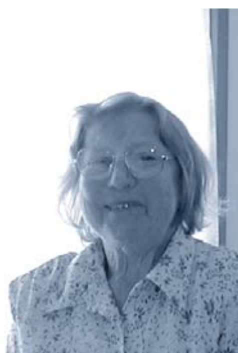
The Successes of Take the Pressure Down

Summary of project findings for the
Hypertension Integrated Disease Management Program
Banyule Nillumbik Primary Care Alliance

BNPCA
Promoting Better Access to Health Services



Lois Menteith
Consumer Reference Group Member

Dare to Dream

Many of us dare to dream, to embark on a journey to fulfil our ambitions. From my earliest childhood I had a dream to become a screenwriter and later in my life to travel to the U S and Britain to work in the exciting film world. Thus, my journey began, at five years of age. Today at 74 it continues.

I grew up in a conservative Western Australian family, beset by ambitions, dreams, secrets. The 1939 War changed my life; it destroyed my childhood and my family. On my 17th birthday, I began work in the writing world. As with all journeys, obstacles beset me. At 24, I married, bore three sickly children, two later died. I kept secret the violence and terror of a drunken husband. For 29 years he broke my life and the family. At 50, I escaped. Alone, I set out to work; to complete an Honours University Degree and joyfully, to return to writing.

Suddenly, one night in 1999, a stroke changed my life. It screwed my face; I was disabled. Rheumatoid arthritis followed, and further strokes. I almost lost my voice. The path to recovery… another journey… was hard, impossible. I lost hope, separated from everything and everyone. I was lost. I knew I had to change to get back on the path, or die.

In August 2001, I read a local advertisement inviting interested people with hypertension to become part of a Consumer Reference Group which was to work with an exciting Project in Banyule Nillumbik, researching hypertension in the community. Scared, but determined, I applied and was accepted. It changed my life. What followed with the Group and Project, took me onto a new journey, and another ‘Dream’. It restored my hope and my decision to help others.

The Coordinators were wonderful. Marie and Jane invited me to take the self-management course. I learnt much, above all, that I was part of a community. If I tried, I could recover, following this. Marie and Jane invited me to venture into the Leaders’ Training Course, to become a Peer Leader and working with a Health Professional, to lead our own self management group. This was so hard, but it changed my life. Marie asked me to undertake presentations to health groups and organisations, with her, to put forward everything that the Project transpired. I did so, scared, but determined. We succeeded.

Thus I began a new journey that included others, not just me. I followed a new path that the project was already inspiring. I felt committed to ideas and goals. For all of us in the project, the Consumer Reference Group, we dared to dream, on a journey, exciting, innovative and wonderful. Dared to hope and dare to succeed. When all seems lost and the journey too hard I live it, be it; We only have to dare!!!!

This document is a summary of key learnings and recommendations of the BNPCA Hypertension Integrated Disease Management Program. The final program documentation and evaluation report will be available on the BNPCA website in February 2004. www.bnpca.org.au

Kate Lorig R.N Dr P.H
Director of the Stanford Patient Education Research Center

How exciting to see that self-management has made its way across the Pacific and is helping people in Australia to gain more control of their health and their lives. Just as important, you have taught us ways to better disseminate this program. Learning goes two ways. This is exactly what we had hoped would happen. Congratulations on a great project.

The successes of this project are a result of hard work and commitment from both health professionals and consumers in Banyule and Nillumbik. The *Take the Pressure Down* team would like to acknowledge their inspirational contributions

Marie Gill, Jane Willcox
Project Coordinators

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"Take the Pressure Down" A Thumbnail Sketch

Blood Pressure Causing Tension For Many!!!

We know.........

- More than 1 in every 4 Australians over the age of 25 years of age has hypertension (high blood pressure).[1] Half are untreated or undiagnosed.
- Hypertension is a major risk factor for coronary artery disease, stroke, heart failure and peripheral vascular disease. Hypertension increases overall cardiovascular risk two to three fold.
- The risk of disease increases as the level of blood pressure increases.
- Consumers told us that high blood pressure was important to them and there was a lack of available community programs, education and resources to meet their needs[2]. Consumers felt health professionals did not place importance on blood pressure and reported dismay that they often had to ask to have their blood pressure checked.

The *Take the Pressure Down* project sought to pilot a program to redress some of these gaps.

An Integrated Disease Management Project

The Banyule Nillumbik Primary Care Alliance (BNPCA) *Take the Pressure Down* project was a 3 year pilot project, funded in 2001, under the Department of Human Services (Victoria) Integrated Disease Management Initiative. It was seen as an important part of the Primary Care Partnership Strategy.

Aiming to Improve Quality of Life for Those With High Blood Pressure

The *Take the Pressure Down* project aimed to improve health outcomes and quality of life for consumers with, or at risk of hypertension, in the Banyule & Nillumbik Local Government Areas.

Spanning the Care Continuum

Key components for successful integrated disease management, identified from the evidence, indicated the need to include the over-arching strategies of:

The commitment and enthusiasm of all associated with this project, in particular the opportunity to work with the consumer reference group, has made chairing the steering committee an exciting opportunity for me.

Maggie Scott Manager Royal District Nursing Service

Noeleen Tunny Manager Policy Implementation Heart Foundation Victorian Division

This project has given the National Heart Foundation of Australia the opportunity to promote best practice in the management of high blood pressure within the Banyule and Nillumbik Communities. The added bonus for the Foundation is the valuable input the project's Consumer Reference Group has given to the development of our educational literature for people with high blood pressure.

- consumer engagement and participation
- sustainable partnerships
- service provider engagement including General Practitioners
- planned and coordinated evaluation

These four over-arching strategies facilitated the following key strategic projects that spanned the care continuum:

- consumer self management with peer and health professional lead self management programs
- coordinated and planned care based on evidence of "best practice" and care pathways
- primary prevention through physical activity
- awareness and detection of hypertension.

Evaluation

Evaluation of the project encompassed 2 streams of evaluation:

- *External evaluation*: Conducted by the Australian Institute for Primary Care: Latrobe University and involved the 4 Integrated Disease Management Projects across the state.
- *Internal evaluation*: Conducted by Kim Hider and Dr Ros Hurworth from the Centre for Program Evaluation: The University of Melbourne and looked at the processes, models, impact and outcomes of the project.

1 Dunstan D et al. (2001) Diabetes & Associated Disorders in Australia, The Accelerating Epidemic. International Diabetes Institute, Melbourne.

2 Market Access (2002) Take the Pressure Down: Report of Consumer Consultation www.bnpca.org.au

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Consumers: Key Players in the Project

The *Take the Pressure Down* strategy was underpinned by consumer orientation as a key guiding principle and aimed to place consumers at the centre of primary care delivery.

"We Have a Voice…": The Consumer Reference Group

The establishment of a consumer reference group (CRG), as a central part of the project management structure, ensured consumers drove the development, implementation and evaluation of the project. The CRG was established at the start of the project and consisted of people with, or caring for someone with, high blood pressure.

The group strongly influenced all aspects of the project including program planning, consumer representation on committees, peer led intervention, resource development, evaluation and results dissemination.

"We Made a Difference….."

Evaluation of the perceived impact of the CRG found:

- CRG members felt valued and important to the project and that they had "influenced the project a great deal".

> ***"The Consumer Reference Group …. gives a voice to consumers and is a force for change".***
> **Peg Smyth CRG member**

- The forming of the CRG has provided individual benefits to members including social, connecting with community and health.

> ***"I feel I have a place in the community"***
> **CRG member**

- The project co-coordinators reported that the CRG had contributed more than (they) could have ever hoped.

> ***"Consumer input provided a framework to work within and often resulted in the project taking a direction that could not have been anticipated or identified without access to consumer views."***

- The non-consumer steering committee members described the CRG as being "excellent" and "innovative" as well as giving "legitimacy to the project" and providing "good publicity".

"High Blood Pressure Has Changed My Life": Qualitative Research Of Community Needs

A component of the extensive community consultation and needs assessment phase included a qualitative research study. The two-phase qualitative research program employed interview and focus group methodology and was conducted by Michael Murphy from Market Access (see www.bnpca.org.au for full report).

Consumer Reference Group (CRG)

To Find The Answer Go To The Source

The results of the focus groups, along with the input from the CRG, provided valuable information on:

- how consumers perceived high blood pressure and it's effect on their lives
- how to target programs and the language to use in information and promotional material
- the structure and delivery of the project and consumer programs

Recognition

The project was a finalist in the Consumer & Community Participation section of the Primary and Community Health Network Awards for Innovation and Excellence in Primary Health Care. Members of the CRG were also invited to present at the PCP Statewide Forum in February 2003 and a number of other state forums.

Ian Brown Chair CRG

It made a very pleasant change to be asked as a consumer what I needed to control my blood pressure problems and not to be told what I needed to do by health professionals. Being part of the Consumer Reference Group was most rewarding and I really felt I was contributing towards informing the community of how important good blood pressure control is.

Self Management for Consumers

Better Health Self Management

The Better Health Self Management (BHSM) Program (Stanford University) was part of the active intervention for consumers. Consumers indicated they wanted a self management style program with hypertension information that was sustainable beyond the length of the project.

The BHSM programs were chosen because of their applicability to all chronic diseases and prior evaluation which demonstrated:

- improved health and reduced health care use
- reduced health care costs
- increased consumer self efficacy[3]

The BHSM Program

The BHSM program focuses on supporting participants to develop strategies to deal with the common problems that most people with a chronic disease face.

Strategies such as goal setting, action planning, problem-solving and communication are key components of the program and applicable to all chronic diseases.

Participants have the opportunity to explore and learn from others in the group.

Program discussion topic include:

- relaxation techniques
- changing their diets
- managing sleep and fatigue
- using medications correctly
- physical activity
- communication with health providers
- pain management (if applicable)

Strengthening Social Capital

This consumer centric model included peer leadership allowing consumers to learn from one another and strengthen social capital.

Building Capacity And Providing A Framework For Health Professionals And Consumers To Change Their Role

Seven peer leaders and 33 health professionals from 8 agencies completed 4 days of training on self management and hypertension.

Building Resources

The consumer reference group (CRG) directed and assisted in the construction of hypertension resources to supplement peak body resources. The blood pressure record card developed and distributed through the BHSM programs was seen by consumers as a valuable self management tool.

"The BP cards have been a huge hit" … **Program leader**

Program Coordination

Consumers and health professionals told us that the biggest obstacle in getting to, or referring to, a program is knowing who to contact.

The project supported the implementation and coordination of programs across health agencies with a single point of contact into the programs.

John Dollimore Peer Leader

Taking control is daunting. The reality is as a result of attending a course I am doing things now that I thought I couldn't do. Being a peer leader for me means I can give something back. The rewards from the course are so great , if participants only got 10% of what I got out of it they will have gained a lot.

This allowed leaders to coordinate their programs and provide choice for consumers to attend programs at a range of venues, times and days.

Direct Targeting Of Consumers

Over 80% of contacts to the program resulted from the direct targeting of consumers. This allowed consumers who were not usually engaged with health services access to the program.

Successful direct targeting of consumers was made through media techniques such as letter box dropping and local newspaper advertisements.

Supporting Service Coordination

Consumer consent and privacy, receipt of referral and appropriate feedback mechanisms are all aspects of primary care reform local agencies have to address. The project was able to support agencies involved in providing self management programs by developing protocols and proformas for the program to support these aspects of the reform.

Focusing On Groups At Risk

On analysis of the consumers attending the programs it was identified that 2 groups, the rural dwellers and men over the age of 65 years, required further targeting. Programs to meet the needs of these groups have been developed.

Transferring To The Community

In June 2003 the coordination role of the BHSM programs was taken on by Eltham Community Health Centre (ECHC). Programs were expanded to include all chronic health problems which was a strategy organisations identified for keeping the program sustainable.

3 Lorig K et al. (2001) Effect of Self-Management Programs on Patients with Chronic Disease. Eff Clin Pract. 2001;4:256-262.

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Positive Outcomes for Consumers

Lifestyle Changes Maintained At 6 Months

- 91% of consumers stated they were continuing to do at least one thing differently, as a result of attending a hypertension self management program.
- Key lifestyle changes that were being maintained at 6 months were increases in exercise and activity, dietary changes and increases in stress management and relaxation techniques.

Increased Confidence To Manage Hypertension

- 91% of consumers felt their knowledge about blood pressure had changed as a result of the hypertension self management program.
- 89% of consumers felt their ability to manage their own blood pressure had improved as a result of attending a hypertension self management program.

Quality of Life Improved

- The general health survey (SF12) showed statistically significant improvements in the mental component summary, pain management, vitality and social functioning scales for consumers, 6 months after completing a hypertension self management program.

Satisfaction With Program High

- All consumers were satisfied with the information provided to them during the programs and the interaction of the program leaders.
- 98% of consumers were either very satisfied or satisfied with the effects the program had on their health six months after completing a hypertension focused self management program.

Program Reach

- 21 hypertension focused self management programs ran between February 2002 – May 2003 with 181 consumers completing.
- 7 general chronic disease self management programs ran between July – November 2003 with 57 consumers completing.
- 33 health professionals from 8 community agencies, and 7 consumers trained as self management leaders.

Consumer Representation

- A larger proportion of males participated in the hypertension focused self management programs than anticipated. Overall 67% were female and 33% male.
- 60% of consumers who participated in the programs were between 45-64 years of age. 35% of participants were over 65 years of the age suggesting this group were under-represented compared to population numbers
- The cultural mix of participants, represented by country of birth, was consistent with the catchment, as was the Aboriginal and Torres Strait Islander representation.
- People living in low socio economic areas in the Banyule Shire were under represented, as were those living on the urban/rural fringe in the Nillumbik Shire.

The centralised coordination of the self-management facilitated recruitment of participants and provided leaders with support in organising and conducting the programs contributing to their sucessful delivery.

Kim Gray Physiotherapist Austin Health

"The course was very beneficial to me, and I learned a lot of ways to improve my health. It gave me confidence to manage my blood pressure better. Towards the end of the course my blood pressure improved and my medication was reduced. I felt relaxed and positive by the end of the course" Course Participant.

Positive Outcomes For Leaders

Leaders Benefited And Are Keen To Continue

A survey of leaders indicated;

- leaders would like to keep running the program
- skills developed in the training have also been put to good use in many other aspects of their client work
- the coordination role was one of the main benefits of the program
- the level of communication between leaders and project staff was highly valued including the quarterly newsletters and regular leader meetings

Evaluation Continues

Evaluation of the data continues with full results available in the full report on www.bnpca.org.au from February 2004.

Janine Scott
Program Coordinator
Eltham Community Health Centre

Building upon the success of the Project, Eltham Community Health Centre will continue to support the Better Health Self Management Programs across Banyule and Nillumbik through the provision of leader training and promotion of self management in managing chronic illness.

Building Capacity, Developing Partnerships and Ensuring Sustainability

The Project Ends But The Work Continues

Building capacity, developing partnerships and ensuring sustainability were key foci of *Take the Pressure Down*.

The project took the Vic Health message "Together we do better" to heart in planning the project and the outcomes are exciting.

Banyule Nillumbik: A Centre for Self Management Excellence

Agencies in Banyule and Nillumbik are well equipped to meet consumer demand for support with self management and hypertension.

The coordination role of the BHSM programs was successfully taken on by Eltham Community Health Centre (ECHC) in June 2003. In addition ECHC have trained staff to become Master Trainers for the BHSM programs. This will enable ECHC to provide leader training within the catchment and provide a focus for Banyule-Nillumbik as a centre for self management expertise and excellence.

Consumer Advisors

The consumers from the Consumer Reference Group (CRG) are moving on and taking their expertise to be advisors to local HARP projects, peak bodies and ECHC's self management initiatives.

The Local Pharmacy

The CRG identified local pharmacists as key players in chronic disease management. Eight local pharmacies indicated an interest in being involved in the project. The project worked with these pharmacies to build knowledge around self management, explore the role of pharmacy in promotion of self management, develop tools and systems to ensure systematic referral to self management programs and support links between the pharmacists and local health care providers.

The Local General Practitioners

The project worked with the North East Valley Division of General Practice and local general practitioners (GPs) to spread the word on self management, hypertension and the *Take the Pressure Down* programs. This included:

- presentations to GPs, practice managers and practice nurses
- resources including GP resource folder, consumer posters and brochures and referral pads
- feedback to GPs from community health providers regarding consumers attending BHSM programs.

The above work expended considerable time and effort for the project unfortunately this did not translate into referrals to the program. A full discussion of the reasons for the low referral rates can be found in the full report.

The project promoted the Heart Foundation's Multiple Cardiovascular Disease (CVD) Risk Factor Clinical Management Audit to local GPs. 46 GPs chose to complete the audit. Audit results clearly show local GPs are managing blood pressure significantly better than all other GPs who have completed the audit and significantly better than GPs in the region who completed the audit 3 years ago.

Peter Eizenberg Local General Practitioner

Take the Pressure Down demonstrates a valuable collaborative approach to an important health problem that is common in our community.

It uses an innovative self management approach with a focus on what the individual can achieve in partnership with their GP to reduce the harmful impact of Hypertension and its complications.

Local Government

The primary prevention focus of the project was promoting physical activity and was integrated with BNPCA health promotion activities.

Agencies identified that a key issue in promoting physical activity was linking individuals with appropriate activities. All organisations identified that much time and effort was spent developing and updating their own physical activity directories.

The project has worked with Banyule City Council and local service providers to develop an interactive and sustainable physical activity directory that will be accessible to both health professionals and consumers.

Building Capacity Around Social Marketing And Hypertension

Eltham CHC, on behalf of the project, is undertaking a social marketing project around hypertension. The aim is to develop a transferable model for social marketing of health issues, utilising hypertension in the first instance.

The outcomes will include:

- a documented model
- increased workforce competencies (general and specialised) in social marketing including the use of media; and
- a range of tested strategies to utilise marketing health issues at a local level.

More details will be available in the final report.

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Key Learnings and Recommendations

The consumer reference group felt quite strongly that it was important to use the term " high blood pressure" rather than hypertension. Most people understand " high blood pressure" means your blood pressure is too high but they don't always know what hypertension means.

Patricia Grydzyn CRG Member

Hypertension Is Important And So Is The Terminology

High blood pressure (hypertension) is important to consumers and has a major impact on many of their lives. In contrast, many health professionals and peak bodies view high blood pressure as "just a risk factor".

Consumers identified that the word hypertension was a term not well understood and often confused with tension and stress.

The Diagnosis Of Hypertension: A Missed Opportunity For Change

Hypertension is often the first chronic disease people are aware they have and the first long term medication they are subscribed.

Our consumer research showed that when diagnosed with hypertension, most consumers are aware of the need to make lifestyle changes but find services and information difficult to access.

The rise in chronic metabolic diseases is creating stress on health care services and health care budgets. The diagnosis of hypertension offers an excellent opportunity for intervention and promotion of self management for consumers.

Consumers Participation Offers A "Win, Win" For All

Individual consumers and the project gained extensively from consumer participation, in particular, the contributions of the Consumer Reference Group (CRG).

The bringing together, and building the skills, of this essential group of consumers to help plan, implement and evaluate the project has resulted in an empowered group of people who will carry on after the life of the project and a project that was significantly richer for their contributions.

Successful Establishment of a Community Self Management Program.

A self management program can be established in a community with key benefits to consumers and health professionals.

Our consumer research demonstrated that consumers were hungry for information and programs related to hypertension, lifestyle and behaviour change.

Direct consumer outcomes have been demonstrated thus far with changes in knowledge, lifestyle change and ability to manage health.

Self Management Education For Health Professionals Is Required

Self management has been identified as essential in helping manage chronic disease in the community. The continued national and state focus on self management is welcomed. This needs to be accompanied by health professional education of the processes, outcomes and benefits to consumers.

The project findings that health professionals "struggle" with selling self management and recruiting to programs is consistent with national and international self management program experiences and highlights the need for further work in this area.

Darnelle Eckersall Convener BNPCA PMG

Take the Pressure Down is an exciting and innovative project that demonstrates how key health service providers and consumers can work together creatively to produce outstanding results. This work has strengthened the reach of the BNPCA to a range of residents who would have not otherwise been involved in the Primary Care Partnerships Strategy and has contributed to our knowledge of how to effectively engage with and empower consumers. Congratulations to all involved.

Consumers Respond To Direct Approach

Direct targeting of consumers through media delivered to their home is a cost effective method that accessed consumers not normally engaged with health services.

Centralised Coordination Proves Effective

Collaboration between multiple agencies provided clear benefits for consumers, participating agencies and health professionals. The model of a lead agency providing a central point for coordination of programs has advantages to both leaders and consumers:

Benefits for leaders:

- coordination of programs across the catchment
- decreased time in planning and developing promotional material.

Benefits for consumers:

- choice of venues, times and days to attend the program
- ease of access, one phone call to register.

General Practitioner Engagement

In comparing our experience of general practitioner engagement with that of other of IDM and self management programs there appears to be a number of factors that can support General Practitioner referrals and engagement with programs:

- program is delivered through a Division of General Practice
- linked to other initiatives/financial incentives
- targeting a "priority" disease
- program not labelled "self management"

Evaluation processes need to be practical

Privacy and consent issues are important but evaluation processes need to be streamlined to accommodate practical implementation.