. Kate and her family have experienced home care from 2 different providers. Kate reflected that her daughter receiving her treatment at home makes their lives so much easier and was very convenient. She commented that her daughter is happier, that they get to stay in their own beds, whereas it would otherwise be a 2 week stay in hospital, so it is a significant amount of time they are able to stay home. They also have a younger daughter who would struggle with daily trips to the hospital.

*\*names changed to protect privacy*

## Accessibility and Transparency

In the workshops the issue of system transparency was discussed extensively. Participants in the workshops felt that the process of decision making about suitability / eligibility for home-based care needed to be transparent.

The decision-making process and criteria need to be clear to the patient, so they understand their options and why those options exist / don't exist.

This could be done by:

1. Providing comprehensive information about the decision-making process (including in language they can understand)
2. Supervision and oversight of the program
3. Complaints resolution process / way of addressing issues / raising concerns

## The Regions

Participants in the workshops talked about the usefulness/ benefits of this program for residents of regional areas. Whilst participants understood that the program is currently targeted at the metropolitan area, the group identified that regional provision of this service could be of great benefit to regional residents / communities.

## Risks

It is important to note that overwhelmingly participants in the workshops were supportive of the proposed My Home Hospital initiative. However, we did ask workshops participants to identify if they could see any risks associated with the My Home Hospital initiative that they wanted to raise.

They raised the following key issues-

- **Monitoring service provision** – participants reflected on the Ann Marie Smith case and the importance of ensuring that people don't fall through the gaps. Care standards need to be maintained
- **Challenges of supporting single people** – People identified a number of issues for single people including-
  - There is no one in the home to monitor changes in condition of the patient.
  - Who will look after the everyday needs of the patient?
  - There is no one to make sure that any required technology is working.
  - It is harder for medical staff to visit – especially if the patient is confined to the bed.
  - No one to take emergency action in case of things going drastically wrong.

“I like the idea of hospital @ home – would be great, takes pressure off the system. People are happier being cared for in their own homes, especially as they get older. Infection control is better – less risks”

Workshop 1 Attendee

- **Risks associated with technology failure** – this could be a particularly significant issue **if** the person is on their own and hence can't get help.
- **Risks of community acquired infections** - such as Covid19 need to be taken into consideration. For example, if someone else in the household acquires a virus and it infects the patient. Social distancing is hard in a home environment.
- **Risks of education/ information about the service** – that inadequate information is provided to the patient explaining the service, how it is provided, what the needs of their diagnostic condition will be and how these will be met etc – to enable them to make an informed decision about whether it is the right service for them.
- **Risks of access and eligibility** – there is a risk that people who do not have household arrangements that easily 'work' for the provision of this service <sup>3</sup>are not supported sufficiently in accessing the program. The program needs to ensure that those who choose to access care through My Home Hospital are supported to do so.
- **Lesser levels of care are provided than in hospital** – in particular concerns were raised about the service being provided by a private provider that is contracted in rather than by the government like hospital services.
- **Care isn't appropriate for non-English speakers** – there are issues in delivering the service in different languages and hence language barriers for the patient.
- **Emergency management** – There needs to be a plan should the patient's condition change. Concerns were raised that standard response times may not adequate, in case of an emergency. Concerns were raised about the possibility of family members panicking in an emergency. Concerns were raised that it may be harder to pick up on changes / deteriorations in condition, which means that the need to move the patient in the hospital may be picked up on too late.

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<sup>3</sup> What household arrangements 'work' -will differ with the individual – it may be that that someone is single, and hence doesn't have anyone to help them at home.

# 'Diagnostic specific' design considerations

Feedback from participants of the lived experience interviews did not provide specific condition reflections over and above what has been reported in general terms above.

Some people commented that it was simply reassuring to have a nurse that understood their condition and had thorough knowledge of and someone who they could ask questions about their condition. Management of medication was another generic comment that participants reflected on, that it was also reassuring to see strict adherence to medication management and administration, especially for complex conditions.

As our sample size of those with Lived Experience was not large, it is hard from the information gained to identify the specific needs of those with diagnostic conditions. Further detailed research would be needed, to identify anything more specific than provided above.

## Engagement Recommendations

democracyCo were asked to talk to the community about how they would like to be engaged with the program in an ongoing way and for democracyCo to use this as a basis for providing recommendations for ongoing engagement in the program.

Participants were asked to reflect on how they have been engaged previously to help them in identifying how they would like to be engaged moving forward for My Home Hospital. Participants in the Principles Workshop identified the following general areas for improvement by "Health communications" -

1. **Improving transparency** – be more open and more genuine
2. **Go deep not broad** - Involving the community deeply in specific tasks or issues – as advisors and also in design of programs and initiatives.
3. **Use a combination of face to face and online engagement** – "We are adept at both, and both offer multiple ways for people to contribute. Online provides opportunities we have never had to be more inclusive of regional / remote South Australians."
4. **Show your humour more when using social media** – and be more interactive
5. **Act on recommendations** or tell us what you are doing as a consequence of the engagement (close the loop)
  - Anytime engagement occurs, a commitment should be made to come back to the community engaged and tell us what happened as a result of our engagement

Communication and honesty are the most important things  
Principles Workshop Attendee

Things to avoid -

1. **Surveys** – "death by surveys"
2. **Mass communications**

In addition, to the above, participants in the Principles Workshop identified the following specific ideas for consideration

- Establish an independent body of citizens to hold government to account – i.e. to check that government goes back to communities to keep them up to date on projects and make sure government does what it says it is going to do
- Advisory committee may be valuable as long as there is follow through and change
  - The group preferred a ‘pop-up’ approach to these – not a long-term commitment ie don’t appoint community members to a mid-long-term position

“We are willing to give our time for the public good – all we need is to see our input valued”

**Principles Workshop Attendee**

# DemocracyCo recommendations on Engagement

Wellbeing SA asked democracyCo to include in this report some high level recommendations of how they might move forward with involving the community in future stages of the program given the feedback provided by the community through the workshop/s (as above) and the next stages/ objectives of the government.

democracyCo understands that Wellbeing SA foresees three future stages where they will need to involve the community

1. **The development of the My Home Hospital patient pathway** – design of each step of the process in which a patient accesses and uses the My Home Hospital service
2. **Implementation**
3. **Monitoring / Oversight**

Below we give some ideas about how Wellbeing SA could involve the community at these different stages. It is important to note that these are conceptual at this point, given our limited understanding of the next stages and governments objectives.

It is vital that the shape of your phases of engagement is informed by what you want to achieve – form follows function.

As a consequence, we recommend that each one of these phases has its own detailed engagement strategy. These should be interconnected and form part of the overarching project directions. In particular the engagement strategies need to:

- map out in detail the government's objectives / purpose of the engagement
- identify the different stakeholders/ communities of interest – the nature of their interest, what they can offer the project, what government wants from their involvement and the relationships government wants to have with them
- outline the precise nature of the issue / problem / opportunity that the government wants the community's assistance with
- articulate the detailed methodology – which should respond to the above

## Developing the My Home Hospital Patient Pathway

As we understand it, the next step in the process is to design the steps in the journey for someone who may access the My Home Hospital program.

We understand that once service providers have been appointed that Wellbeing SA intends to bring service providers together to work with medical experts, Wellbeing SA staff, members of the community and others to design the steps in the journey and what will happen in each of those steps.

Wellbeing SA has indicated that they intend to use a 'co-design' process to do this.

We agree that a 'co-design' process makes sense for this phase of engagement and will offer Wellbeing SA the most robust outcomes and would recommend this engagement approach for this stage in the process. From the engagement recently completed – it is clear that there were participants who would like to work with Wellbeing SA in this way. They gain fulfillment and enjoy working deeply in considering complex issues together in this way.

We recommend Wellbeing SA consider the below when designing this phase:

**Form follows function** - the co-designers need to **agree** what they are trying to achieve both in an overarching sense (i.e. what they are trying to achieve from the co-design process) but also– what outcomes they want from each stage in the development of the My Home Hospital program. This approach (going slow at the start to go fast at the end) will result in a very clear, deep and robust understanding of the group's objectives for each phase

**Diversity** –

- Diversity of community inputs – in a codesign process it won't be possible to represent all the different community views needed around the table – there are too many. The Community testing proposed below seeks to address this issue in part, but nevertheless it will still be important that the community around the co-design table are diverse in the following respects – gender, experience with the hospital system, household type and if possible 'socio-economic'.
- Community testing - the group may want to 'test' its thinking with a broader group of experts and a broader cross section of the community to be sure that they have thought of everything and left no stone unturned. When the group has completed its draft thinking it may be useful to take some time to test it with those with lived experience and with different priority care groups to ensure that what is being designed would work for them. The patient journey could also be piloted in some mock real-life situations to inform the development of it.
- Balance between participants – make sure that community members don't feel overwhelmed by the number of experts / professionals.

**Building understanding and knowledge** - Community members will need to be adequately supported in their participation. So that they don't feel out of depth working with experts it will be important to build the knowledge of the community members before the process starts. It may be that you run a session with the community members prior to the co-design process to 'upskill' them in some basics, and particularly to help them understand the language/terms likely to be used by the group.

**Time** – adequate time is allowed for the process. It will take time for the group to reach agreement with each other and to consider the breadth of the issues sufficiently. We recommend that Wellbeing SA consider what can be done in parallel to use time efficiently, and not compromise the codesign process

**Commitment** – that Wellbeing SA is committed to implementing what the group recommends.

In providing the above advice we draw on the central principles of deliberative democratic practice.

## Implementation

Wellbeing SA has indicated that as the program is implemented that there may be the need for ongoing engagement around particular elements such as communications or to get some general feedback on how well the process is working as part of a continual process of review.

We recommend that these processes are designed in line with the specific objectives at the time, but also in line with the principles of deliberative democratic practice document we have provided.

Implementation must involve and include the community and patients.

Methodologies that may be appropriate at this stage include-

- Pop up workshops – with community members invited to participate / or recruited through an open process
- Surveys
- Interviews
- Co-design processes

## Monitoring and oversight

As the project is implemented Wellbeing SA have indicated that they want to have a process of continual review involving the community. The intent of this will be to improve the transparency of the system as well as to enable improved quality control and refinement of service provision.

For this stage we recommend an ongoing advisory group which involves community members as well as service providers and experts.

This stage will require continuity of involvement over time to enable the community members to build up knowledge and understanding of the system as well as a mid-long-term view of the scheme to see how it changes. The 'terms' for community members on such a group will need to be carefully thought through – as although continuity and knowledge will be important, it will also be important that community members involved don't become 'institutionalised', reducing their ability to provide a community perspective. We think that a 2-year term may best balance the need for continuity and the need for renewal.

As with the co-design process the deliberative democratic principles will also be really important here.

We would encourage Wellbeing SA to spend considerable time considering what they want to achieve through the establishment of this group and carefully construct the groups terms of reference in line with this. Setting this group up for success will rely on getting the objectives of the group right (its terms of reference). Without this being done well – unintended consequences may occur, presenting significant risks to the program.

Clear systems and processes will also be required and built into service providers contracts to ensure that such an oversight group achieves its objectives.





# Priority Care Group Report

My Home Hospital

August 2020

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# Process Overview





## Background

This report should be read in conjunction with our report entitled *My Home Hospital, Outcomes of Community Consultations Report, August 2020* (referred to throughout this report as “the August Report”).

The intent of the consultation process reported on in the August Report was to interview approximately 25 people with lived experience. For a variety of reasons this was not possible, and we interviewed only 16 people.

The insights gained from this group were exceptional, however we were concerned that there were some gaps. As well as seeking to talk to more people with lived experience of hospital in the home care - It was identified early that it would also be useful to obtain greater insights into the needs of particular priority care groups that can be hard to access. In particular, CALD, those experiencing mental health issues, those with disabilities and the LGBTQI community.

As a consequence, we ran a combination of lived experience interviews and further workshops to check in with this group about the Design Principles developed and provided in the July Report and make sure that they met their needs.

This report provides the individual reports for each group, identifies themes that emerged from these discussions and makes recommendations regarding changes to the Principles outlined the July Report that will enable the Principles to respond to the needs of these Priority Care Groups.

## Process

democracyCo ran different processes for the different groups as follows

1. Disability Workshop with 7 participants over 1 hour
2. Cystic Fibrosis Interviews x 2
3. Mental Health Workshop involving 2 participants
4. LGBTQIA+ community Workshop involving 10 participants
5. Culturally and Linguistically Diverse Participants over 1 hour

# Findings & Recommendations



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## Summary of Findings

### There was considerable enthusiasm across the Priority Care Group conversations for the My Home Hospital program.

All groups indicated, that if the condition they were experiencing allowed it, they would prefer to be treated at home than in a hospital.

In particular, they indicated that being treated at home would:

- Be more comfortable,
- Enable a greater degree of rest/ sleep
- Potentially save money
- Enable time with family
- Improve flexibility
- Enable people to have food that meets their personal requirements



“The proposed design principles sound very good.”  
Interviewee 2

In general terms the Principles developed through the initial consultation process and outlined in the August 2020 report were strongly supported by those involved in the Priority Care consultation processes.

However, the Priority Care Group conversations-

1. Provided a depth of understanding and hence detail about the meaning of some of the Principles as well as improving contextual understanding of some of the Principles
2. Refined the precise wording of some Principles
3. Added a new Principle which more explicitly focuses on the importance of Diversity

This section summarises the key findings from these conversations – focusing and honing the focus on issues such as -

1. Dignity and respect
2. Empathy, caring and understanding
3. Control
4. Cystic Fibrosis specific considerations
5. CALD specific considerations

In the following section we then translate these themes into changes to the Principles outlined in the August 2020 report.

## Dignity and Respect

A significant theme emerged around the importance of carers/ medical staff having respect for patients emerged through the Priority Care group conversations. The Disability PCG indicated that they want to know who is seeing them – if they don't know in advance this does mean that the worker needs to put effort in when they meet them at the door for the first time, and effort into getting to know them well during the first visit.

**“First impression – moment of first contact is very important. The attitude the person displays is really important. Warm, genuine, personable. Understand the case and tells you what is going to happen. I might be a bit stressed and apprehensive – so this will help to set my mind at ease.”**

Mental Health Priority Care Group Conversation

## Empathy, Caring and Understanding

A significant theme across the Priority Care Group conversations also emerged about the importance of carers/ clinical staff being clearly and obviously empathetic, caring individuals who are respectful of diversity. Those consulted wanted to feel like they were being listened to and that the carers/ medical staff were responsive to their needs, concerns, and view.

The Mental Health Priority Care Group highlighted that carers/ medical staff need to be trauma informed not just clinical experts. They need to understand the impact and implications of panic and anxiety and how this may impact on the behaviour of the patients they are caring for.

The LGBTQI Priority Care group raised the vital importance of clinical staff and carers understanding and respecting their personal circumstances. The group reported that they feel that there “is supreme ignorance of our needs and the history of our community” by the health profession in general terms. The group raised concerns about the fact that they may have to keep explaining themselves to different clinical staff and carers as they come into their homes.

**“When people come into your home, they are surprised that there are two men together / two women together – and their reaction is challenging for us.”**

LGBTQIA+ Priority Care Group

**“If someone is prejudiced – it's one of the most hurtful things”**

LGBTQIA+ Priority Care Group

The LGBTQIA+ Priority Care Group indicated that they felt the best solution to this was deep seated training in diversity needs to occur for all staff who have a role in the program and intentional recruitment is required of people who don't have homophobic tendencies.

We have picked up on the issues in our proposed changes to Principles 3 and 9 detailed in the following section.

## Control

A strong theme emerged across the Priority Care Groups but was articulated by the Disability Priority Care Group as the importance of control.

The Disability Priority Care Group highlighted that they (as patients) – want to be in control.



They strongly pointed out that it is their house, their needs and their illness and as a consequence, they don't want to be out of control of what is happening to them, especially when it is happening to them in their own home.

This sentiment was articulated by the LGBTQIA+ Priority Care Group as feeling devalued and disempowered.

**“My experience of my own body is being devalued.  
We are the experts (in our own bodies).”**

LGBTQIA+ Priority Care Group

We have picked up on this theme in the changes we have proposed to Principle 3 in the next section.

## Cystic Fibrosis – Specific

A specific issue identified by those we talked to with Cystic Fibrosis – was the heightened importance of highly trained medical staff. For those with cystic fibrosis it is necessary to not only have carers/ medical staff who understand the illness they are being treated for, but also the general medical issues they experience as a consequence of having cystic fibrosis.

The importance of continuity of care was highlighted as important to this condition. The nurses need to know what is happening with the daily management of the individual's condition.

**“Most importantly experienced nursing staff specifically trained in CF management is absolutely critical (managing IV lines / continuity of care)”**

Cystic Fibrosis Priority Care Group Interviews

**“Current service does a very, very good job!! The current provision of Cystic Fibrosis services in the home are excellent and uphold all of these principles.”**

**Interviewee 1**

We haven't proposed any changes to the Principles as a consequence of this feedback,

## CALD

The CALD workshop identified a range of considerations, but two stand out as very important.

The provision of translators – for people who had language barriers was one which needs considerable thought and attention. Participants described the pool of translators in SA as being very small – and for small multi-cultural communities, this is even more obvious. As a consequence, there was concern about using translators who might be known to patients. Another issue raised was the reliance on family members to support translations – some people expressed a concern that their family member might not have the appropriate level of health literacy to communicate between a doctor and a patient. Others said that family members might not share the whole picture with the patient –

as a way of protecting them from 'bad news'. An idea emerged in the workshop to use the services of interstate translators – especially for small multicultural communities in SA.

This group also discussed the issue of feedback – and many people commented on issues around feedback – which are in the workshop notes. A key thing here is to ensure that people can give feedback 'safely' and without the risk of impacts. Participants from some communities also said their history and background meant they were not confident, or adept at giving feedback to a government institution – and there may be retisense to do so. There is a need to consider this for CALD communities.

No changes have been proposed to the principles as a result of this feedback – these are important to consider in the next phase around designing the patient journey.

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## Recommendations for Changes to Principles

### Principle 3

There was extensive feedback from across the Priority Care Group discussions which directly proposed changes to Principle 3. In addition, there was extensive discussion across the groups which have led us to understand the concept behind this Principle differently and reword it accordingly.

Priority Care Groups proposed direct changes to Principle 3 in the following respects –

- It was proposed that Principle 3 – Patient centred, be amended to make it clear that the community/ patient should determine what the definition of 'dignity and respect' means to them.
- It was highlighted by the Mental Health Priority Care group that the concept and language associated with "patient" undermines the intent of this principle – that it is suggestive of 'doing to' rather than 'working with' – and being centred on the needs of the person being supported requires medical practitioners to 'do with' not to.

In line with this last dot point a strong theme emerged across the Priority Care Groups that clinical services can disempower the individual and this is particularly challenging / wrong in the context of a hospital in the home environment. This theme was summarised in the previous section.

To this end it is proposed that the Principle be reworded as follows:

*"Clinical staff and patients are partners in their care.*

*As "partners' patients must have an equal voice in their care, enabling them to help determine what care is provided and the way it is provided. As 'partners' - patients, their loved ones and carers must be treated with dignity and respect. It is the patient that defines what dignity and respect means to them.*

*All homes are different. Culture, religion, sexuality, disability and/or personal choices all affect how we live our lives and hence our homes. Hospital in the home services must be conscious of these differences, respectful and responsive to them."*

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## Principle 10

**Principle 10 states "Quality management systems and monitoring** – Continuous self-improvement systems must be foundational in the design of the My Home Hospital Program. The Program must continuously seek not only to identify faults and problems within its delivery but also seek to identify better and more efficient ways of delivering its patient services."

We received feedback through the Mental Health Priority Care Group that feedback from patients is needed as part of this process. As a consequence, we propose to re-word the Principle as follows

**"Quality management systems and monitoring** – Continuous self-improvement systems must be foundational in the design of the My Home Hospital Program. The Program must continuously seek not only to identify faults and problems within its delivery but also seek to identify better and more efficient ways of delivering its patient services. *Patient should be central to this process of continuous improvement.*"

## An additional Principle – Principle 11

As outlined in the previous section - it was identified that a greater focus on respect, understanding and responsiveness to diversity is needed in the principles.

Rather than adjusting / changing existing principles it was proposed that a new Principle be added which recognises that the needs of people are diverse and hence that practice needs to recognise these diverse needs.

The LGBTQIA+ Priority Care Group agreed on the following form of words –

*"Recognise diverse needs - The service needs to be provided in a way that recognises and demonstrates peoples' diverse needs."*

## Minor changes

**It was proposed that Principle 9 be amended by replacing EQ with a reference to caring and empathy.**

The changes recommended are as follows -

**"Adequately resourced -**

- *Medical staff should have the right clinical skills as well as being caring and empathetic*
- *The appropriate equipment, technology and 'hardware' should be provided for home care"*

# REVISED - Design principles

The Principles developed by the Participants in the Design Principles Workshop – with revisions from the Priority Care Group conversations are summarised here - .

- 1. Clear / Transparent Eligibility** - Apply a robust method for determining suitability which uses a combination of diagnostic condition, home environment and home location.
- 2. Enable patient choice.** Patients need to be able to opt-in and opt-out of the program seamlessly and at any time
- 3. Clinical staff and patients are partners in their care.** As “partners’ patients must have an equal voice in their care, enabling them to help determine what care is provided and the way it is provided. As ‘partners’ - patients, their loved ones and carers must be treated with dignity and respect. It is the patient that defines what dignity and respect means to them. All homes are different. Culture, religion, sexuality, disability and/or personal choices all affect how we live our lives and hence our homes. Hospital in the home services must be conscious of these differences, respectful and responsive to them.”
- 4. Be holistic.** Apply a common-sense flexible approach to service delivery which balances clinical needs with patient needs.
- 5. Quality care.** Pursue outcomes which are at least equivalent to those which are achieved in hospital. Great assessment up front will support the pursuit of great patient outcomes.
- 6. Coordinated team** - Be supported by a multi-disciplinary management system with a single point of coordination for the patient. Information and communication must be clear, complete and timely.
- 7. Accessible** - Be available to and inclusive of all South Australians who are eligible to access the program
- 8. Safe** - Be safe for everyone – for patients, their families, carers and clinical staff
- 9. Adequately resourced** -
  - Medical staff should have the right skills as well as being caring and empathetic
  - The appropriate equipment, technology and ‘hardware’ should be provided for home care
- 10. Quality management systems and monitoring** – Continuous self-improvement systems must be foundational in the design of the My Home Hospital Program. The Program must continuously seek not only to identify faults and problems within its delivery but also seek to identify better and more efficient ways of delivering its patient services. Patient should be central to this process of continuous improvement.
- 11. Recognise diverse needs** - The service needs to be provided in a way that recognises and demonstrates peoples’ diverse needs.

