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**THE CONTRIBUTION OF CONSUMER HEALTH
ORGANISATIONS TO CHRONIC DISEASE SELF
MANAGEMENT IN THE CONTEXT OF PRIMARY CARE**

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CONTEXT

Countless research reports and policy statements document the challenges facing the health system due to the increasing prevalence of chronic disease. Recent discussions arising from the Australian Government's health system reform agenda identify shortfalls in the system's ability to manage complex chronic conditions and highlight high levels of fragmentation, poor system coordination and limited patient engagement.^{1,2} Australia needs a health care system that is patient-centred and provides the mechanisms and resources to support patients, families and carers to be actively engaged in their health care.²⁻⁴ To achieve this goal, health consumers must be equipped with the skills and confidence to participate actively in decision making and self management.

It is in this context that chronic disease self management has gained policy prominence. The push for self management draws from the growing body of literature that advocates informing, empowering and actively engaging people in their own care as a key strategy for optimising people's chronic disease management capacity. It draws from mounting, though sometimes mixed,⁵ evidence identifying the range of benefits for individuals and health systems; including better clinical outcomes, health status, quality of life, knowledge of the condition and efficient use of health services.⁶⁻¹⁰

While self management is prominent in many key policy statements and agendas,¹⁻⁴ further input, including high level evidence, is needed to identify systematic processes to advance these goals and deliver the ascribed benefits. A range of approaches is required – no single, uniform approach will be sufficient to respond to the diversity of needs and maximise health, wellbeing and knowledge outcomes. Health systems need to identify, evaluate and develop multiple strategies.^{5,11} This is underlined by recent critiques of the self management approach, which highlight access issues, restricted models, reliance on the individual without due concern for wider support structures, the heterogenous nature of chronic illness and the individuals who experience them as possible limiting factors.^{9,12} The notion of "self management support"¹³ addresses some of these concerns by emphasising the need to provide resources that enable people to engage in self management. Similarly, Fisher et al.¹² argue for recognition of the context in which self management occurs and the degree to which people's capacity for self management is influenced by an array of social, community and health system factors. This perspective maintains a need for a range of community resources to support individuals in ongoing and flexible ways as they manage their conditions on a daily basis.¹⁰ Such resources must extend beyond standard clinical services to address the ongoing and multidimensional demands associated with chronic illness; they must also be integrated with the wider health system to establish and maintain structures for reliable provision.

Consumer Health Organisations (CHOs) – nonprofit organisations that promote and represent the interests of users and/or carers¹⁴ – are an existing and relatively low-cost community resource with the potential to expand the repertoire of self management interventions available in the community. They can provide information, educational resources, psychosocial support, and skills development for those experiencing chronic illness and their carers^{12,15-20} and their goals are closely aligned with those of the self management agenda. As such, they offer a valuable extension to the structurally limited 15 minute primary care consultation^{8,21} by complementing and reinforcing clinical care. Information acquired through CHOs may encourage more effective use of services and offer practical solutions to problems associated with living with chronic illness.^{18,22}

Consumer Health Organisations (CHOs) are nonprofit or voluntary sector organisations that promote and represent the interests of users and/or carers.¹⁴

Little research has been conducted into the role of CHOs in the health system, particularly in relation to the support of those with chronic disease. What is known is that referral pathways to the CHO sector are poorly developed²²⁻²⁵ and that many people who may stand to benefit from CHOs do not gain access to them. In the United Kingdom, Ellins and Coulter²⁶ found that CHOs were grossly under-utilised by people with chronic illness. Yet, CHOs have the potential to provide critical supportive and educational services that may not be readily available in the

formal health system¹⁶ and some evidence suggests they can complement and support existing approaches to chronic illness care.¹⁹ A review of 45 studies of CHO effectiveness across a diverse range of conditions showed improvements in psychosocial wellbeing, knowledge, mastery, coping and control were common to many studies.²⁷ Comparing 33 participants and 67 non-participants in a scoliosis self-help organisation following similar medical treatments, Hinrichsen et al.²⁸ found adult participants had: a more positive outlook on life; greater satisfaction with the medical care they received; reduced psychosomatic symptoms and an increased sense of mastery. Diabetes organisations have also been shown to be effective in terms of diabetes knowledge, coping, psychosocial outcomes, and glycemic control.^{29,30} A recent study examining the referral of 108 patients with psychosocial problems to a range of CHOs and social care agencies, via a facilitator, identified a decrease in the number of GP visits and reduced levels of psychological distress and use of psychotropic medication.²³ In what appears to be the only published randomised control trial involving CHOs, Grant et al.²⁵ in the United Kingdom evaluated a formal process of linking GP patients with voluntary organisations. At 4 months, 90 referred patients had significantly better scores on 7 of 9 outcome measures, including anxiety, pain, daily activities, and overall health compared with 71 non-referred patients.

Australian research remains scant, but our own earlier research indicates the potential for CHOs to enhance chronic illness management.^{31,32} Members report greater understanding of their illness, enhanced confidence in participating in decision-making and improved ability to communicate with health professionals.³²

The present research, the first of its kind in Australia, sought to gain a more detailed understanding of the actual and potential contributions of chronic disease focused CHOs in the primary health care system. The overarching research question was: Could more people with chronic disease use and benefit from CHOs? If so, how might contact with CHOs be increased?

STUDY AIMS:

The study had three primary aims:

- To document the nature of CHO participation among people with chronic illness: who uses chronic disease related CHOs, how, why and with what benefits?
- To inform empirically the development and implementation of a CHO referral strategy suitable for delivery to patients with chronic disease in the primary care setting.
- To evaluate the above strategy in terms of: referral and access to the CHO sector; frequency and type of CHO usage; and a range of chronic illness related outcomes among general practice patients.

The research, based in Brisbane, Queensland involved two studies: a comprehensive survey of 323 people who had contacted a CHO; and a randomised control trial designed to evaluate a strategy to increase CHO access among 276 general practice patients with chronic disease. Both studies were approved by The University of Queensland's Behavioural & Social Sciences Ethical Review Committee.

APPROACH

STUDY ONE: SURVEY OF PEOPLE WHO CONTACTED CHOS

KEY AIMS

- To document the nature of CHO participation among people with chronic illness: who uses chronic disease related CHOs, how, why and with what benefits?
- To inform empirically the development of a CHO referral strategy suitable for delivery to patients with chronic disease in the primary care setting.

Preliminary analysis of the data also generated a valuable opportunity to explore whether patterns of contact differ according to the extent to which CHOs are embedded in the formal health system.

METHODS

CHO RECRUITMENT

The study involved initial consultation with 13 CHOs, all of whom enthusiastically supported the goals of the research. Nine CHOs agreed to join the study and seven recruited participants. Some CHOs, while willing to participate in the research, were not in a position to do so due to competing demands and limited resources.

Inclusion criteria for CHO involvement were: private/non-government, managed by a voluntary board, non-profit distributing, formally organised and self-governing.³³ Participating CHOs also fulfilled the definition of a nonprofit or voluntary organisation, that seeks to promote and represent the interests of users and/or carers.¹⁴

CHOs located in south east Queensland, Australia were identified using a "multi-source approach"³⁴ with organisation details collected from a composite of government, private and community organisation databases and other records. Thirteen organisations operating in the Brisbane region were invited to be involved - nine agencies providing information, support and services to people with: arthritis and osteoporosis; diabetes; chronic hepatitis; ankylosing spondylitis; haemochromatosis, heart and circulatory disease, and renal disease agreed to participate and seven organisations recruited participants (see Table 1 for the full list of organisations). In the main these diseases are prevalent and contribute to a large proportion of the burden of morbidity in Australia^{35,36} and have been identified as chronic disease priority areas.⁴

SURVEY PARTICIPANTS

The CHOs invited eligible people who contacted their organisation to participate in the study. Each organisation's main avenue for people making contact was used for recruitment; for four organisations it was by telephone (Arthritis Queensland, Diabetes Australia, Hepatitis Council of Queensland, Kidney Support Network) and for three CHOs it was via attendance at group activities (Ankylosing Spondylitis Group of Queensland, Arthritis Friendship Group Queensland, Heart Support Australia).

People who contacted the organisations between the months of June and August 2006 were invited to take part in a computer assisted telephone interview (CATI) conducted by the University of Queensland. Participant eligibility criteria included: being aged 18 years or older; sufficient English to complete the interview; telephoning the CHO or attending a group meeting during the period of recruitment; and contacting the CHO in relation to their own or someone else's health. CHO workers recorded the age and gender of all eligible participants and the contact details of those who agreed to take part were forwarded to the research team. The researchers contacted the CHOs weekly to facilitate the systematic recruitment of contacts to their organisations. Those who agreed were posted information about the project on University

of Queensland letterhead, along with a \$5(AUD) supermarket voucher. Informed consent was obtained verbally and recorded by the interviewer.

Participants completed two telephone interviews four months apart and each 20-30 minutes duration. During the recruitment period 497 eligible people contacted the participating CHOs, of whom 367 (73.8%) agreed to participate. A total of 323 people completed the first interview (64.9%), of whom 306 (94.7%) completed the four month interview. Table 1 outlines participants based on organisation of contact.

We initially had planned to include only new CHO contacts in the survey in order to gain a detailed picture of patterns of participation and their associations with health related outcomes over time (the four month study period). This proved not to be feasible due to the difficulty for CHOs of establishing whether a caller was “new” or not. Recruiting a broader range of participants resulted in a more meaningful snapshot of CHO users with differing patterns and exposures to CHOs. There were no statistically significant differences between response rates for the different CHOs nor between respondents and non-respondents with respect to sex or age.

Table 1: Participating CHOs and numbers of recruited contacts

	Frequency	Percent
Diabetes Australia	146	45
Arthritis Queensland	108	33
Ankylosing Spondylitis Group of Queensland	13	4
Heart Support Australia	33	10
Hepatitis Council of Queensland	5	2
Arthritis Friendship Group	12	4
Queensland Renal Association	6	2
Total	323	100

QUESTIONNAIRE

The interview collected data on health and socio-demographic characteristics; reasons for, nature, and perceived benefits of CHO contact; health actions taken; and patient activation. It contained a mix of standard items and scales, as well as customised items. Items measuring health, demographic characteristics and health actions taken following CHO contact were derived from the Australian National Health Survey.^{37,38} Items measuring organisational contact were developed from the CHO literature and prior research undertaken by the authors.^{31,32} Indicators of CHO contact included: time of first contact with the CHO, how they found out about the CHO, timing of contact (e.g., ‘wish you made contact sooner’), main reason for contact (e.g., ‘you were recently diagnosed or experienced an event with your health’), and benefits from contact (e.g., ‘to gain confidence in talking to doctors and other health professionals’). Physical and psychological health were assessed using the SF-12 Version 2,³⁹ a validated 12 item scale widely used in research worldwide.

Level of activation was measured using the Patient Activation Measure (PAM) short form, a 13-item measure that assesses a person’s knowledge, skill and confidence to manage one’s health or chronic condition.^{40,41} Example items include “When all is said and done, I am the person who is responsible for managing my health condition” and “I am confident that I can maintain lifestyle changes like diet and exercise even during times of stress.”

The questionnaire was pre-tested with CHO members and people from the wider community.

RESULTS

A SNAPSHOT OF CHO USERS

The age of participants ranged from a 19 year old with a form of arthritis to a 93 year old with diabetes (mean age 61 years, median age 62 years). Table 2 shows the majority were Australian born, two thirds were women and about one third were in the paid work force. Almost half had a post school qualification and 59.3 percent had some form of private health insurance.

CHO USERS TENDED TO BE...

*Older
Female
Not in the paid workforce
Of middle socioeconomic status*

For those people who contacted organisations on their own behalf (n=286) over half indicated they had diabetes and 72.7 percent had some form of arthritis, including ankylosing spondylitis. Conditions of the circulatory system, including hypertension, affected 62.9 percent and 12.6 percent had kidney disease. Two thirds rated their health as excellent, very good or good.

Overall the majority had contacted their CHO on a previous occasion, which included people who had had long standing contact with the organisation (8.6% had made contact over 20 years ago), while 100 (31.0%) were first-time contacts. Most participants (88.5%) contacted a CHO for their own health, with a small number contacting for someone else's health.

Table 2: Socio-demographic characteristics of 323 participants

Characteristic	Frequency*	Percentage	
<i>Gender</i>	Male	104	32.2
	Female	219	67.8
<i>Highest level of qualification</i>	No qualification	83	27.6
	Secondary	76	25.2
	Certificate	78	25.9
	Degree/diploma or higher	64	21.3
<i>Employment status</i>	In paid workforce	102	31.7
	Retired	167	51.9
	Other	54	16.4
<i>Marital status</i>	Married or living with a partner	208	64.4
	Other	115	35.6
<i>Private health insurance</i>	Yes	191	59.3
<i>Country of Birth</i>	Australia	262	81.4
	Overseas	60	18.6
<i>Main language spoken at home</i>	English	315	97.8
<i>Health Status (Self-rated)**</i>	Excellent/very good	75	26.2
	Good	108	37.8
	Fair/poor	103	36.0
<i>Chronic health conditions**◆</i>	Diabetes	149	52.1
	Arthritis/Ankylosing Spondylitis	208	72.7
	Heart disease/Stroke	180	62.9
	Kidney disease	36	12.6
	Hepatitis	11	3.8
	Chest problems/Asthma	51	17.8
	Haemochromatosis	5	1.7
<i>First time contacting CHO</i>	Yes	100	31.0
<i>CHO contact for</i>	Self	286	88.5
	Someone else (e.g., family member)	37	11.5

*Total number of respondents may be less than 323 for some variables due to missing data

**The results are reported for the 286 people who contacted a CHO in relation to their own health only

◆Multiple responses were possible

HOW DID THEY FIND OUT ABOUT THE CHO?

Researchers frequently report that GPs do not refer to organisations.²²⁻²⁴ In our study 23 percent found out about the CHO through a GP. Of these the majority were people with diabetes (84.3%); the remainder had contacted Arthritis Queensland.

The second most common referral pathway was via a friend, relative or social encounter (17.4%). Pathways were also established via medical specialists (9.2%) and other health professionals (16.1%). Television, radio or print media was another key source of information about CHOs (14.8%).

Table 3: Source of first hearing about CHO among 323 participants

Source	Frequency*	Percentage
GP	70	23.0
Friend, relative or social encounter	53	17.4
Other health worker or agency	49	16.1
Media – TV, radio, newspaper or magazine	45	14.8
Specialist	28	9.2
Organisation, brochure, advertising or representative	26	8.6
Phone book or directory	14	4.6
Internet	11	3.6
Known about the organisation for some time	8	2.6

*19 respondents could not recall how they first found out about the organisation

The remaining discussion focuses on the results for the 286 people who contacted a CHO in relation to their own health.

WHY DID THEY CONTACT?

The main reason people contacted a CHO was to obtain more information about their chronic disease or for information on how to better manage it (41.8%). Of the respondents who contacted for more information, nearly one in five (19%) wished they had made contact sooner. Demonstrating the practical support provided by CHOs, approximately one in four people (21.8%) contacted organisations to receive services (e.g., exercise classes) or condition related products (e.g., insulin testing strips).

HOW DID THEY PARTICIPATE?

CHOs provide a range of services and supports to cater for the diverse needs of their constituents, yet it seems many people hold misconceptions about their activities and what it means to 'participate'. Demonstrating the diversity of participation, our results indicate a cross section of people engaged in a variety of ways ranging from more common "low intensity" involvement (e.g., 81.8% read a newsletter) to active participation and involvement in organisational operations (e.g., 16.8% engaged in weekly activities and 11.9% worked as a volunteer).

BENEFITS OF CONTACT WITH A CHO

Perceived benefits

Consistent with the above finding that people contacted their CHO to seek information, gaining health information was also the most frequently cited benefit (get information about your health, 91.6%; learn better ways to manage health problems, 88.8%; information about treatments, medications or latest medical research, 81.5%; information about available health professionals and services, 74.9%).

Other benefits included: access to services, such as medical aids, counselling, exercise classes or seminars (69.6%); social support or connecting with others with similar health issues (68.1%); and gaining confidence in talking to doctors and other health professionals (54.7%).

Increasing health behaviours

The two main health behaviours participants reported taking following their contact with the CHO were starting to exercise (46.2%), and changing diet (44.1%). Seeking treatment and information was also a commonly reported health action, with 36.4 percent seeking information from another place such as the Internet or books, and 32.2 percent seeking advice, assessment or treatment from a doctor (see Table 4).

Over half (56.2%) the participants reported engaging in at least two health behaviours as a result of contact with the CHO, with around a quarter (26.6%) reporting they had not engaged in any behaviours. Those who had made contact for the first time were more likely to report they had taken no health actions (41.1% of first timers versus 19.9% of people with long term contact, $p < .001$). By the time of the second interview, people who had made their first contact at baseline had “caught up” in relation to the number of health actions taken as a result of CHO contact. After four months, 62.2 percent had engaged in two or more actions (69.1% for first time contacts versus 62.5% for longer term CHO users) and 13.9 percent reported no health actions (14.3% for first time contacts and 13.8% for longer term CHO users).

Table 4: Health actions taken among 286 participants

Health Action	Frequency *	Percentage
Sought advice, assessment or treatment from a doctor	92	32.2
Sought advice, assessment or treatment from an allied health worker or complementary therapist	60	21.0
Started exercising	132	46.2
Changed your diet	126	44.1
Attended a seminar	59	20.6
Sought more information from another place e.g., the internet, books or library	104	36.4

*Multiple responses were possible

Patient Activation

Fostering knowledge, skills and confidence, or patient activation, to self-manage health⁴⁰ is a potentially important role for the CHO sector. Participants in the study seemed more likely to have reached a higher stage of activation in comparison to findings reported in a population based study in the United Kingdom.²⁶ This is perhaps to be expected given that the participants had been motivated to make contact with a CHO about their health. People who contacted their CHO for the first time had significantly lower activation (mean=63.0) than people who had previously contacted a CHO (mean=68.8, $p = .003$). For those who made contact for the first time there was an increase in activation over the four month period (mean change=1.29), and this was a greater increase than for those who had been in contact over the longer-term (mean change=0.57); however a considerably larger sample size would be needed to be certain that this trend reflects a real difference between the two groups.

CASE STUDY: COMPARING DIABETES AND ARTHRITIS

Referral pathways to CHOs are under-developed,^{24,25} but links to diabetes based CHOs may be an exception. The National Diabetes Services Scheme (NDSS), an Australian Government scheme providing subsidised services and products, is administered through Diabetes Australia.⁴² By referring patients to Diabetes Australia, doctors can increase access to subsidised equipment and products. As a result access to this CHO appears to have become an implicit part of standard diabetes care. This contrasts with arthritis, for example, where no such system is in place: a number of key arthritis CHOs exist but operate outside the formal health system. The following case study provides a brief summary of some key differences between CHO participants demonstrating distinct levels of health system integration.

Most of the 279 respondents contacting diabetes and arthritis organisations were women (70.0%; n=196), but more men had made contact with diabetes (34.9%) than arthritis (24.1%) CHOs (p=.05). The diabetes and arthritis groups were similar in age (mean = 59.27 years); marital status (65.2% were married/living with a partner); and workforce participation (64.7% were not in the paid workforce). Consideration of the socio-economic status of respondents, indicates differences between people contacting diabetes and arthritis organisations. Using the Socio Economic Index for Areas (SEIFA), a composite measure of disadvantage at the community level developed by the Australian Bureau of Statistics, individuals contacting the diabetes CHO were more likely to live in a disadvantaged area (67.8%) than people contacting arthritis organisations (50.4% p=.003). They were also less likely to have private health insurance than those from arthritis CHOs (48.6% and 65.2% respectively, p=.006).

Focusing on the 249 respondents (diabetes, n=127; arthritis, n=122) who had contacted for their own health, prior contact with the CHO was significantly more likely for those with diabetes than for those with arthritis: only a minority (16.5%) had contacted the diabetes CHO for the first time compared with more than half (55.7%) for arthritis (p<.001). Two-thirds (68.0%) of the diabetes group had first contacted three or more years ago, and 30.4 percent more than 10 years ago. For the arthritis groups, less than one-third (27.9%) had first contacted three or more years ago and only 6.6 percent had contacted more than 10 years ago (p<.001). Of the 41 people who reported being diagnosed with arthritis more than 10 years ago, 53.7% (n=22) were first time contacts, compared with just 3.7 percent of the 54 people who had been diagnosed with diabetes for more than 10 years. The majority with diabetes (69.3%) first found out about the CHO from a health care professional compared with only 26.2 percent of people with arthritis (p<.001). When asked about timing of first contact, significantly more in the arthritis group wished they had made contact with the CHO earlier: 27.0 percent compared with 13.4 percent for the diabetes group (p=.007).

Summary

In comparison with arthritis contacts, people contacting a diabetes CHO were more likely to:

- *be referred via GP, specialist or health professional*
- *have had previous contact with the CHO*
- *contact the CHO sooner following diagnosis*
- *report having made contact "at about the right time"*
- *not have private health insurance*
- *be male*
- *seek services/products from the CHO*
- *report changing their diet following CHO contact*

KEY FINDINGS

- People who contacted CHOs tended to be older women of middle socioeconomic status and not in the paid workforce. Other subpopulations were less well represented.
- Patterns of CHO contact were markedly different for diabetes and arthritis, the two major chronic diseases addressed in the study. Compared with arthritis, those with diabetes contacted the CHO sooner following diagnosis and were more often referred by a health professional. The diabetes CHOs also had a higher representation of men and people from lower socioeconomic backgrounds. These differences appear to reflect the greater integration of the diabetes CHO into the health system that has occurred as a result of the Australian Government subsidy of services and products (National Diabetes Services Scheme, NDSS).
- General practice referral to CHOs was limited, with the exception of diabetes where pathways to the organisation were more clearly established.
- People who contacted CHOs did so mainly to gain information about their condition and how to manage it and to access services such as exercise classes and medical aids.
- CHO users reported that their contact with the organisation prompted them to take positive health-related behaviours: almost half said they had started to exercise or changed their diet as a result of contacting the CHO and one-third reported that CHO contact had led them to seek advice, assessment or treatment from a doctor.
- People who contacted CHOs were likely to have higher levels of patient activation (knowledge, skills and confidence to manage their chronic condition) than found in the general community. Those who had been in contact over a longer period of time tended to have greater levels of activation than those in contact for the first time.

POLICY RECOMMENDATIONS

CHOs are a health system resource that people with chronic disease access for information, services and support with managing their condition. The potential value of CHOs is seen in the context of current health system constraints, including the standard 15 minute medical consultation, during which GPs have limited opportunity to provide all the information, support and skills management that patients require. CHOs are very well-regarded by those who do make contact, and CHO users report engaging in key health behaviours following their contact.

Integration of CHOs in the health system, as seen in Diabetes Australia via the NDSS, appears to have helped establish referral pathways between primary health care and CHO settings. Strategies to embed other chronic disease focused CHOs in the health system are required if the benefits associated with CHO contact are to be extended to include people who are recently diagnosed, disadvantaged groups and subpopulations that typically experience barriers in accessing health care. Ensuring self-management interventions and resources are well-integrated with the formal health system is essential to maximising access, appropriateness and sustainability.

STUDY TWO: RANDOMISED CONTROL TRIAL OF A CHO REFERRAL STRATEGY

High level evidence is fundamental to high quality primary health care policy and practice.^{43,44} With regard to the potential role of CHOs in the health system, high level evidence is difficult to find. Most studies have been of insufficient rigour to guide policy recommendations. With the exception of Grant et al.,²⁵ research has been largely descriptive and based on small highly selected samples. Most studies report only on CHO participants so little is known about non-participants or their reasons for not participating. In Study Two, we sought to redress some of these methodological shortcomings by conducting a randomised control trial of an intervention designed to increase awareness of and access to a relevant CHO among general practice patients with chronic disease.

Our study encountered a number of obstacles, most notably initiating and maintaining general practice involvement for the recruitment of patients. This is a well-documented constraint in general practice based studies, where researchers must balance rigour and the practicalities of the general practice settings.⁴⁵

METHODS

RECRUITMENT

Recruiting a representative sample of general practice patients with chronic disease involved a two-stage process: the recruitment of GPs, followed by the recruitment of patients. We recruited GPs directly, with the assistance of two Brisbane-based Divisions of General Practice who advertised the project to members. Patient recruitment was at "arms-length": participating GPs were responsible for identifying, inviting and gaining the consent of patients to participate. Only when patients had completed a study consent form were they contacted by the research team.

Based on initial power calculations, our goal was to recruit 650 eligible patients, 25 GPs each recruiting 26 patients. A feasibility study involving five GPs had indicated that this was readily achievable. Yet, recruitment proved more challenging in the study proper. Both the recruitment of GPs and their recruitment of patients was much slower than anticipated and maintaining the involvement of some practices required intensive follow-up. Even with an expanded recruitment process, to complete the project within its extended timeframe, it was necessary to cease recruitment with just over half (57.5%) our target sample: a total of 374 eligible patients recruited by 18 GPs.

RECRUITMENT OF GPs

A random sample of 100 GPs in each of the South East and Brisbane South Divisions of General Practice was invited to participate in the study. The GPs were mailed an invitation letter, study information and a consent form to sign and return to the researchers. Only eight GPs were recruited by this method.

Given the low response rate, nine GPs with links to the research team were approached to participate of whom six recruited patients. Chain referral resulted in a further seven GPs agreeing to take part, four of whom subsequently recruited patients. Overall 24 GPs agreed to participate in the study; however, only 18 recruited patients.

Prior to patient recruitment, a project team member visited each GP and relevant practice staff to discuss the project. This ensured a stringent process was in place for patient recruitment, the recording and forwarding of details to the research team, and adhering strictly to ethics requirements. We were attuned to the importance of minimising the demands placed on GPs and their practice staff and worked flexibly with the practice to adapt the process to meet differing needs and preferences, while conforming to the study protocol. Contact was made with the practice soon after their agreed recruitment start date and regularly thereafter to ensure recruitment was proceeding as planned and to resolve any issues.

RECRUITMENT OF PATIENTS

Participating GPs were asked to approach consecutive patients (18 yrs and over and with sufficient English language skills to complete a telephone interview) with a diagnosis of one or more of: diabetes, arthritis, osteoporosis, ankylosing spondylitis, asthma, chronic hepatitis, haemochromatosis or renal disease. Standard diagnostic criteria were provided to participating GPs. The GP provided an information sheet to patients who expressed interest and obtained written consent from those who agreed to participate.

To assist GPs to achieve a consecutive sample of patients and so minimise selection bias, we developed a "running sheet" for GPs to record all patients seen in terms of their eligibility (yes/no) and, if eligible, their willingness to participate (yes/no). The running sheet was piloted with several GPs and refined based on their experiences and comments. Using tick boxes wherever possible, GPs were asked to record the reason for patients who were ineligible. For each eligible patient, they were asked to record the patient's age, sex and main chronic condition. They then recorded whether the patient was willing to participate (yes/no). Only if yes, were the patient's name and contact details recorded. GPs were asked to maintain their running sheet until at least 26 patients had been recruited and to fax the completed sheet to the researchers.

DATA COLLECTION, QUESTIONNAIRE AND RANDOMISATION

All patients who consented to participate in the study were asked to complete a computer assisted telephone interview at baseline, 4 months and 12 months. Data collection commenced with the baseline interview in April 2007 and concluded in November 2008. Each telephone interview took between 10 and 20 minutes to complete and was conducted by a trained and experienced interviewer.

The survey instrument used many of the same measures as those in Study One, including health and socio-demographic characteristics, participation in CHO activities, patient activation and health actions. Other measures included participants' access to health services such as consulting a GP (derived from National Health Survey 2004-2005³⁸) and perceived barriers to contacting a CHO.

Following the baseline telephone interview, usually within two weeks of recruitment, patients were randomly assigned to receive either the CHO referral package (intervention package; see below) or a general letter welcoming them to the study (control package). These were sent by mail. The randomisation procedure involved stratifying participants by their main health condition and using the computer tool 'Research Randomizer'⁴⁶ developed by the Social Psychology Network to generate random numbers to determine the two groups. GPs were not made aware of the group to which the patient had been assigned and continued to care for patients in the study according to their usual practice.

Repeat telephone interviews were conducted after approximately 4 months, and again at 12 months after recruitment into the study. At these follow-up interviews, in addition to questions asked of all participants, we asked those in the intervention group about their perceptions of the intervention package and whether they had used it.

INTERVENTION PACKAGE

The intervention package was designed as a low-cost method of reaching people with chronic disease to increase their awareness of and access to a relevant CHO. It needed to be easily accessible to a wide cross-section of the general practice population with diagnosed chronic disease, acceptable to patients and GPs, and easily implementable in a general practice setting.

The package was developed from a detailed literature review of the evidence base for health education interventions using print materials and in close collaboration with participating CHOs, consumers and GPs. Versions of the package were field tested with CHOs, their members, GPs and members of the general community. Information collected from Study One was used to inform its development. The intervention package included a letter of endorsement from a GP (one of the researchers) with a personalised invitation to contact a CHO relevant to the participant's main chronic condition (see box 1); a postage paid post card addressed to the CHO requesting further information and resources; and information about CHOs including the potential benefits of contact. The package was compiled in a professionally designed compendium including additional gifts of a pen and three note cards. Participants in the control group received a letter from the GP welcoming to the study and thanking them for their involvement with a gift pen.



Box 1: CHOs to which patients were referred

- *Ankylosing Spondylitis group of QLD*
- *Arthritis Foundation of QLD*
- *Diabetes Australia QLD*
- *Haemochromatosis Society of Australia*
- *Hepatitis Council of QLD*
- *Asthma Foundation of QLD*
- *Kidney Support Network*
- *Osteoporosis Foundation of QLD*

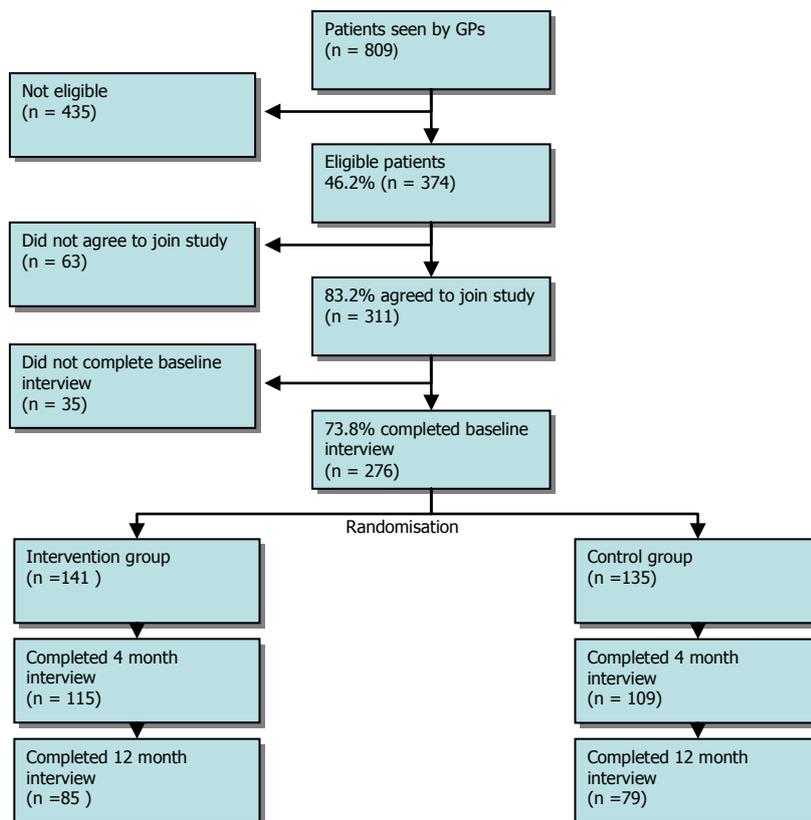
RESULTS

We evaluated the intervention package in terms of: access to and awareness of CHOs; chronic illness related outcomes; and acceptability to general practice patients. The data also offered a unique opportunity to gain insights into why relatively few people with chronic disease contact CHOs. As Study One showed, diabetes CHOs present a contrasting picture in terms of patterns of use when compared with other CHOs. Specifically, those with diabetes were expected to have had more prior contact with a CHO and this was borne out in the preliminary analysis of GP patients in Study Two. For this reason, subgroup analysis was planned *a priori* and undertaken with diabetes analysed separately from the other conditions. Analysis of the main outcome variables was on an intention to treat basis. That is, when comparing the intervention and control groups we made the assumption that all participants remained in the group to which they were randomised following the baseline interview. An additional assumption was that participants who dropped out of the study had no further contact with the CHO. Intention to treat analysis is intended to address potential biases caused by, for example, those motivated to participate in the study being more motivated to contact a CHO. Our analysis therefore provides a stringent and conservative test of the intervention.

STUDY PARTICIPANTS

Figure 1 shows the number of participants in the study. A total of 374 eligible patients were invited by 18 GPs to join the study, of whom 276 (73.8%) completed the baseline interview. They were randomised to either the intervention or control group, resulting in 141 patients in the intervention group and 135 patients in the control group.

Figure 1: Overview of study participation



Baseline completers did not differ significantly from eligible patients who did not complete the baseline survey in terms of sex, age or main chronic condition, as recorded by the recruiting GP. The proportion lost to follow-up at 4 and 12 months was 18.9 percent and 26.8 percent respectively, with a 12 month response rate of 59.4 percent (164 of the 276 participants who completed the baseline interview). These proportions were similar across the intervention and control groups and for the diabetes and other conditions groups. The response rates compare favourably with Grant et al.²⁵ who reported a loss to follow-up of 32 percent at four months in the only other published randomised control trial involving CHOs. Those lost to follow-up did not differ from those who completed the 12 month interview with regard to age, sex, main chronic condition, highest educational qualification or employment status.

CHARACTERISTICS OF PARTICIPANTS

Table 5 shows the main chronic condition for participants in the study. Arthritis, together with osteoporosis and ankylosing spondylitis, accounted for 52 percent of the sample, followed by diabetes (23%) and asthma (15%).

Table 5: Main chronic condition for 276 participants

Main Chronic Condition	Frequency	Percentage
Arthritis	93	34
Osteoporosis	42	15
Ankylosing Spondylitis	8	3
Diabetes	64	23
Asthma	41	15
Kidney Disease	17	6
Chronic Hepatitis	6	2
Haemochromatosis	5	2
	276	100

The socio-demographic profile of participants shows that a wide cross-section of patients was recruited to the study (Table 6). It also shows that the intervention and control groups, and diabetes and other conditions groups, were broadly similar at the baseline interview. The participants were predominantly Australian born (77.5%) and for most (89.4%) English was the only language spoken at home. Four participants (1.4%) identified as Aboriginal or Torres Strait Islander. Within the diabetes and other conditions groups, there were no statistically significant differences between the intervention and control groups on any of the variables shown in Table 6. Comparing diabetes and other conditions, there is one prominent exception. This pertains to prior contact with a CHO: 81 percent of patients with diabetes, compared with 11 percent of those with other conditions, reported ever having been in contact with a CHO for their condition.

Table 6: Socio-demographic characteristics of 276 participants at baseline interview

		Diabetes n = 64		Other n = 212		Total n = 276	
		Intervention n = 31 (%)	Control n = 33 (%)	Intervention n = 110 (%)	Control n = 102 (%)	Diabetes n=64 (%)	Other n=212 (%)
<i>Gender</i>	Male	14 (45.2)	14 (42.4)	35 (31.8)	32 (31.4)	28 (43.8)	67 (31.6)
	Female	17 (54.8)	19 (57.6)	75 (68.2)	70 (68.6)	36 (56.3)	145 (68.4)
<i>Age (yrs)</i>	Mean	63.61	61.85	65.31	63.11	62.70	64.25
	Median	63.00	65.00	65.00	65.00	64.50	65.00
	Range	24 -83	24 -85	26 -91	27 -99	24 - 85	26 - 99
<i>Highest qualification</i>	No qualification	5 (16.1)	5 (15.2)	23 (20.9)	15 (14.9)	10 (15.6)	38 (18.0)
	Secondary	15 (48.4)	14 (42.4)	45 (40.9)	42 (41.6)	29 (45.3)	87 (41.2)
	Certificate	7 (22.6)	6 (18.2)	31 (28.2)	27 (26.7)	13 (20.3)	58 (27.5)
	Degree/diploma or higher	4 (12.9)	8 (24.2)	11 (10.0)	17 (16.8)	12 (18.8)	28 (13.3)
<i>Employment status</i>	Paid workforce	8 (25.8)	12 (36.4)	22 (20.0)	24 (23.8)	20 (31.3)	46 (21.8)
	Retired	19 (61.3)	18 (54.5)	69 (62.7)	57 (56.4)	37 (57.8)	126 (59.7)
	Other	4 (12.9)	3 (9.1)	19 (17.3)	20 (19.8)	7 (10.9)	39 (18.5)
<i>Marital status</i>	Married/ living with partner	21 (67.7)	27 (84.4)	60 (54.5)	50 (49.5)	48 (76.2)	110 (52.1)
	Widowed	3 (9.7)	1 (3.1)	19 (17.3)	25 (24.8)	4 (6.3)	44 (20.9)
	Separated	5 (16.1)	1 (3.1)	23 (20.9)	16 (15.8)	6 (9.5)	39 (18.5)
	Never married	1 (3.2)	2 (6.3)	8 (7.3)	10 (9.9)	3 (4.8)	18 (8.5)
	Divorced	1 (3.2)	1 (3.1)	0 (0.0)	0 (0.0)	2 (3.2)	0 (0.0)
<i>Private health insurance</i>	Yes	15 (48.4)	20 (60.6)	57 (51.8)	58 (56.9)	35 (54.7)	115 (54.2)
	No	16 (51.6)	13 (39.4)	53 (48.2)	44 (43.1)	29 (45.3)	97 (45.8)
<i>Prior Contact with CHO</i>	Yes	23 (74.2)	29 (87.9)	10 (9.1)	14 (13.7)	52 (81.3)	24 (11.3)
	No	8 (25.8)	4 (12.1)	100 (90.9)	88 (86.3)	12 (18.8)	188 (88.7)

DID THE INTERVENTION PACKAGE REACH THE INTENDED AUDIENCE AND WHAT DID THEY THINK OF IT?

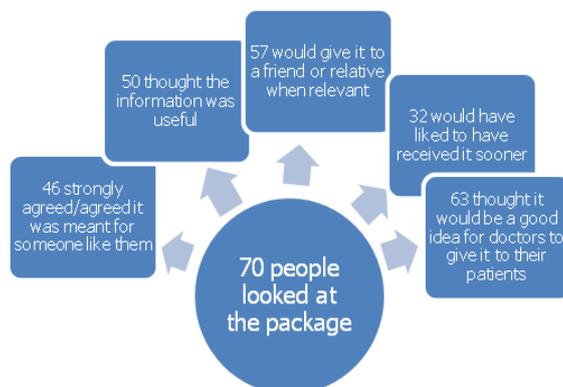
Of 141 participants who were mailed an intervention package following random assignment to the intervention group, 115 completed the four month interview. Most (81%; 93) said they recalled receiving the intervention package. More than half (61%; 70) said they had taken time to look at the package and almost as many (54%; 62) said they had read its contents (Figure 2).

Figure 2: Receipt, recall and use of the intervention package



There was strong endorsement of the package among those who had looked at it (Figure 3). The majority agreed or strongly agreed that the package: “was meant for someone like me” (66%; 46); “contained useful information” (71%; 50); and was something they would give to a friend or relative if relevant (81%; 57). Almost half (46%; 32) said they would have liked to have received the package sooner. The vast majority (91%; 63) thought it would be a good idea for doctors to give the package to their patients.

Figure 3: Perceptions of the intervention package



When interviewed 12 months later, 85 members of the intervention group remained in the study. The package appeared to have some sustainability as a health information resource. Most (79%; 67) recalled the package; 41 of those 67 (61%) had kept it and 20 of those 41 (49%) had looked at it or read it since the last interview (Figure 4).

Figure 4: Recall of the intervention package at the 12 month interview

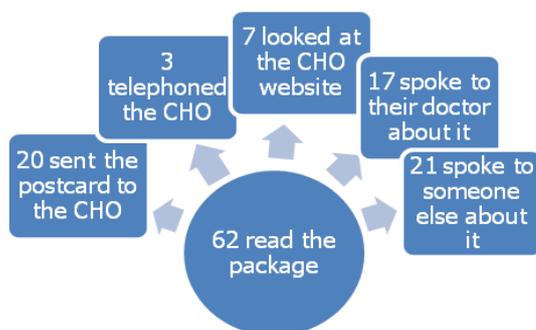


DID PARTICIPANTS USE THE INTERVENTION PACKAGE AS INTENDED?

One of the intervention package components was a pre-addressed postage paid postcard for participants to send to the recommended CHO to enable them to make contact and receive further information as relevant. Participants were also given the telephone number as an alternative form of contact. At the four month interview, of the 62 people who had read the

package 20 had sent the postcard to the CHO to obtain further information. Not surprisingly, 19 of the 20 people who reported returning the postcard to the CHO had conditions other than diabetes. A smaller number had telephoned (N=3) or used the CHO website (N=7). A number of people had spoken with others about the package: 19 had spoken with their doctor or other health professional and 21 had spoken with someone else (including spouse, family, friends or work colleagues).

Figure 5: Use of the intervention package at the 4 month interview



DID THE INTERVENTION PACKAGE LEAD TO GREATER ENGAGEMENT WITH CHOS?

A primary aim of Study Two was to increase patients' access to and use of a CHO relevant to their main chronic disease. Table 7 compares the frequency and nature of CHO contact for the intervention and control groups. The figures shown indicate the number and percentage of study participants who reported each form of contact at *either or both* the 4 and 12 month interviews. As expected, those with diabetes had greater levels of CHO contact across the board and this differed little across the intervention and control groups (perhaps because the opportunity for change was minimal). There were two exceptions: those in the diabetes intervention group were significantly more likely to use the CHO website than those in the diabetes control group; and diabetes controls were more likely to use CHO services. These data are difficult to interpret, but they may simply be anomalous, or perhaps the package provided a prompt for people who were already engaged with the CHO to do something new (i.e., seek out the organisation's website).

For conditions other than diabetes, those in the intervention group were significantly more likely to have had some form of contact with a CHO for their condition: 41 percent compared with 21 percent ($p=0.001$). In particular, those who received the intervention package were more likely to have engaged in 'low intensity' contact during the course of the study: reading the CHO newsletter or other printed materials (31% compared with 15%; $p=0.005$) and discussing information received from the CHO with others in their social network (18% compared with 8%; $p=0.03$). Few study participants telephoned the CHO or talked with other CHO members and only a handful of people attended a CHO seminar or support group meeting.

Overall, the trial provides tentative results for the value of the intervention package in terms of increasing access to CHOs. There are some grounds for optimism for exploring ways to refine this intervention further: the effect size might be reasonably useful in getting people to access CHOs; and we should concentrate on chronic disease types in which there is normally little routine referral from the medical profession into CHOs, such as arthritis, kidney disease and asthma.

Table 7: Contact with CHO related to main health condition at 4 month interview or 12 month interview or both♦

	Diabetes n=64		Other n=212		Total n=276	
	Intervention n = 31 (%)	Control n= 33 (%)	Intervention n=110 (%)	Control n=102 (%)	Diabetes n=64 (%)	Other n=212 (%)
Telephoned CHO	6 (19.4)	3 (9.1)	2 (1.8)	3 (2.9)	9 (14.1)	5 (2.4)
Read newsletter	18 (58.1)	22 (66.7)	34 (30.9)	15 (14.7)***	40 (62.5)	49 (23.1)
Visited website	8 (25.8)	2 (6.1)**	8 (7.3)	4 (3.9)	10 (15.6)	12 (5.7)
Attended seminar	0 (0)	1 (3.0)	6 (5.5)	3 (2.9)	1 (1.6)	9 (4.2)
Talked with other CHO members	4 (12.9)	4 (12.1)	4 (3.6)	1 (1.0)	8 (12.5)	5 (2.4)
Attended a support group	1 (3.2)	1 (3.0)	0 (0.0)	0 (0)	2 (3.1)	0 (0.0)
Used CHO services	11 (35.5)	20 (60.6)**	2 (1.8)	3 (2.9)	31 (48.4)	5 (2.4)
Used CHO info to raise awareness among others	6 (19.4)	13 (39.4)*	20 (18.2)	8 (7.8)**	19 (29.7)	28 (13.2)
Member	13 (41.9)	18 (54.5)	2 (1.8)	1 (1.0)	31 (48.4)	3 (1.4)
<i>One or more CHO activities</i>	20 (64.5)	26 (78.8)	45 (40.9)	21 (20.6)****	46 (71.9)	66 (31.1)

♦ Intention to treat analysis was used. Participants in both the intervention and control groups who did not complete interviews at 4 and 12 months are included in the analysis. Those who did not complete 4 or 12 months are recorded as having had no contact with the CHO at either 4 or 12 months. For those who completed an interview at 4 months, but not 12 months, CHO contact is recorded according to their 4 month responses but, at 12 months, it is assumed no CHO contact was made.

* <.10; ** <.05; ***< .005; **** <.001

DID THE INTERVENTION PACKAGE LEAD TO CHANGES IN OTHER HEALTH-RELATED OUTCOMES?

Table 8 shows mean scores at each of the three study interviews for the main health-related outcomes assessed in the study: the Patient Activation Measure and the SF-12 Version 2 (Physical and Mental Component Summary Scales). The scores range from 0-100, with higher scores reflecting better outcomes. As above, intention to treat analysis was used, providing a conservative test of the intervention. Comparison of the mean scores at each of the interviews revealed no statistically significant differences between the intervention and control groups for either diabetes or other CHOs.

TABLE 8: Mean scores (with standard deviation) for the 276 participants on Patient Activation Measure and SF-12 Physical and Mental Component Summary Scales at baseline, 4 month and 12 month interviews[◆]

	Baseline		4 months		12 months	
	Intervention n = 31	Control n = 33	Intervention n = 31	Control n = 33	Intervention n = 31	Control n = 33
DIABETES n=64						
Patient Activation Score	59.63 (10.37)	58.60 (11.71)	61.89 (10.74)	59.86 (13.62)	62.56 (13.01)	61.16 (12.18)
SF-12 Physical Component Summary Score (sd)	40.04 (10.82)	41.47 (11.13)	39.98 (10.25)	41.90 (12.26)	41.49 (9.98)	38.42 (14.11)
Mental Component Summary Score	50.74 (12.30)	51.19 (12.71)	50.61 (11.25)	50.67 (13.11)	50.56 (10.51)	52.36 (11.72)
Other Health Conditions n= 122						
Patient Activation Score	63.31 (12.80)	61.45 (13.49)	62.67 (12.12)	61.39 (13.03)	62.64 (11.15)	63.70 (15.03)
SF-12 Physical Component Summary score	39.69 (12.95)	38.30 (12.63)	39.13 (12.70)	38.38 (12.96)	39.03 (12.83)	38.61 (12.40)
Mental Component Summary Score	51.14 (12.18)	51.69 (10.41)	51.20 (12.19)	52.40 (9.89)	51.28 (11.66)	51.55 (10.62)

◆ Intention to treat analysis was used. Participants in both the intervention and control groups who were lost to follow up at 4 or 12 months are included in the analysis. A return to baseline approach is used to handle missing data; that is, for those who did not complete 4 or 12 months their baseline score is recorded.

WHAT STOPS PEOPLE WITH CHRONIC DISEASE CONTACTING CHOS?

Only a small minority of people with chronic conditions ever make contact with a CHO.²⁶ At the baseline interview, 27.5 percent of our sample reported ever having contacted a CHO relevant to their condition. For those with conditions other than diabetes, this figure was much lower: 11.3 percent (compared with 81.3% for diabetes). About 40 percent of those (with conditions other than diabetes) who were sent the intervention package, with personalised referral to a CHO, made some form of contact with a CHO during the study period. At the 12 month interview, we asked participants directly about potential barriers to CHO use and the extent to which these would stop them from making contact with a CHO at this time. There were no statistically significant differences between the diabetes and other CHO groups, or between the intervention and control groups. For this reason, Table 9 shows the responses for the 164 participants who completed the 12 month interview.

The barriers that emerged seemed to relate strongly to the context in which people experience health problems and in which they make decisions about using services. The vast majority (88.3%) indicated they relied on their doctor to provide the care they needed. This, together with two-thirds of respondents stating they had not made contact with a CHO because their

doctor had not suggested it, underlines the integral role of the doctor in facilitating patients' access to resources for self management. More than half the respondents (58.5%) would not contact a CHO because they considered their health problems to be "not serious enough".

Having had recent contact with a CHO appeared to moderate these perceptions. In comparison to people who made some form of contact with a CHO over the previous year, those who had made no contact were significantly more likely to agree that 'your doctor hasn't suggested that you contact a CHO' (71.2% versus 54.9%), 'your health problems are not serious enough' (72.6% versus 47.3%) and 'you don't have enough time or are too busy' (53.4% versus 35.2%).

Those who had never contacted a CHO were asked if they could imagine a time they might contact a CHO in relation to their health. Responses to this open-ended question indicated many regarded CHOs as a "last resort", while again underlining the role of the doctor as a conduit to community-based services. Indicative responses in these two key themes are shown in Box 2.

BOX 2: WHEN MIGHT YOU CONTACT...

"if my situation became life threatening"
"it would have to be very bad"
"probably when it was too late"
"if directed by my doctor"
"if my GP recommends it"
"at my doctor's request only"

Table 9: Reasons why participants would not contact a consumer health organisation (164 participants who completed the 12 month interview)

	Frequency	Percentage
Your doctor gives you all the care and information you need	144	88.3
You are managing at the moment and don't need any extra information or support.	138	84.1
Your doctor hasn't suggested that you contact a consumer health organisation	102	62.2
Your health problems are not serious enough	96	58.5
You don't know enough about what consumer health organisations offer	91	55.5
You don't know what organisations exist	80	48.8
You don't really like being part of an organisation or group	80	48.8
It's too hard to get to consumer health organisation activities	79	48.2
You don't have enough time or are too busy	71	43.3
You don't have enough energy or are not well enough to be involved	65	39.6
The organisation wouldn't have anything useful to offer me.	64	39.0
It would cost too much money	41	25.0

KEY FINDINGS

- At baseline, around one in four patients with chronic disease recruited through general practice had ever contacted a CHO relevant to their condition. Patients with diabetes contrasted markedly with those with other chronic conditions: 81% had contacted a diabetes CHO at some time compared with 11% for other conditions.
- Tentative results support the delivery of the intervention package to general practice patients with chronic disease. Those with conditions other than diabetes who received the package were significantly more likely to make some form of contact with a CHO than those who did not receive the package: 41% compared with 21%. “Low intensity” contact such as reading the newsletter and discussing information received from the CHO with others were the most commonly reported forms of CHO activity.
- The intervention package did not lead to greater CHO access among patients with diabetes, most probably because of already high levels of CHO contact.
- The intervention package received strong endorsement from patients. The intervention package ultimately “reached” about half the intended audience: 54% said they had received it, recalled it and read its contents. Almost all who read it thought it would be a good idea for doctors to give the intervention package to their patients, and almost half would have liked to have received it sooner. Two thirds reported that they kept the package 12 months later.
- Receiving the intervention package did not lead to changes in chronic disease related outcomes measured in the study. Those who received the intervention package and those who did not had similar scores in terms of mental and physical health and patient activation at all data collection points.
- Two main attitudinal barriers seem to stop people contacting CHOs. The first is the perception that their doctor provides all the care and information they need. The second is that they are currently managing and have no additional need for support or information. Among those who had never contacted a CHO, there was a commonly held view of CHOs as a “last resort”. They would only be motivated to contact a CHO if they became substantially more unwell or at their doctor’s direction.

POLICY RECOMMENDATIONS

A print based intervention package to refer patients with chronic disease from GP settings to CHOs has potential with further refinements. This strategy is likely to be most efficacious in relation to chronic disease types in which there is normally little routine referral from the medical profession into CHOs such as arthritis, asthma and kidney disease.

Strategies to embed CHOs in the health system should be cognisant of the widely held perceptions that CHOs are viewed as a “last resort” and that managing health is something that takes place mainly in the doctor’s consultation room. This points to an underlying disparity between current health policy orientations and community perceptions, that is, between policy advocating community supported self management initiatives and community attitudes regarding pathways in managing a chronic health condition. Any such strategy must also take into account the practicalities and constraints of the general practice setting and ensure there are clear benefits for both health professionals and patients from any referral process that is prescribed in health policy directives.

CONCLUSIONS

The overarching question we set out to address was: Could more people with chronic disease use and benefit from CHOs? If so, how might contact with CHOs be increased?

The findings confirm the potential value of CHOs as a resource for chronic disease self management. People who contact CHOs report benefits, including the prompting of health actions that are conducive to chronic disease self management. However, those who make contact with CHOs represent only a minority of those with chronic disease. Our survey of GP patients with diagnosed chronic disease confirmed this.

Diabetes provides a notable exception. Arguably, one of our study's most compelling findings is that the integration of the peak diabetes CHO into the formal health system is associated with better and more timely access for patients. The question of how this model might be adapted to maximise the integration of CHOs that address other major chronic conditions warrants further detailed consideration.

Providing a low-intensity print based intervention package to general practice patients met with limited but promising success in increasing CHO contact among people with conditions other than diabetes. Patients viewed the intervention package favourably but further refinements, including stronger doctor endorsement, are likely to be needed to overcome some strong and pervasive attitudinal barriers in relation to CHOs.

A core strength of our study is the inclusion of a consecutive sample – of CHO users and general practice patients. However, caution needs to be exercised in the generalisation of findings. Our sample is confined to a small number of CHOs and general practices over a relatively short period of time and includes only those who could speak English to a sufficient level to complete a telephone interview. The response rates in both studies also need to be considered. While respondents and non-respondents did not differ in terms of key socio-demographic variables it is not possible to know whether they differed in other ways. It is also important to acknowledge that all data collected were by self-report and therefore subject to reporting error, including social desirability.

Despite these limitations, many of which are inherent in research of this type, the study provides the first detailed picture of CHOs in Australia and their potential to contribute to the chronic disease self management agenda. Taken together, the findings suggest CHOs are a valuable existing resource with an important place in a comprehensive multi-strategy approach to chronic disease self management. Strengthening linkages with the broader health system might be expected to enhance their current contribution and further evaluation of such efforts is warranted.

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