

"I've had a second chance, so I want to spread the message that cancer doesn't always have to be a death sentence. I also want to pay back some of the wonderful support I received from Cancer Council."

Margaret Royall, pancreatic cancer survivor and Cancer Connect volunteer

Pancreatic Cancer Support Project Final Report, February 2009

**Prepared by
Cancer Council NSW
for
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Executive Summary

This final report provides a descriptive analysis and evaluation of Cancer Council NSW (CCN) and NSW Pancreatic Cancer Networks (NSWPCN) program of supportive care - the Pancreatic Cancer Support Network, developed under the Cancer Australia funding program. It presents an overview of the three stages

1. Research Phase
2. Program development and evaluation
3. Strategic Promotion and Awareness Plan

undertaken to identify and evaluate approaches to increasing supportive care to individuals whose lives are impacted by pancreatic cancer.

In parallel to this project, the NSWPCN (NSW Pancreatic Cancer Network), funded through CCN (Cancer Council NSW) Strategic Partnership (STREP) Grant program led by Associate Professor Andrew Biankin, has focused on identifying and implementing a platform to improve research and clinical care for individuals diagnosed with pancreatic cancer.

Pancreatic cancer is a challenging disease for all affected, impacting on patients, carers and their family. Pancreatic cancer poses unique challenges for clinicians from all disciplines, and cancer researchers. Late diagnosis, poor prognosis, high mortality (<5% at five years), limited treatment options all contribute to high levels of psychosocial distress for people affected by pancreatic cancer. Unlike other tumour groups there have been no significant research developments in the area of pancreatic cancer for several decades. Prior to the establishment of the Pancreatic Support Network, there were no dedicated pancreatic cancer support services in Australia.

There are two key components to this project:

- analysis of the supportive care and information needs of individuals diagnosed with pancreatic cancer, their carers and family.
- development and evaluation of models of supportive care for those affected by pancreatic cancer.

Key Findings

The research identified significant unmet needs for information and support for people affected by pancreatic cancer; patients, carers and family.

Key stressors identified by participants in the research included:

- nihilism
- isolation
- constant threat of dying
- lack of support and information.

The findings demonstrated the need for a dedicated program of supportive care to alleviate high levels of psychosocial distress. This was developed and evaluated in the second phase of the project. The model represents a template adaptable for other tumour groups and is transferable to supportive care programs outside of NSW.

The Pancreatic Cancer Support Network offers interventions in a range of modes based on CCN's "10 Ways" Program. This report outlines the **six** new modules tailored to meet the identified needs of this cohort.

The partnership with NSWPCN is fundamental to the success of the program. It is a cooperative and beneficial relationship for both CCN and NSWPCN – providing support and information for people affected by pancreatic cancer - that enables both organisations to achieve maximum reach and impact within the target group.

This report recommends that this relationship continue and that a dedicated Pancreatic Support Network is an effective way of meeting the supportive care needs of people affected by pancreatic cancer.

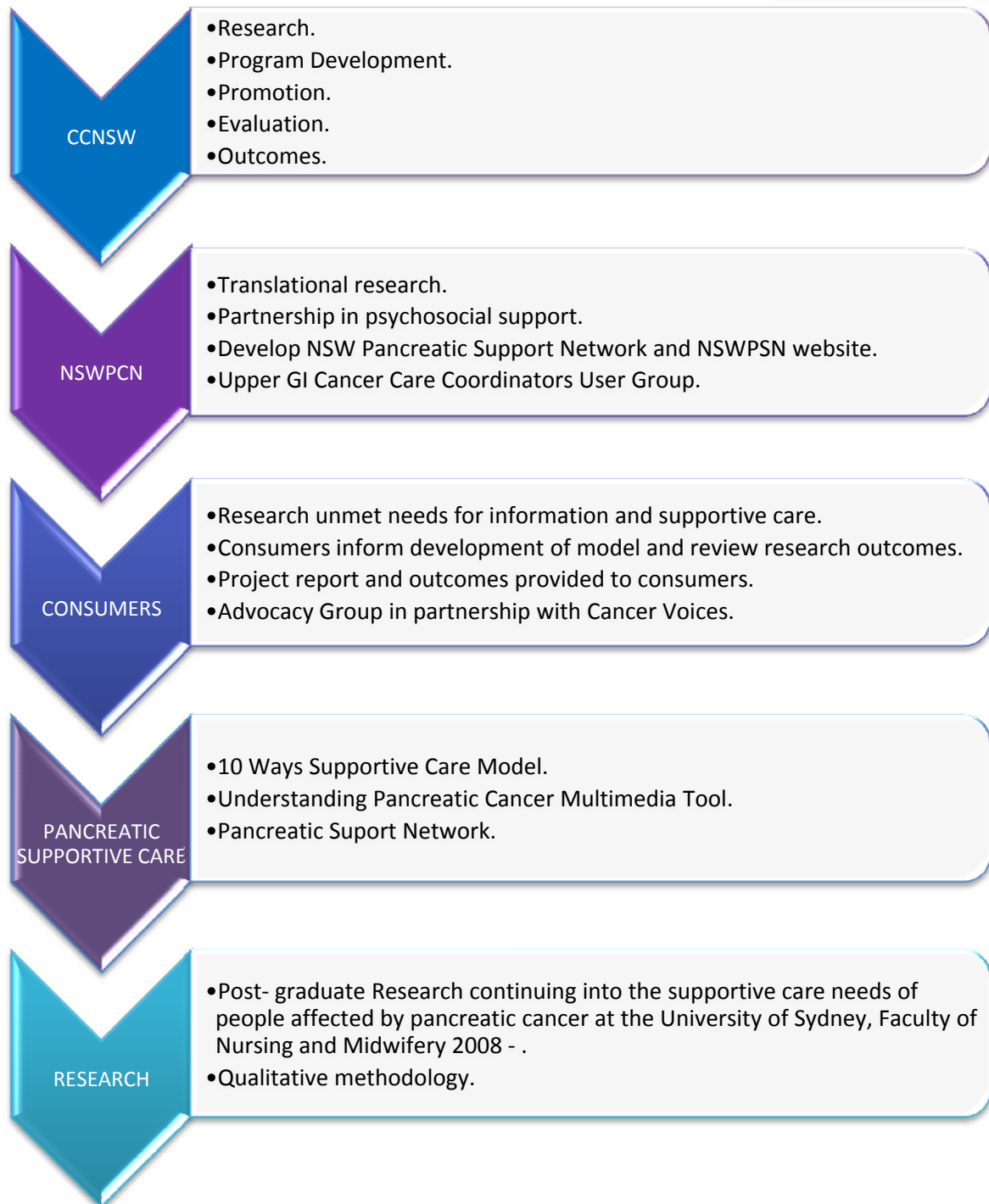


Figure 1: Pancreatic Support Network Flow Chart

Figure 1 provides:

- a layout of the critical roles of CCN and NSWPCN working together with consumers to develop the Pancreatic Supportive Care Model- the Pancreatic Support Network;
- an outline of ongoing psychosocial research for people affected by pancreatic cancer and outcomes identified as consumer priorities.

Pancreatic Cancer Support Project Final Report, February 2009

The Cancer Australia, "Building Cancer Support Networks Program Grant" has enabled Cancer Council NSW (CCN) to partner with NSW Pancreatic Cancer Network (NSWPCN) and jointly develop a Pancreatic Supportive Care Model (see Appendix) - the basis of the NSW Pancreatic Support Network (NSWPSN). This Final Report will present an overview of the Pancreatic Support Network and a List of Activities undertaken with funds June – December 2008.

- 1. Research Phase**
- 2. Supportive Care Model**
- 3. NSWPCN Partnership**
- 4. Consumer Involvement**
- 5. Conclusions**
- 6. Presentations and Publications**
- 7. Recommendations**

1 Research Phase

1.1 Aims of the research

1. To identify unmet needs for support and information, and
2. To develop a supportive care model that will meet those needs.

Due to the limited data available on pancreatic cancer patients' supportive care needs, a qualitative interpretative research design was used to guide the study. This approach allowed the perspectives of patients, carers and families to be explored, without predetermining what these might be.

Following ethics approval by CCN Human Research and Ethics Committee (HREC) in May 2007, recruitment commenced in June 2007 completing in June 2008.

Participants were individuals diagnosed with pancreatic cancer, carers or family members, recruited through CCN web information and fliers.

1.2 Data Collection Method

Data was collected using individual semi-structured interviews (phone or face-to-face) and focus group interviews patient and carer. Both individual and focus group interviews were audio-recorded, and transcribed prior to analysis.

13 Patients and 22 carer/family member participated in individual interviews. 6 patients and 5 carers/family participated in the focus group interviews.

1.3 Results

- 61 expressions of interests in participation.
- 43 returned written consent. 60% compliance for self-reporting distress levels on “Distress Management Thermometer” (NCCN:2008).
- 65% of participants reported their distress level as Moderate – Severe (Rating: 6-8).
- 35 interviews completed (13 patients, 15 carers and 7 family).
- 6 participants unable to be interviewed due to deteriorating health or death.

1.4 Analysis

Data was analysed using thematic analysis (as outlined by van Mannen). Three main themes were identified:

- Pancreatic cancer nihilism
- Dying/death
- Isolation

1.4.1 Nihilism came up as the most significant challenge faced causing distress in addition to their diagnosis particularly around:

- **prognosis**
“And he told her over the phone well yeah, what’s going to kill her first is the jaundice is going to move to her brain and that’ll kill her but aside from that if that doesn’t kill her, she’s probably only got 6 to 8 months with the tumour. Why would he tell my mother? You know I was very upset about that actually.” Female patient (#4), 50 years.
- **lack of treatment options**
“...he looked at the disc on the computer and then he pretty much just turned around and said to, you know, a 38-year old man that he had pancreatic cancer, it was in his liver, there was nothing much he could do and gave him 4 to 6 months. And then a nurse walked in and asked him a question and he walked out and left us. We all just sat there in shock. It was just, you know, M. said to him, I’m going to fight it and I’m going to prove you wrong and he didn’t even respond, it was just, you know, you don’t do that to a young man. It was just horrific.” Female carer (#12).
- **reluctance to refer on for surgical consultation**
“...we don’t operate, we don’t generally operate on anything that’s over about 2½ cm. Yours is bigger than that.” Female patient (#4), 50 years. (Family pursued second opinion and patient subsequently had surgery + chemo and is clear of disease two and a half years later. Now has returned to work.)

1.4.2 Dying/Death- Living under the constant threat of dying and the confusion and lack of understanding about what to expect, exacerbated distress:

"Every time I went to the doctor with my father he told us he was going to die but nobody will tell us what that exactly means." Male Carer/Family (# 1).

And:

"...he (doctor) didn't say he was dying. He didn't expect to die. We thought we had more time." Female carer (#6).

1.4.3 Isolation was increased by lack of support and information compared to other cancers:

"Yes, so yeah, it's been tough. I have to say, I don't feel like there's a lot of support out there for people with pancreatic cancer, I mean, all I hear about is breast cancer. I just kind of sit there and think, what about all the other cancers? Female carer (#12).

1.4.4 Participants expressed strong emotions particularly; anger, frustration, grief and sadness in both the interviews and the focus groups:

"I am sad, but, I am not sad that he died, as I wouldn't want his suffering to go on, but I am angry that no-one trusted us with the information that he was dying. I feel robbed. We would have prepared more, done things differently, the fact that it was so quick. Pancreatic cancer is so quick. The doctor must have known he was so sick. Why didn't he tell me when I asked him?" Female carer (#6) Husband died 13 weeks after diagnosis.

1.4.5 Six critical areas of need

Psychosocial support and information needs identified as at:

- diagnosis/prognosis
- hospital admission/start of treatment
- post-surgery/pre-chemo vacuum (gap in service)
- treatment end/ survival
- palliative care
- bereavement.

This research is being continued through post-graduate research. The full results will be published and made available to Cancer Australia.

1.5 Summary

Pancreatic cancer is one of the most devastating and lethal human cancers. It persists as a major unresolved health problem. There have been no breakthroughs in research and treatment in pancreatic cancer for more than thirty years. This situation contributes to the marked nihilism surrounding this disease.

Nihilism is a significant barrier to medical and health professionals making referrals to this supportive care program. The ongoing and widespread assumption is that nothing is available. To combat this nihilism, a strategic program of promotion involving health and medical professionals is crucial. Such a program allows people affected by pancreatic cancer to access much needed psychosocial support.

Feelings of isolation and the *constant threat of dying* mean people affected by pancreatic cancer are at high risk of distress and demoralization. Simon Wein, (2008:160) a prominent Palliative Care Physician, suggested that care should be exercised when using the term dying, as "it is prone to misinterpretations and may lead to demoralization." He also states that "dying must not preclude living".

The aim of the Pancreatic Support Network is to offer realistic hope for quality of life to end-of-life: "A limited life expectancy can include plenty of activities, until dying (or death) supervenes." Wein (2008).

The Pancreatic Support Network is a program of tailored psychosocial support interventions available in separate modules that are designed to reduce levels of significant distress.

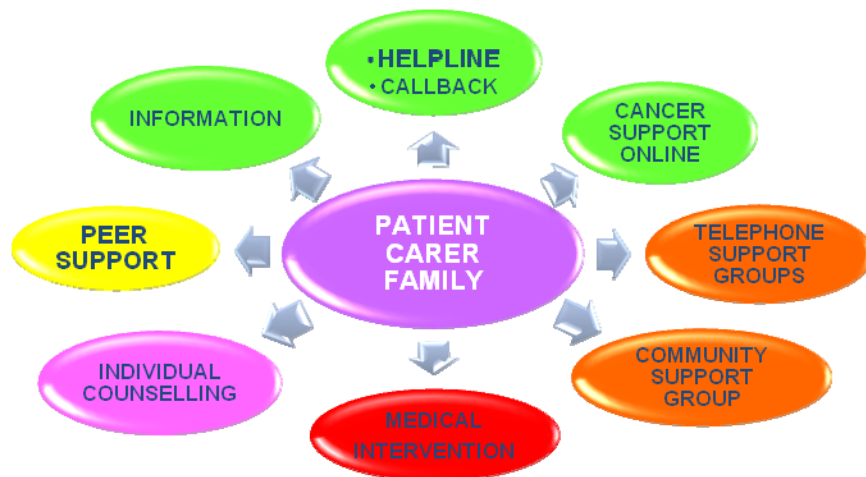
The core modules are designed for adaptability, transferability and reachability.

- Adaptability to other tumour sites e.g. brain, myeloma.
- Transferability - to other Cancer Council interstate programs.
- Reachability - a plan to engage with stakeholders and gatekeepers, to enable the program to reach out to end users with high mortality cancers in a short time frame.

2 Supportive Care Model

The Pancreatic Supportive Care Model (PSCM) is based on CCN's '10 Ways' Program of Support and Information. The research phase, which identified areas of supportive care need for people affected by pancreatic cancer, informed the development of this model. Below is a report of new supportive care services built into the '10 Ways' Program that forms the core of the Pancreatic Support Network. It offers **five** levels of intervention according to assessed level of distress (Figure 2). It is delivered in a range of modes to suit consumers' different preferences and accessibility.

- Print
- Online
- Telephone
- Face-to-face
- Individual
- Group



LEVEL 1: (0-1) Universal Care -Information, triage to model interventions.
LEVEL 2: (2-3) Supportive Care - Psycho-education, emotional support, and peer support.
LEVEL 3: (4-5) Extended Care - Coping skills intervention.
LEVEL 4: (6-8) Specialist Care - Individual Counselling.*
LEVEL 5: (9-10) Acute Care - Referral to specialist medical service.

Figure 2: Pancreatic Supportive Care Model

- Levels 1, 2 and 3 interventions, (Pancreatic Telephone Support Groups) have national potential.
- Level 4 and 5 interventions are easily adaptable to existing local services in each State.

* 'Individual Counselling' is a CCN program offering subsidised phone or face-to face counselling to people affected by cancer, who cannot access those services through their own treatment provider.

2.1 Print

“Understanding Pancreatic Cancer” (UPC) booklet was published in May 2007. It was produced with input from researchers, clinicians and health professionals from the NSWPCN. It provides information on the latest treatment and care of pancreatic cancer. It includes a detailed section on ‘Diet and Nutrition’, highlighted in the research as an area of particular need.

- 6627 UPC (Understanding Pancreatic Cancer) booklets distributed throughout NSW and nationally to SA, WA and QLD.

It is the keystone of the Pancreatic Cancer Support & Information Pack (PCSIP) which contains:

- Understanding Pancreatic Cancer booklet
- Emotions and Cancer booklet
- Food and Cancer booklet
- Caring for someone with cancer booklet
- 10 Ways flyer
- “I’ve had cancer too!” Connect - Peer Support flyer
- Telephone Support Group flyer
- My Cancer Care Diary
- Cancer Helpline fridge magnet
- Feedback Form.

200 of these PCSIPs (Pancreatic Cancer Support & Information Pack) were initially distributed in a Pilot Program June 2007- June 2008, at Bankstown Hospital in conjunction with two NSWPCN Upper Gastro-Intestinal (Upper GI) surgeons and the Chemo-oncology Cancer Care Coordinator.

64 PCSIPs have been sent out through Cancer Council Helpline from June 2008 to date. They are also distributed directly to consultants in the NSWPCN, Cancer Care Coordinators and treatment centres on request. The demand is constant and almost 400 are now in circulation.

2.1.1 Discussion

The PCSIP feedback (previously reported) was positive overall. It showed that this was an effective tool to provide information and pathways to supportive care services:

“After the shock, it was something to give me help in understanding and give me contacts etc”. Male 40-49 years (given pack at diagnosis by surgeon).

General user consensus on:

- the colour-coded ‘purple pack’
- tailored support and information resource available to give to patients around diagnosis
- discretely labelled opaque plastic pack
- useful to keep everything together.

Barriers highlighted by end users:

- large amount of printed information
- only available in English.

Barriers highlighted by consultants distributing the PCSIPs:

- volume of information
- heavy and cumbersome to handle (foolscap purple plastic envelope).

2.1.2 Summary

The packaging of the Pilot PCSIP is deliberately colour coded 'purple'. As 'pink' is for breast cancer, 'purple' is for pancreatic cancer. The purple plastic pack – an easily obtainable product – met consumer's demand for a discreetly packaged and dedicated support and information pack. It attracted both positive and negative comments.

PCSIP feedback has informed the re-design of the CCN's, Cancer Support and Information Pack (SIP) and the subsequent production of a Pancreatic Support Multimedia Tool.

Without dedicated funding, the PCSIP - at \$10.75/unit - is not cost-effective on an ongoing basis to distribute as a separate resource. In its current format, the PCSIP (Purple Pack) will continue to be distributed to June 30 2009.

From July 2009, the Pancreatic Cancer Support and Information Pack will be distributed as the Pancreatic Support Multimedia Tool packaged within a re-designed CCN SIP (Cancer Support and Information Pack). To continue producing this resource as a separate and colour-coded resource will require additional funding.

2.2 Pancreatic Support Multimedia Tool

CCN awarded 'Media One' the contract to produce a Pancreatic Multimedia Support Tool in January 2009. The production time is four to six months. This package consists of:

- 12 video modules presented in DVD (1 hour) format for people affected by pancreatic cancer (with LOTE options), distributed (clamshell or standard case) within CCN SIP
- two modules for medical professionals (Best practice/Research and Support Options)
- a micro-site housed within CCN website which will be linked to NSWPCN
- reply-paid card.

It is designed as a resource to complement print material to be distributed around diagnosis, as part of the CCN SIP. The 12 web ready video modules will present:

- information specific to pancreatic cancer in line with the "Understanding Pancreatic Cancer" booklet
- advice from a range of health and medical professionals from the NSWPCN
- patient and carer testimonials
- supportive care services, including vision from SPRING UP! Community Support Group sessions.

Video modules will be produced in DVD format. These will also be uploaded onto a CCN micro-site which is linked to the NSWPCN website. They can also be uploaded to social network sites, e.g. YouTube, to enable maximum access for the user group. The micro-site will enable open web access and retains the potential to be updated.

The professional modules, loaded onto USB Data-sticks, are designed to be distributed with the reply-paid postcard to General Practitioners, all consultants treating pancreatic cancer and clinicians in the NSWPCN.

The reply-paid postcard is a cost-effective way to deliver the supportive care resource to the target group, via direct contact with medical professionals. This mode of distribution will be evaluated for reach and impact.

This support tool fulfils the objectives of the Pancreatic Support Network by providing easily accessible up-to-date information and pathways to support services in the shortest possible timeframe, via print, visual and online (with CALD options) modes.

2.3 Cancer Connections - Pancreatic Forum

The Pancreatic Forum is an online community support service for people affected by pancreatic cancer that can be accessed twenty-four hours. It forms part of our Online Cancer Support www.cancerconnections.com.au which is moderated by a CCN facilitator. It provides opportunities for people:

- to connect with others who understand and are willing to share their journey
- to engage in Live Online Forums with health and medical professionals.

People access the site locally, nationally and internationally.

Three 'Live Forums' were held in 2008 with medical and health professionals:

- **Diet and Pancreatic Cancer**, April 2008 - with two oncology dieticians
- **Clinical Trials and Pancreatic Cancer**, August 2008 - with clinical and medical researchers
- **Coping with the Festive Season**, November 25 - with a specialist oncology clinical psychologist and a counsellor.

2.3.1 Evaluation

Since the site's launch in November 2007, as 'Cancer Support Online'- Pancreatic Forum has maintained the highest volume of traffic of all tumour-specific forums (Table 1). This has proven to be a pivotal part of the Pancreatic Support Network.

The Live Forums attracted participants globally. Participants in each Live Forum requested more to be held. Plans are in place to continue a program of Live Forums with health and medical professionals throughout 2009. Based on this model they will be promoted across the whole of the Cancer Support Online Forums.

Cancer Support Online	Forum-Views	Message Streams	Discussion Topics	Comments
<ul style="list-style-type: none"> • 12 Tumour-specific Forums • 1 Carers Forum • 6 Topic-based Forums including General Forum <p>LIVE FORUM NOV 25: "Coping with the Festive Season"</p> <ul style="list-style-type: none"> • 90% Aus. Participants • 55% from Sydney Metro • 10% International from USA, Canada, UK, Malaysia, NZ. 	10000+	150	34	<p>"I am new here, I have been looking for a place to get advice, vent and let out all the emotions that go with this awful, ugly monster! 😞 Not to mention what it does to families, they always say that when things are low you see the "real" people, how true! "Chat 9.30pm July 2008</p> <p>Reply 1: "I'm so glad you've found somewhere to vent!! We all need it at times. I was diagnosed in Aug 05 and I have some idea on the burden on the family. I honestly think my diagnosis was harder on my family than it was on me!! Hang in there; just know you are storing memories with your mum that the others are missing out on." Chat 10.49pm July 2008</p>

Table 1: Pancreatic Online Forum Evaluation Summary

2.4 Peer Support - Pancreatic Connect Volunteers

This service provides one-on-one telephone support for up to four calls. Both volunteer and client are followed up after matches, throughout program to debrief. Training and guidelines are provided to set personal boundaries and maintain safety for Connect Volunteers:

- two pancreatic cancer survivors of two years plus since diagnosis have been trained as Connect Volunteers as a result of this project
- one male 50-59 years and one female 50-59 trained early 2008
- both have had Whipples surgery, chemotherapy and were given a prognosis of less than six months. With regular monitoring, they are living disease- free. Both have now returned to work.

Cancer Council Connect (Connect) and the pancreatic cancer volunteers are promoted through Connect's (Cancer Council Connect) program promotion plan as implemented in the hospital setting and through Cancer Council Helplines nationally. The Connect volunteers are a valued part of the Pancreatic Support Network and work effectively to support people newly diagnosed with pancreatic cancer.

2.4.1 Evaluation

Connect is a key element of the Pancreatic Support Network, directly meeting the needs of people affected by pancreatic cancer. Being able to connect with others who understand, helps significantly reduce the sense of isolation. The fact that there are survivors living well offers hope for those diagnosed.

The presence and input of survivors also lessens the sense of 'nihilism' around this disease for the target group and medical professionals alike. As a telephone support service, the Connect program is available nationally via Helpline in each state (Table 2). Referrals are increasing due to program promotion.

Connect Referrals	Matches	Average Age	Barriers	Comments and Feedback
8	5 (3F, 2M)	50 years	<p>Metastatic Disease- volunteers not trained to support this group. Program boundaries exist to ensure wellbeing of volunteers and to work within resource and budget allocations.</p> <p>Male Connect volunteer had some time out of the program this year. Some male clients particularly wanted to speak to another male. This precluded all matches being made.</p>	<p>Client: "I need to talk to someone who has had the whipple resection procedure, someone who could tell me how to fight the cancer. 2 months after my surgery I am still too weak for chemo. My surgeon seemed to have given up on me. How do you cope when doctor told you that you had no hope because the cancer has started to regrow?"</p> <p>Connect Volunteer: Felt call to above client went well and she was told she was 'inspirational' at the end of the call. Client asked lots of questions about recovery and diet and referred her back to Dr for specific medical questions.</p>

Table 2: Connect Evaluation Summary Jan-Dec 08

2.5 Pancreatic Telephone Support Group

CCN facilitates Telephone Support Groups (TSG) specifically to enable geographically and physically isolated people and marginalised patient groups such as those affected by pancreatic cancer to participate in professionally led support groups. The aim of the Pancreatic Patient Support TSG (Telephone Support Group) is:

- to improve and increase equity of access to psychosocial support for pancreatic patients in NSW (and nationally within budget constraints, as no other dedicated services exist)
- to reduce the emotional, physical and practical challenges for this marginalised patient population.

This support service has proven to be the crucial service module of the Pancreatic Support Network enabling people diagnosed with pancreatic cancer throughout Australia, to access a support group. It is:

- a tele-conferenced support service provided free of charge to all participants
- led by two trained facilitators
- an 'open' group held fortnightly for one hour for between 3-7 participants
- a 'safe-space' for participants to share their related experiences/challenges
- possible to participate from anywhere; landline, hands-free, mobile.
- time-economical.

2.5.1 Distribution of participants

TSG clients were drawn from an extensive range of localities throughout metropolitan, rural and regional New South Wales with additional participants being included, where possible, from Western Australia, and Queensland and ACT. e.g. Table 3 shows the spread of participants for the last half of 2008.

NSW- REGIONAL	METRO	INTERSTATE- ACT	QLD	WA
2528 - Barrack Height	2000 - Haymarket	2904 (ACT)	4489 – Wyandra(rural)	6057-Maida Vale WA
2536 - Batemans Bay	2022 - Bondi Junction			6069-Victoria Pk WA
2660 - Culcairn	2044 - St Peters			
	2095 - Manly			
2730 - Batlow	2097 - Collaroy			
	2119 - Beecroft			
2785 - Blackheath	2137 - Concord			
2795 - Bathurst	2147 - Kings Langley			
2800 - Orange	2220 - Hurstville			
	2233 - Engadine			

Table 3: Participant Postcodes/Localities - period 1/7/2008 – 31/12/2008

On the basis of the data in Table 3, it can be seen that participants in the Pancreatic TSG in the period 1/7/2008-31/12/2008 were drawn from urban and rural and regional areas in roughly equal measure. Although geographical distance is reflected here, the degree to which a participant is 'isolated' cannot be simply reduced to this one objective measure.

Anecdotal (self-reported) evidence from the Pancreatic TSG indicates the isolation people feel (in addition to the terminal nature of their condition) is heightened by negative attitudes and related clinical experiences within the health system and with health professionals. Participants feel marginalised within the health system by their disease:

"I was going to a general support group but most of the people there had breast cancer or prostate cancer. There is a lot of help for them. I felt lonely. In the Pancreatic TSG I can talk to people who understand what pancreatic cancer is like. I don't have to be positive all the time. It is comforting."
 Female participant, 60-69 years. Stage 4 Advanced non-resectable ductal adenocarcinoma.

2.5.2 National Links

The continued involvement of Western Australian participants continues a significant trend begun in the first half of 2008 and is based upon a strong relationship with a key Upper GI (Upper Gastro-Intestinal) Cancer Care Coordinator in that state's capital. Since the inception of the Pancreatic TSG, and beginning in early 2008, there have been seven (7) referrals from that same health worker, a pattern that reinforces the importance of establishing and maintaining relationships with key 'gatekeeper' staff to enable ongoing referral stream activity.

Presentations at national and international conferences have consolidated a number of working relationships with key medical and health professionals throughout Australia. COSA 2007 Poster Presentation facilitated this ongoing engagement with the program for medical and health professionals from WA treatment centres and Cancer Council WA.

2.5.3 Evaluation

Helpline C25 TSG Referrals June-Dec 08	Group Participants	Gender	Average Length in Group	Feedback
33	21 Active Pancreatic 10 Carers 3 Bereavement *	11F; 10M 10F 3F	128 days	<i>"I love the phone group and get lots out of it- very reassuring to me that others are having similar problems."</i> WA Participant Dec. 08.

Table 4: Pancreatic TSG Jun-Dec 2008

2.5.4 Summary

The TSG is a safe place where participants share and support each other via mutual understanding. The 'open' group format allows people to come into the group as they are able. Death and thoughts on dying are openly discussed in the group. Participants typically stay in the group, even when severe illness and imminent death have prevented all other social activities. The average length of stay in group is 90 days overall.

The severe illness and high mortality rates for pancreatic cancer impact significantly upon fortnightly participation and long-term retention rates in Pancreatic Patient TSG. Given the nature of this cancer type, this situation is unavoidable, yet heightens the importance and value of psychosocial support being provided to this patient group.

2.6 SPRING UP! Community Support Group Program

This program is a new program of community support, designed specifically as a result of this project. Based on CCN's community support program, it offers a model of information and mutual-aid. The distinctive design of 'SPRING UP!' gives an identity to the Support Groups that moves away from the negative connotations of pancreatic cancer. SPRING UP! is for patients, carers and family offering:

- face-to-face support
- practical coping skills
- mutual understanding
- sharing together with others
- hope for a way forward
- quality of life till end of life.



The research noted multiple mentions of the need for face-to-face support groups for people affected by pancreatic cancer. The disease itself presents considerable barriers for attendance to community support groups such as:

- rapid progression of disease
- small window of opportunity to access support services
- comparatively low decentralised incidence
- geographical divergence.

Factors that will enable the target group to access face-to-face groups are:

- NSWPCN support
- Strategic promotion and engagement with key stakeholders
- Ease of referral system into group
- Proximity to treatment centres
- Convenience of location; parking and transport
- Time and duration of group
- Frequency of group
- Trained facilitation
- Availability of facilitator

A six month initial pilot group based at Bankstown Hospital June – December 2007 (previously reported), demonstrated interest from the target group.

Identified barriers to the viable hosting of this service in the acute care setting by in-house staff were:

- insufficient staff capacity
- conflicting time pressures
- overlapping of roles
- acute-care focus rather than supportive care delivery.

These factors informed the subsequent development of the 'SPRING UP! Community Pancreatic Support Group' model in early 2008.

Two groups commenced in April 2008, with NSWPCN support, a CCN facilitator and two volunteer facilitators in two CCN regions. We recognised that these groups would take time to develop and allowed a twelve month plus timeline to June 2009.

Two locations were found that fitted the criteria:

- Metro west (St Joseph's Hospital Palliative Day Care Centre, Auburn).
- Metro north (Roseville Uniting Church Hall).

2.6.1 Strategic Promotion Plan

The plan engages with stakeholders and gatekeepers to enable these dedicated supportive care programs to reach people affected by pancreatic cancer. The four critical components of the plan are:

- effective partnerships i.e. Cancer Care Coordinators, oncology nurses, treatment centres.
- support of NSWPCN clinicians
- streamlined referral process
- local media and promotion.

NSWPCN clinicians are solid supporters of the Pancreatic Support Network. The Metro north experience (see below) has shown that actively engaging with medical and nursing staff establishes effective pathways to supportive care in the shortest possible timeframe. However, **all four elements** above need to be in place to enable a face-to-face support group to become well established.

2.6.2 Metro west SPRING UP!

The Metro west SPRING UP! has not developed into an established group. A different approach is currently being trialled Feb-June 2009. Groups will rotate around three newly formed CCN Community Hubs - outreach CCN services formed in partnerships with local government areas. Hubs have been progressively opened from May - Nov 2008 in Casula, Penrith and Rouse Hill.

Hub Community Network Coordinators seek to establish partnerships and forge networks with key stakeholders in their local treatment centres e.g. Bankstown Hospital, Liverpool Hospital, Nepean Hospital and Westmead Hospital. Their responsibilities include promoting and coordinating Support Groups in their areas.

The Metro west region in particular covers a vast geographical area. This has been a barrier to establishing a SPRING UP! group at one location in this region. Individuals who have attended have usually travelled considerable distances to meet with others. Regular participation has been difficult to achieve.

The Upper GI Cancer Care Coordinator's role here is crucial. Their key role in identifying psychosocial support needs and being the point of contact for referral into support must be acknowledged.

An Upper GI Cancer Care Coordinator was only appointed at Bankstown Hospital in November 2008. We are currently working together with the new Care Coordinator and the Hub Community Network Coordinators, to establish whether a community support group is an appropriate resource to meet the needs of people affected by pancreatic cancer in Metro west.

2.6.3 Metro north- SPRING UP! Evaluation

Presented here is a process evaluation as the final outcome is yet to be determined.

The Metro north SPRING UP! Group developed steadily from June 2008. From August 2008 the Group has met monthly with 17 occasions of attendance. Members attend according to their time-commitments and state of health. One foundation member has attended every group thus far.

The facilitator’s role, in addition to the groups, includes:

- contacting each member monthly pre-group
- conducting regular needs assessment
- triaging to other supportive care services as per need.

A coordinated approach, with all four elements in the Strategic Promotion Plan, has resulted in this Group functioning and growing steadily.

Metro north Group Referrals June-Feb 09	Group Participants	Gender	Age	Feedback
19 Helpline 11 Cancer Nurse Coordinator	15 Patients 3 Carers 5 Contacts ongoing 5 Referrals pending 2 Deceased	7 F; 8 M 3 F	45y-72y	<p>Facilitator: The Roseville face-to-face group has really ‘grown’ since it first functioned in August. All participants have expressed their gratitude for the program and most have attended more than once. The delivery of the program has also ‘grown’ with the development of the group agreement and format of the group so that participants feel safe and have ownership. As a facilitator I look forward to watching the group continue to develop.</p> <p>Member: <i>I was diagnosed 18 months ago and all the Drs wanted to write me off. I wanted to talk to other people but couldn’t find any support groups. I saw this on the internet. I am going to come every group. I’m doing OK and I want to tell others. I feel really strong and I reckon I am healthier than before. We need to show just because you’ve got pancreatic cancer... you’re still alive.</i></p>

Table 5: Evaluation Metro north SPRING UP!

2.6.4 SPRING UP! Summary

The Metro north SPRING UP! Group is growing strongly and feedback from the members validates the importance of providing community face-to-face groups for people affected by

pancreatic cancer. This disease presents specific challenges to providing community support.

The strategic promotion plan of awareness, referral, and engagement is critical to the success of all modules of the Pancreatic Supportive Care Program. The establishment of this service module demonstrates the importance of raising awareness and engaging with the medical and health community.

3 NSW Pancreatic Cancer Network

The partnership with NSWPCN is vital to the success of this comprehensive supportive care program for people affected by pancreatic cancer. This relationship has facilitated:

- Ready access to clinicians and researchers.
 1. Acknowledgement of importance of psychosocial care.
 2. Expertise to inform into program development and support materials.
 3. Willingness to participate in information/education programs.
 4. Pathways of promotion and awareness of program in NSWPCN Newsletter.
 5. Good referrals into supportive care programs.
- Translational research.
 1. Two-way flow of information: research <-> consumers needs.
 2. Opportunities for consumers to inform into future research directions.
 3. Consumers feel their voice is heard.
- Credibility of program for consumers and stakeholders.
- Access to a network of health and allied health professionals.
- Establishment of NSW Pancreatic Support Network.
 1. Dedicated webpage
 2. Credible links to information
 3. Promotion of support program and special events e.g. Live Online Forums
 4. Tailored information in response to consumers needs e.g. Clinical Trials, Dietary Issues
- Professional links to promote supportive care program e.g. Australian Gastro-Intestinal Trials Group (AGITG); Australasian Pancreatic Club. Invited to speak about Pancreatic Supportive Care Program at 2009 AGITG Scientific Meeting in Queensland.
- Further research. Further research into the supportive care needs of people affected by pancreatic cancer is being continued at post-graduate level by Ms Helen Gooden, Project Coordinator, with two supervisors from NSWPCN, Professor Kate White and Associate Professor Andrew Biankin.
- Partnership with CCN for professional support for Upper GI Cancer Care Coordinators (CCC).
 1. User group to network Upper GI CCC's (Cancer Care Coordinators) around Australia to share best practice.
 2. Online support forum.
 3. Professional debriefing to avoid burn-out-
In the course of this project there has been a high turnover of Cancer Care Coordinators. The workload in this position is considerable. The CCC's role is crucial for the consultants, the patients and their families. CCN and NSWPCN recognise the importance of supporting them in their role and wish to encourage more CCCs to be appointed. At present, there are less than 10, Upper GI CCCs Australia-wide.

We value them and want to support them to stay in their roles. Enabling them to connect together and support them in their role promotes professional development, reduces burn-out and minimises staff turnover.

4 Consumer Involvement

Consumers involved in this project have expressed a depth of commitment well beyond their immediate needs. There is a strong motivation to make a difference for others affected by the disease. Particularly with regard to:

- Advocacy
- Research
- Awareness and Fundraising

Advocacy Groups: In partnership with Cancer Voices, CCN will support interested consumers with training and resources to form advocacy groups. Two consumers, one in Victoria and one in NSW, have registered their interest as prospective group leaders.

Research: CCN and NSWPCN support consumer involvement in research. CCN provides consumer training for research review panels. Through this project two consumers have been invited to participate in two independent research programs. Partnership with Cancer Voices facilitates access to consumer review opportunities across health and medical research.

Fundraising: There is strong support and interest from consumers to dedicate a day to Pancreatic Cancer Awareness. CCN regularly receives enquiries regarding purple ribbons and ideas to raise money and awareness for pancreatic cancer.

"I have recently had an unwanted awareness of pancreatic cancer. My wife's father was recently diagnosed after he was asked to have an anomaly on an x-ray for an unrelated condition examined.

Why is it that the research into the 4th greatest cause of cancer deaths has been neglected for so long? It seems that for over 50 years, the mortality rate has remained unchanged. Why is it that there is early diagnosis testing for breast, bowel and prostate cancer, but not for pancreatic cancer?

I had a chat to the people at the Garvan, which supports one of the very small number of research institutions dedicated to pancreatic cancer research. I get the impression that they struggle for funding over the other types of cancer that provide more "good news" stories about diagnosis and cures.

Well, that's not good enough! I've started a fundraising campaign locally where people can make donations in return for seeing me vandalise my face with a purple moustache for the month of November. I've approached over 350 business and personal contacts for support and am seeking some media coverage to further spread the word. I want to raise around \$40,000 for the month of November for Pancreatic Cancer research." Excerpt from post on Pancreatic Forum Nov. 2008

Pancreatic cancer deeply affects many people. Strong motivation exists within the community to promote and further research into pancreatic cancer, as evidenced by the recent response to a CCN targeted campaign in 2007-2008 Financial Year.

5 Conclusions

The research phase identified the challenges faced by people affected by this disease with 'nihilism' being a constant theme. Participants in this project, and all who continue to contact CCN looking for support and information for coping with pancreatic cancer, express relief that finally, 'something is happening to help those affected by pancreatic cancer'.

This project has enabled people affected by pancreatic cancer to have their voice heard. It has also provided a contact point for this community to gather, express their concerns and needs, and promote their ideas in order to make a difference for the future for pancreatic cancer.

While it will take a breakthrough in research to completely breakdown the nihilism surrounding this disease, a tailored supportive care program demonstrates to this community that they are no longer isolated. Support and information empowers people, gives them coping skills to find a way forward and a way to live well in the face of death.

People affected by pancreatic cancer frequently spoke of their 'death sentence':

"I was given a death sentence over the phone at 5pm on a Friday night... and I hadn't even killed anyone." Patient #10, Female, 57 years.

They strongly expressed the need to engage with others who understood, to be able to talk about their feelings, laugh and cry together over what it is like to **live** with death. For that is the focus of the program, realistic hope for quality of life, "living until death supervenes."

The Pancreatic Support Network is designed to empower with information, and support with coping skills to enable best quality of life. Working together with the medical and health professionals, we aim to provide the best outcome for people affected by pancreatic cancer.

6 Conference Presentations and Articles

Presenting the Pancreatic Support Network Program to the national and international academic and professional community is a vital component of the Strategic Promotion Plan:

- TITLE: *"Nobody gives a sh.. about pancreatic cancer!" - A Tumour-specific Support and Information Model.* Poster Presentation. COSA-IACR-ANZGOSA 2007. Adelaide SA.
- TITLE: *"Involving the Consumer in Pancreatic Cancer Research- Pancreatic Cancer Support Project 2006-2009."* Oral Presentation. Involving People in Research Symposium. March 2008. Perth WA.
- TITLE: *"Empowering Families, Empowering You"*, Oral Presentation. Cancer Nurses Society of Australia (CNSA) 11th Winter Congress 'Cancer and the Family', June 2008. Gold Coast QLD.
- TITLE: *"Partnerships- The key to meeting needs of people affected by pancreatic cancer: A Tumour-Specific Supportive Care Model."* Oral Presentation. International Conference on Cancer Nursing. 15th International Congress, Singapore, August 2008.
- TITLE: *"Pancreatic Cancer Supportive Care Model - Unmet Needs For Psychosocial Support For Patients, Carers and Families"*. Oral Presentation by Gillian Batt, Director Cancer Information and Support Services, Cancer Council NSW at the UICC World Cancer Congress 2008, Geneva, Switzerland, August 2008.
- TITLE: *"SAY NO TO NIHILISM'- People affected by pancreatic cancer, patients, carers and family voice their unmet needs for psychosocial support."* Poster presentation. COSA-IACR-ANZGOSA 2008. Sydney NSW.
- TITLE: *"Recommending research priorities in pancreatic cancer: listening to the consumer voice."* Poster presentation. COSA-IACR-ANZGOSA 2008. Sydney NSW.
- TITLE: *"As the bell tolls – A foundation study on pancreatic cancer consumers' research priorities."* Submitted for publication to BMC Cancer, November 2008.

7 Recommendations

Continue the partnership with NSWPCN to continue to provide support and information to people affected by pancreatic cancer.

Further research:

- to develop needs assessment tool for people affected by pancreatic cancer
- to measure quality of life effect of supportive care interventions for people affected by pancreatic cancer
- to develop and evaluate closed online community support groups as an intervention for people affected by pancreatic cancer.

Further funding for:

- national telephone support group for people diagnosed with pancreatic cancer
- Pilot Pancreatic Support Network Model for other tumour sites that have low incidence and high mortality.

Appendix



Pancreatic Supportive Care Program

**Cancer Council Helpline
13 11 20**



- Call Back Service
- Pancreatic Cancer Support and Information Pack
- Understanding Pancreatic Cancer DVD
- Peer support- Pancreatic Connect Volunteers
- Telephone Pancreatic Support Group
- SPRING UP! Community Support Groups
- Cancer Connections - Online Pancreatic Forum
- Individual Counselling
- Living Well After Cancer Workshops
- Bereavement Telephone Support Group

10 ways



**Australian Government
Cancer Australia**

