ASTHMA AUSTRALIA

COMMUNITY RESPONSES TO ASTHMA IN THE MID NORTH

FINAL REPORT

JULY 2020

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Term of Project	Commencement Date:		01/09/2019
	End Date:		30/06/2020
Location of Project *e.g., towns or regions*	Mid North Region South Australia (Jamestown, Peterborough, Orroroo and surrounding area)		
Name of Project	Community responses to asthma in Mid North, South Australia		
Approval by:		**Approval date:**	

PART ONE
EXECUTIVE SUMMARY

This Project undertook co-planning and co-design with people with lived experience in the Mid North, of South Australia (Peterborough, Jamestown, Orroroo and surrounding areas). This area was identified through a readiness report as being highly disadvantaged and having high asthma prevalence of one in five[1] compared to the national average of one in nine, with hospitalisations 45 per cent higher than the national average[2].

This was a partnership project with the Australian Centre for Social Innovation (TACSI), who were engaged to provide their experience in co-design methodology and peer researcher training. This project was funded by the Country SA Primary Health Network (CSA PHN) and took place between September 2019 and June 2020.

Asthma Australia (AA) believes that people living with asthma and/or multiple chronic conditions, those close to them and the surrounding community networks are a largely untapped resource when it comes to the management of asthma and other chronic conditions. Asthma needs to be addressed as part of an holistic approach to improving the health outcomes of people with asthma and other chronic conditions that accounts for the social context and the determinants of people's lives. Therefore, 3 local people living with asthma - two women and one man - who had one or more chronic condition(s), were trained as 'peer researchers' to gather the in-depth local perspective of living with asthma. The interviews with 17 other people with asthma, uncovered how asthma was experienced and highlighted the social determinant issues for this community.

The aim

This Project aimed to understand and test how to reduce preventable, asthma-related hospital admissions by creating communities that support multiple chronic condition management and enable people living with these conditions to be partners in their care.

***1.Country SA Primary Health Network, 2018**, Mid-North 2018 Data Report*
***2. Public Health Information Development Unit (PHIDU) 2018,** Asthma Atlas of Australia, accessed online*
http://www.atlasesaustralia.com.au/asthma_aust/atlas.html

The project engaged over 100 people; including the steering group members, the peer researchers and their interviewees and other key local influencers such as the mayor. The majority of participants were based in Peterborough, with some people living in Jamestown and Orroroo and on neighbouring farms. Engagement strategies ranged from anonymous engagements via the newly established social media page, other online interactions like surveys, phone conversations, visits by the project team and social interactions.

The co-design process

Co-design is a method and a mindset that people are experts in their lives and should have the opportunity to play an active role in decisions that shape them. This approach means people with lived experience, other community members and professionals develop a mutual understanding of the real experience of people living with asthma, the opportunities for community responses to improve outcomes and test some of the identified concepts. This project was about discovery, and using the deep insights from people with asthma, creating concepts for potentially new, community-based services. TACSI were the facilitators of this process; however, it was directed by the community members themselves who were primary players in each stage of the process. (see figure 1)

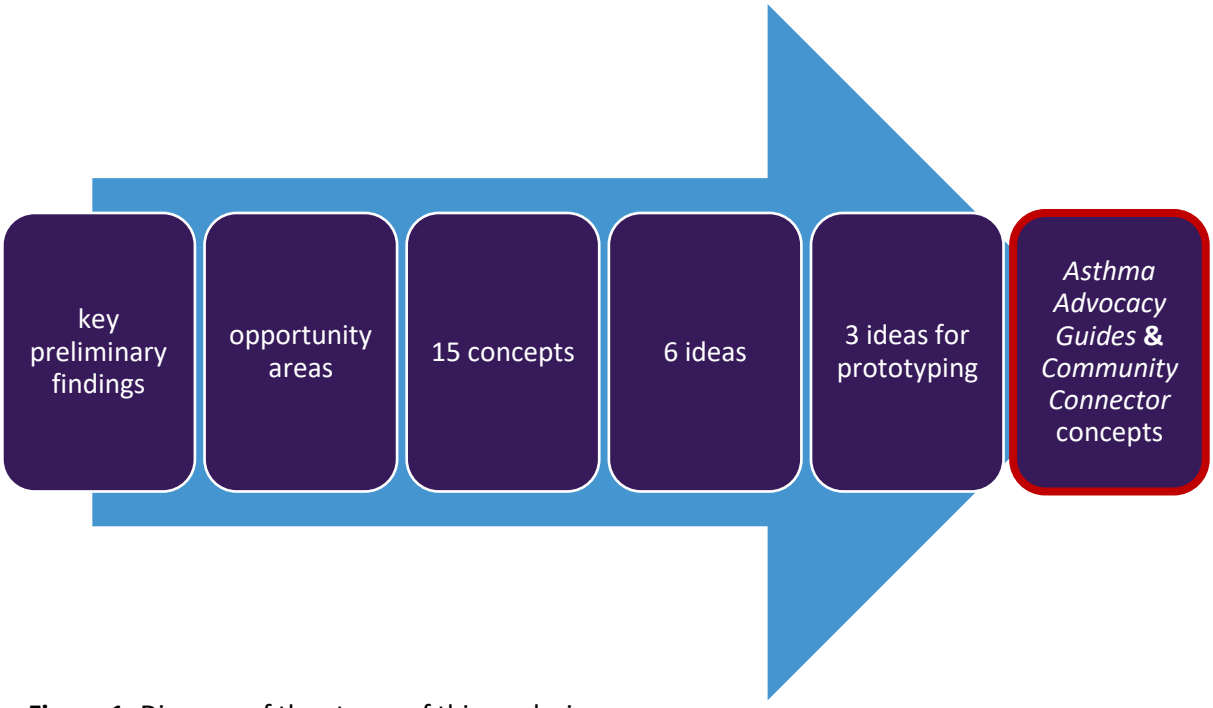

Figure 1: Diagram of the stages of this co-design process

Results

The two concepts selected for further exploration and development are *Asthma Advocacy Guides* and a *Community Connector.* Each stage to arrive at these has involved extensive co-design work with the diverse co-design team and then input from the steering group and a range of community members. The key findings based on interview analysis that are the foundation for these concepts are:

- People base their asthma management behaviour on three main sources of information: health care professionals, friends, families and their experience and what makes them feel better. This leads to sub-optimal care
- Stigma is an issue for people of all ages, preventing help seeking. However, peers with asthma can be a great support
- Many people say they are allergic to their occupation, hobbies or location; leading to people leaving the area or changing careers, controlling it as best as possible or accepting uncontrolled asthma
- People with multiple conditions often fail to distinguish between asthma and other conditions like anxiety
- Independence is important- again leading to limited help seeking, but in severe asthma they want to know there is someone to help

These led to the development of 15 concepts that can be grouped into 4 themes

- Correct and accessible information. This was more than just information provision but involved several ideas involving people with asthma providing support and advice trough a range of media.
- Good asthma management. This included developing an integrated model of care and related more to the health system and accessing service support.
- Community responsibility. This related to providing a 'go to' person in the community who understood the condition and also related to providing 'guides' for community members. Both the final concepts came from this area.
- Overcoming stigma. This is clearly, directed at upskilling the community generally through supports or advocates to provide assistance across the community. The concepts of an 'asthma friendly town' and a 'buddy system' were mentioned

Originally, it was planned that the concepts would be presented to the community in 'small events' and to workshop the ideas. When this became impossible, it was decided that the groups of people already involved with the project would prioritise the ideas.

The concepts developed were:

- Asthma advocacy guides
- Championing evidence-based care
- An asthma peer network
- A Community Connector
- Local asthma advertising
- Collaborative care

Similar processes were undertaken to identify the preferred concepts. The final 3 concepts included a model of collaborative care, which was favoured by health care professionals. However, in keeping to the philosophical underpinnings of the project, the top community concepts were chosen: *Asthma Advocacy Guides and A Community Connector*

Next steps

This phase of the project has ended but AA's commitment to the community has not. The enthusiasm of the community has been an unexpected outcome and should be harnessed. There is a responsibility on AA following the success of this project, and now that the trust has been built to ensure this community does not feel abandoned now that this project has ended.

One way is to continue to support the peer researchers to be active in the community. This presents a great opportunity to maintain the face of AA in the local community and so ways of continuing their involvement in order to remain upskilled in asthma knowledge, and interviewing, and to keep a connection with AA more broadly are being explored. The newly launched *Asthma Champions* program will be offered to them.

The relationship between AA and CSA PHN has also strengthened throughout this project. AA has also worked with another Local Health Cluster to deliver education to the community and health professionals and further opportunities are being discussed. Conversations are occurring to fund the next phase of the project; however, AA will continue to have a presence, even if digitally through the online Facebook group, and hopefully the peer researchers.

A travel underspend has enabled a series of community and health professional webinars to be delivered over the next 3 months to replace face-to-face training that wasn't delivered.

PART TWO
SHARING PROJECT OUTCOMES

AA is now in the process of sharing the story of the project with the wider community. Originally it had been hoped that a community event would be held, but the COVID restriction have necessitated digital strategies be employed.

These included:

- A joint media release from AA, CSA PHN and TACSI to be released late July
- Updated information on the AA website
- Articles in 3 local papers: *The Jamestown Newsletter, The Goyder's Line Gazette and The Peterborough Informer,* to be published within the next 2 weeks
- Social media posts on the platforms of all organisations and the newly established Mid North Facebook page for community members with asthma. This page will remain in place and be monitored and administered by an AA staff member, with regular updates and posts.

In addition, online education sessions will provide an opportunity to share information about the project and its outcomes and enable AA to remain connected with the community. These sessions became possible due to a redirection of underspent travel funds due to the COVID-19 restrictions.

The sessions will be available for both health professionals and community members and cover:

- Paediatric asthma management
- Allergies and asthma
- Asthma First Aid for health care professionals
- The use of asthma devices 1
- The use of asthma devices 2
- Asthma First Aid for the community
- Empowering people with asthma and their carers

Online spirometry updates have also been provided to all general practitioners across the 3 towns and 30 AA Asthma First Aid Courses have been made available to the peer researchers, participants in the interviews, the Facebook members and as prizes for the session participants.

PART THREE
PROJECT REFLECTIONS AND LEARNINGS

This project did not have a specific evaluation component; instead learnings and reflections were documented throughout. The CSA PHN was particularly interested in the impacts of the co-design process on the participants and also in the impact of the project on the wider community. Eight key questions were asked. Answers to these questions are presented below and are compiled from the analysis of all sources of information.

All project team members, peer researchers and the Steering Committee documented their thoughts or were involved with a conversation with one of the peer researchers. To gain the deepest understanding of the success of the project in the broader community, the team also distributed two community surveys via various channels.

Overview

The Community Responses to Asthma in the Mid North project was always brave and ambitious; especially in the 10 month timeframe. The concept was also previously untried by both AA and the CSA PHN, and there was no guaranteed expectation of success. However, as a new project, it was believed that all learnings would be beneficial to inform future work.

One of the first learnings from the project was the value of Readiness Report.
Including a readiness component to the project was the first step to increasing the possibility of success and engaging with the local community. This was a very short 'desktop' study that explored local health and social data, and included phone conversations with identified key local stakeholders. This proved to be very valuable. The initial contact with stakeholders was appreciated by the community and facilitated buy in from key people when forming the Steering Committee.

A report of this nature should be a key piece of work in any future project. In the case of a larger community and or one where there may be limited engagement, more time and funds need to be allocated to do this community exploration more thoroughly; including consultation with key stakeholders. For instance, in this project, general practitioners were a primary stakeholder and fundamental to the project going forward, and from the beginning the key practice was supportive.

However, time constraints were always an issue and over time other general practice issues were identified. It would have been very worthwhile at the beginning of the project to explore these and gain a deeper understanding of the 'practice journey' in relation to asthma care; in order to explore what potential solutions could be offered by the project. It is the intention of the project team (and funds requested), if Phase 2 continues, to work with the practices to undertake this work.

To what extent do the response concepts reflect the identified needs of people living with asthma in the region?

When the co-design stages are studied closely, it is clear to see the progression from themes from the interviews to the concepts chosen. It is the depth of the interview responses and the ongoing involvement of people with lived experience that has ensured this.

The Steering Committee members felt strongly that he two final concepts reflected the needs of the community and they also believed there was high interest in implementing the concepts. These sentiments were reiterated by all who were directly involved in the project. Survey responses from the community, although low to date have also been positive. This is encouraging because currently there is very little information on exactly what the two concepts will look like or how they will be implemented.

Peer researchers

Feedback from the Peer Researchers on the process and experience - what went well, what needs to be improved?

Consulting with consumers is NOT new for AA: using peer researchers is. This brought a unique depth to the information. There are also additional benefits for both the interviewer and the interviewee, which were demonstrated in this project, and are a bonus value-add. For peers this included: connecting with others, feeling part of 'a solution', learning about their condition; especially the link and difference to anxiety, and becoming advocates; although this wasn't a requirement of the position. For interviewees: learning about asthma, sharing for perhaps the first time and feeling validated.

In this role, the researchers became a resource within the community and helped people in relation to the stigma they were feeling. The success of this aspect of the role hints at the potential success of the identified concepts of a Community Connector – a person to link people with asthma to health providers, and Advocacy Guides to provide people with accurate information.

It was difficult initially to recruit to the positions, perhaps due to a reasonable suspicion about our motives and commitment as external providers. AA and TACSI staff made considerable effort to engage with health providers, other stakeholders like council members and school staff as well as community members to demonstrate to the community as a whole our commitment to the area. The success of this strategy has been born-out by the willingness of the community in the later stages to learn about and contribute to the project.

Overall, the response from the peer researchers is positive with few negatives associated with the role. They found it useful that they knew of each other already and discovering that they all had asthma in common was an excellent way to establish themselves as a team. The onboarding process was intensive due to the limits on time when facilitators had to travel larger distances. It was suggested that this could be a limiting factor to future involvement in other areas. Clear communication was also a challenge across different platforms (phone, zoom, face to face, email) leading to some uncertainty about the project timeline and progress. Suggested improvements for the future: make onboarding less ambitious, focusing on 'just-in-time' information and coaching throughout the project; improve communication by having a fortnightly call (or other preferred medium) to check in regardless of project progress.

The co-design process

The what extent has the co-design process increased leadership amongst the peer researchers and resilience in the target community?

Peer researchers are now seen within the community and by themselves as advocates and this is a direct result of their training in co-design and peer interviewing. The form of interviewing, in addition to seeking deep responses, encourages trust building with the participants and this has been demonstrated by the quality and nature of the information gathered. Often people opened-up about their asthma for the first time, never even having shared with family.

The extent to which the process was empowering for both researchers and interviewees was a surprise; however, it has proven to be a valuable part of the community engagement process. The peer researchers have now become the local face for AA and are a valuable resource, which needs to be nurtured.

AA needs to ensure that they remain upskilled in asthma knowledge and co-design techniques. It is important for AA to retain the knowledge and skills developed in this group of locals with lived experience of asthma. An ongoing connection with this group of peer researchers, would also enable AA to draw on their expertise in supporting a new community; with these peer researchers mentoring local recruits. How to best continue to maintain a connection with them is being explored, with the newly launched *Asthma Champions* program providing an opportunity. The issue of remuneration needs to be considered, but due to some underspend of travel funds, there has been an ability to continue to pay them for the next few months for their involvement in the Mid North Facebook group.

AA has also built capacity in working with peer researchers; whilst nascent skills only, with the current skillset within the AA local team in consultation and consumer engagement, in future projects, AA could work with the peer researchers with limited support from TACSI, such as in the role of critical friend.

Has the co-design approach resulted in concepts that the community is interested and equipped to take forward and are supported by key stakeholders?

The philosophical underpinnings of co-design and the processes used have been the main reason this project has been so successful. Co-design brings an authenticity to the involvement of people with lived experience, without requiring huge time commitment and this enabled people to share a depth of knowledge of their experiences that was new for me. This depth of experience was fundamental to the relevance of the concepts that were built. These are fully supported by the Steering Committee members, who are all influencers within the community and will play a role in taking the work further. Most importantly, they also feel the community is interested and with the right support able to progress them.

"The committee and community has worked extremely hard to verify and determine this outcome".

Steering Committee member

> *"Any advice, either by newspapers, on-line or in person, is very valuable to asthmatics. The more publicity that is given to asthma, the more people become familiar with the help available. A person to work as a connection between community members and the health care professionals would be extremely valuable as many people may relate to a helper first before accepting medical help".*
>
> Steering Committee member

What if any are the barriers and enablers to the implementation of the co-design process?

A barrier to overall implementation was always the fundamental issue of communities believing city organisations were coming in, taking what they want and then leaving and showing no further interest. AA was not previously known to the community, so this was an understandable belief. However, over time that the engagement of the community has strengthened and is very genuine. The co-design process itself became an enabler, because of the philosophical approach taken to this project. The process showed very clearly, our belief that people in the Mid North are the experts and that this was all about them.

Circumstances also conspired against us: firstly, with the bushfires and then with the COVID-19 restrictions. Surprisingly, these had fewer impacts than was expected, and unforeseen benefits. The bushfire season created a need to cancel a planned visit to the area due to extreme heat. The fact, that as outsiders we had considered the needs of the local community and sought advice to make this decision, was seen very favourably by the local community and, strengthened their trust in the team and the project.

Thanks to the skills and commitment of the peer researchers and their technological skills the impacts of COVID were reduced because they were still able to be active in the community on behalf of the project. This was another example of the value of having local people as a significant part of the team.

Collaboration

Were stronger collaborative partnerships between people with lived experience, local health professionals and other service providers generated and what did this looks like?

Collaboration is a process. In this project, it seems to have strengthened over time between all stakeholders to varying degrees, as trust and understanding and has developed, and people have grown to know each other.

There are very strong connections, and collaboration has been highly successful between the steering committee members, the project team and the peer researchers, which has been a significant positive outcome for the project. The peer researchers have been key to connect people in the wider community to others with asthma and to health care services. They have enabled people with asthma to become more visible in the community by openly discussing their condition and encouraging them to seek support. This is a significant achievement.

It is also encouraging to see that early community survey results about awareness of the project, show 75% of respondents had heard of the project. Changes due to the project were identified as more asthma awareness in the region and also more involvement of locals in the project. They also identified that more visible information is needed in their community, which again points to future support for the chosen concepts.

AA hopes to continue to facilitate this connection to care through its continuing engagement with the community and promotion of its services. The Facebook page presents a range of opportunities in addition to posting information that need to be explored; such as asking local respiratory experts to 'talk' with the group; or an Asthma Educators doing a Q & A session. The series of online workshops for community which are about self-management and how to get the best out of your relationship with your healthcare professional will also support this connection.

"The group and peer support people are now established. It would be a negligent shame to let the impetus go "

Steering Committee member

How did the project partners collaborate (AA and TACSI) were any lessons learnt?

AA already had a relationship with TACSI and this has been strengthened considerably in this project; trust deepened significantly as the personal developed alongside the professional. AA's content knowledge, project management and community development skills also complemented TACSI's expert co-design knowledge which produced an effective team. This helped to develop pathways of communication and led to effective outcomes. For example, an email communication group was established consisting of Country SA PHN, AA and TACSI communications experts. This translated into effective delivery of project outcomes with wider impact and spread of information.

The AA projects team is also undertaking training in co-design with TACSI. Experiencing the process first- hand in this project has been very helpful in fast-tracking our skill development.

Have there been any unexpected outcomes (positive or negative) brought about due to the process/initiative?

The extent to which the local community have become aware of the project was a surprise; especially after the initial difficulties. Through a recent community survey; despite low respondent numbers, there appears to be a relatively high self-reported knowledge of asthma and confidence to administer first aid with the correct information. This is encouraging and points to community willingness to be involved in the next phase of the project and the online AA educational sessions scheduled in the next 3 months.

It was also pleasing that information about the project reached other local health clusters in regional areas of SA. The Upper Eyre Local Health Cluster have shown an interest replicating this initiative in their region. Conversations continue, but AA has already delivered education in this region, which has begun critical engagement with local influencers.

Strategic collaboration

Another unexpected development was the bringing together of strategic leaders from the CSA PHN, Country and Outback Health, Yorke and Northern LHN and AA. This strategic partnership happened quite serendipitously. The need for a similar project was identified in a Country and Outback Health region, and so informal conversations took place, culminating in a recent meeting of all players.

There is a definite commitment from each agency to work together to explore how to leverage and scale this work; although how this process will unfold is still under discussion. This has been one of the most valuable outcomes from this project, because it is focusing on sustainability.

PART FOUR

CONCLUSION AND NEXT STEPS

The overwhelming success of this project, its learnings and the community engagement were unexpected. The initial readiness report indicated it would be hard to gain trust and engagement from community members. This appeared to be born-out when initial recruiting of people with asthma was difficult; however, the team travelled to the towns to 'get to know people' and we continued this spirit of curiosity and willingness to learn, which was appreciated by locals.

It was opportune, that we had gained traction and built strong relationships prior to the COVID restrictions on travel, because the project did not really lose momentum during this time.
This has been a new type of project for both the PHN and AA and there have been significant insights which will translate to other projects in the future.

In summary, major learnings were:

- Resource the readiness phase: the more unknown the community and larger the area, the more resourcing needed
- Recruiting peer researchers takes time – allow more than you think
- Nurture your peer researchers. They are your ongoing connection to the community – and your representative to them. They are GOLD!
- Spend time getting buy in from disengaged stakeholders, even if it doesn't seem to be a problem.
- Authentically involving people in making decisions about their own care is powerful for them and produces well-developed, relevant and appropriate ideas

In relation to the data

- Stigma is significant issue in relation to asthma that seriously impacts on their lives and engagement with the community
- The extent to which the environment creates problems – people are 'allergic to their jobs', and yet how people battle through on their own

These are powerful learnings and have added considerable depth to the statistics that we already have about the need in the community. The depth and value this information has provided has led to the consideration of a similar co-design process with general practitioners to explore the deeper issues that underpin the difficulties in engaging with the project. This will also help us better understand the issues that people with asthma experience from their perspective. This would be a valuable insight for any project going forward.

Next steps

AA is seeking funding for the next stage of this project, which will see community members leading small trial projects of the two concepts. However, regardless of the outcome of those discussions, AA is committed to working in this area and to continuing to support the peer researchers and people with asthma. A strong partnership has been built with the CSA PHN and this will continue. As will the work with Country and Outback Health and Yorke and Northern LHN.