

---

# **Asthma Innovative Management (AIM) Project**

## **Final Report**

### **Development of a Collaborative Asthma Management Model for Older People Living in the Community**

**RDNS Research Unit**  
**Royal District Nursing Service of SA Inc.**  
31 Flemington Street (PO Box 247)  
Glenside, South Australia, 5065  
Ph: (08) 8206 0111



*Authors: Professor Tina Koch, Director RDNS Research Unit*  
*Peter Jenkin, Research Associate*  
*Dr Debbie Kralik, Senior Research Fellow*

11 June 2003

---

## **CHIEF INVESTIGATOR AND RDNS RESEARCH TEAM**

---

Professor Tina Koch  
Director, RDNS Research Unit  
31 Flemington Street (PO Box 247)  
Glenside SA 5065  
Phone: (08) 8206 0007  
Fax: (08) 8206 0010  
E mail: koch.tina@rdns.sa.gov.au

Mr Peter Jenkin:	Research Associate and Project Manager
Dr Debbie Kralik:	Senior Research Fellow
Ms Kate Visentin:	Research Associate
Ms Natalie Howard:	Research Coordinator

This report was authored by: Professor Tina Koch  
Mr Peter Jenkin  
Dr Debbie Kralik

Edited by: Ms Natalie Howard  
Ms Lois Dennes

## **COLLABORATING ORGANISATIONS**

---

This was a collaborative project between Adelaide's older residents who have asthma, the Research Unit at the Royal District Nursing Service (SA Inc), RDNS Education Centre, Asthma SA and the Centre for Quality Use of Medicines and Pharmacy Research Centre. Representatives from these organisations were on the Project Management Team (PMT)

Ms Julie Black:	RDNS Education Centre
Mr Nigel Cooper:	Asthma SA
Mr Geoff March:	Centre for Quality Use of Medicines and Pharmacy Research Centre

## **ACKNOWLEDGEMENTS**

---

Sincere gratitude is extended to the men and women who participated in this project for their co-operation, collaboration and for sharing their stories.

## Project summary

This project responded to the high prevalence of older community clients living with asthma. The principle aim for this project was to develop, in collaboration with older people, a client led model of asthma management which acknowledged the context of an individuals' life. The secondary aim was that the groups sustain the model after the researchers have left 'the field' and that it was transferable eg. it is taken on board by Asthma SA for further dissemination. The objectives were:

1. To understand from the perspective of older men and women living with asthma how the illness has impacted on their lives;
2. To identify the contexts, barriers and issues that are significant for older people living with asthma;
3. In collaboration with the participants, design, implement and evaluate an asthma self management model;
4. To develop a sustainable and replicable model which facilitates self-management for older people living with asthma.

Recruitment of older people over the age of 60 was sought. Criteria for selection was based on those people who had been medically diagnosed with asthma and were taking, or had been prescribed, preventative medications to use on a daily basis. Recruitment proved difficult, people living with asthma did not place this condition high on their list of ailments requiring focussed attention. Multiple recruitment strategies were tried and are reported. Data were generated from three sources:

1. In-depth interviews with 24 participants
2. Two participatory action mixed gender research groups
3. Open ended questionnaire exploring what is asthma and what is self management

Twenty four older people were interviewed at home and of those, 18 joined Participatory Action Research (PAR) groups. The average age of participants was 76 years; the youngest person was 60 years and the oldest 92 years old. Eight men and sixteen women with asthma participated in this project. Seventeen had severe asthma, three had moderate asthma, three had mild asthma and one person was asymptomatic. Analysis was concurrent to ensure a feedback loop to participants, thus creating the opportunity to build our (participants and facilitators) understandings collaboratively.

In collaboration with participants, we explored self management strategies and identified the constraints to self management. In addition, we have articulated a participatory action process that underpins an asthma self management program.

It is with intent that this report has been written in language accessible to the participants. While pseudonyms have been used and quotes have been provided extensively throughout the text, there is no doubt participants will recognise their own voices. Evidence has been harnessed into common themes; what is asthma? and what is self management? We have sustained an argument that management and 'self' management are distinctly different entities. In the final analysis, this report will be validated by the participants who are the central characters presenting what is self management for an older person living with asthma.

## Findings

It was revealed in this project that the majority of participants used a combination of biomedical and experiential terms to describe asthma. Some participants merged their biomedical understanding of asthma with the impact this condition had on their lives. Other participants ignored biomedical language and focused entirely on the impact of the condition and the way this chronic illness may be incorporated into one's life.

The epitome of management of asthma appeared to be taking medications. Closely tied to taking medications, was following orders from the medical officer. The most important point raised here was that the use of medication was something that was always done. Mostly people take responsibility for management of their medications. In addition to taking medications, prevention of asthma attacks was linked to identification and avoidance of triggers. Included in their accounts were actions that could or have been taken. Preventive strategies were suggested such as sucking a lozenge when a cough or wheeze was first experienced. It was recognised that asthma fluctuates as life and the illness presented new challenges.

Attendance at Asthma Clinics had been valuable as people were most likely to experience being a client in a collaborative model of care. Some GPs were committed to partner their client toward medical management. Operating alongside collaborative models were traditional models where the physician and other health professionals were regarded as experts. However, people with a chronic condition are often expert in their own circumstances and clearly demonstrated that they were in control and made decisions about when to visit the doctor. Those participants with asthma since childhood were experts in their own self management although not always acknowledged as such. It was acknowledged that medical education is vital, but there are other perspectives. What can be done to support management of the self?

The barriers to optimal management for older people who are diagnosed with asthma are related to its recent onset and co morbidity. It is relevant to note that 50% of the older participants (n=24) were diagnosed with asthma within the last one to seven years. In addition to learning to live with asthma, some participants had other co morbidities, in the main diabetes, hypertension, cardiac problems and arthritis, requiring their attention in terms of management. It became quite clear that when other chronic conditions prevailed in the person's life, asthma took backstage. On the whole, living with asthma was placed in the background when not symptomatic, thus confirming our suspicion of the somewhat insignificant role asthma plays in older people's lives. Whilst all participants reported that they utilised the services of a general practitioner (GP), only six people attended an Asthma Clinic held in their GP practice and only four people were members of Asthma SA. Only two people were on the Three Plus program. Four people attended the local hospital for lung tests or visited the outpatient clinics in the acute hospital sector. Navigating one's way around the health care system may be daunting for older people, but those that had found a 'good' GP or even better, an Asthma Clinic, expressed that it was luck not good management. Those people who attended Asthma Clinics appeared better informed about asthma. Only two participants had a formal asthma management plan. Although asthma management plans are often highly acclaimed by health care professionals, people who are self managing, particularly those who have had asthma since childhood, claimed they do not need this resource. They were the experts in their management of 'self', although health care professionals who claimed authority over

expertise did not often acknowledge this. Incorrect and ineffective use of puffers and equipment such as spacers and nebulisers was not uncommon amongst this group of older people living with asthma.

The major constraint to self management was its narrow conception as solely medical management. Much of the literature assumes that self-management means the same to all people, both professionals and those living with a chronic condition. Those participants with asthma since childhood were experts in their own self management although not always acknowledged as such. They were conversant with medical asthma management in the first instance and managed the 'self' in the context of their lives in the second. They were expert about their own lives. Here the term 'self management' makes reference to the activities these people have undertaken to create order, discipline and control in their lives. However, the role of the 'self' is excluded in this dialogue in current self management literatures. Instead, the focus is on medication compliance, or alternative or 'softer' terms such as adherence and concordance are used. Notions of the *patient's* self agency are dismissed. In traditional care models, the person is objectified as 'the patient'. How can health care professionals provide support when people are learning to undertake self management activities? Is this aspect of learning self management not as important as medical education? It is our argument that both aspects, medical management and management of the self, are given scope and platform, and offered concurrently.

In this report we articulate several models through which medical care and self management ideas could be delivered: traditional 'medical' care model, a collaborative care model and a self determinacy model and argue for the latter as the best outcome for the person living with a chronic illness. It is argued that our health care delivery and education programs should have as their central aim, health care professionals working toward assisting self agency of older people with asthma. Or when people with asthma are self determining, we should acknowledge that they are the expert in their own lives and their own management. We need programs or processes where both medical concerns and management of self skills can be learned or harnessed.

We show the way in which a *participatory action process* can enhance both medical and self management of a chronic condition. Participatory action principles provide the framework for intervention. We have articulated components of the participatory action model: setting, education, facilitation, story telling, sharing, action and sustainability. We have shown what happens when we work *with* people who live with a chronic condition. The actual process of working *with* people is the model and the intervention for advancing asthma self management. We advocate that a participatory action process provides a transferable model that health care professionals can use to facilitate self management of their clients living with asthma (or any other chronic condition). The two PAR groups will reconvene on 25 June 2003. Participants will be given this report and the findings will be discussed. Already many of the participants have indicated that they wish to continue meeting with each other. Asthma SA has agreed to facilitate further group sessions once the researchers have left the 'field'.