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Information sharing for the management of chronic conditions in primary health care:

How does it work and what are the outcomes?

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Executive Summary

RESEARCH PURPOSE

This research examined how information sharing within multidisciplinary health care teams can be enhanced to optimise the effectiveness of care planning for chronic condition management. The research is intended to inform policy to maximise the benefits that can be achieved through future resource allocation and expenditure in the primary health care system.

METHODS

A mixed method approach was applied to examine how information sharing operates and how it may be improved. Multiple methods were used to explore the perspectives of both clients and health workers. Data was collected via interviews, focus groups, a national survey and non-participant observation of care planning practice. The data was analysed using a combination of thematic analysis, discourse analysis, quantizing and statistical analysis techniques.

MAIN FINDINGS

The findings revealed several enablers and barriers to information sharing which impacted on the effectiveness of chronic condition management. To be most effective, information sharing should be open, two-way and inclusive of all members of health care teams, including clients and carers.

RECOMMENDATIONS

The following areas should be considered to facilitate a more effective approach to chronic condition management.

- > Formal accreditation should assess the extent to which open sharing of information is occurring.
- > Medicare funding should be provided on the basis of effective care plan use.
- > Information sharing should only be undertaken with appropriate consent otherwise this has the potential to cause clients harm.
- > Consistent guidelines are required to clarify what information health workers can share if they have full consent. The option for selective client consent should be mandatory.
- > Funding systems should support multidisciplinary collaboration by appropriately remunerating all health care providers and by discouraging overlaps in care planning and service provision.
- > Medicare Locals should identify areas of service and care plan overlap in their regions and, in doing so, optimise the benefits that may be achieved through current funding.
- > An expanded care planning role for practice nurses should be considered to allow them to facilitate the collaboration of multidisciplinary teams and, in doing so, reduce overlaps and fragmentation in client care.

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Glossary

Care plan	For the purposes of this report, a care plan is a document that details the strategies for managing a client's chronic health problem(s). A care plan may also contain records of client medical history, symptoms, test results, their goals and the details of the health workers they consult with.
Information sharing	The transfer of information between clients and their health workers, or among health workers, about the health and/or care of a client. This transfer may occur via formal processes, such as during consultations and meetings, or via informal means, such as during impromptu conversations. Information sharing may occur verbally or through written communications.
Rigour	Rigour is a measure of quality in research. It provides a means of assessing the strengths and weaknesses of research in ways that are appropriate to the approaches that are used in this project (1). In general, rigorous research involves sound reasoning, the selection of appropriate methods and in-depth analysis. Rigorous research also involves clear documentation of the approaches applied, the processes used and the findings that have been produced.
Self-management	In the context of chronic conditions, self-management refers to the behaviours used by a person to manage their health problems. These behaviours may involve problem solving, making decisions, utilising available resources, forming and negotiating relationships with health care providers, setting goals and forming plans for action (2).
Triangulation	Triangulation is a technique which assists in the validation of research findings through cross verification. Multiple sources of data and multiple methods are used to study the topic of interest to provide a more detailed, balanced and comprehensive understanding (1). The use of multiple methods also assists in overcoming the biases and weaknesses that may hinder studies which use only one source of data, one method of data collection or one strategy of analysis (1, 3).
Validity	Validity assesses whether research measures what it was intended to measure and how truthful or accurate the research results are (3). In this mixed method research, assessment of validity is undertaken in combination with a focus on rigour to make judgements about the quality of the findings that have been produced.

Introduction

This research investigated the operation and outcomes of information sharing within the context of care planning for chronic condition management. Our aims were to examine how information sharing works within primary health care settings and to explore client and health worker perspectives about the acceptability of current practices. We applied both qualitative and quantitative methods to develop a comprehensive understanding of the information sharing processes used and the experiences and perceptions of those involved. This report explains the rationale for the research, the methods used and the findings that have been produced. The report concludes with recommendations for future policy and practice in the areas of care planning and information sharing.

Background

Chronic conditions are recognised as being among some of the most common and costly to the health system. In Australia, and indeed worldwide, the impact of chronic conditions is increasing. It is forecast that within the next 10 years chronic conditions will account for three quarters of all deaths worldwide (4). Furthermore, in Australia, by the year 2016 the number of people affected by chronic conditions is expected to increase to 3.5 million (5). This will have important implications, particularly in terms of changing workforce requirements, increasing the need for disability support and by creating further demands on already stretched health care services.

Despite these difficulties, chronic conditions are recognised as being among the most preventable of all health problems. These conditions are also particularly responsive to comprehensive, multidisciplinary management and improved self-management support (6-8). Reviewing research in the area of chronic condition management is, therefore, useful in identifying areas where problems exist and where effective changes can be made. Research findings suggest that poor communication and a lack of care coordination impedes the effectiveness of management efforts (9, 10). Conversely, the prevention and treatment of chronic health problems has been shown to be *most* effective in integrated systems where there is active collaboration between clients and health workers as well as among health care professionals themselves (11-13). Effective collaboration can promote clients' management of their conditions as well as delay associated complications by optimising opportunities for client empowerment and by developing approaches that are relevant to client needs (14, 15). The effectiveness of such collaborative, integrated prevention and treatment efforts has been recognised internationally in major health reports, most notably by the World Health Organization (WHO) (16, 17). In 2002, the WHO drew global attention to the rise of chronic conditions and provided a path forward for tackling their impact. This work (16) strongly influenced policy decisions in the development of Australia's National Chronic Diseases Strategy (18) and in drafting work on Australia's First National Primary Health Care Strategy (19). These policy initiatives have provided impetus for a commitment to, and broad implementation of, a structured, collaborative approach to chronic condition management in Australia.

The approach that has been implemented is person centred care (PCC). PCC is described as putting "people at the forefront and centre of their own health care" (18:9). PCC involves clients improving or maintaining their health in relation to their own self-identified needs, challenges and goals (20). This occurs through collaboration, with the vision for care being negotiated between health workers and the client (20). Overall, PCC involves clients becoming active partners in managing their health care to co-determine priorities and plan preferred approaches with their health workers (21).

The task of implementing PCC in Australia has involved the development and maintenance of care plans for chronic condition management. A central role of a care plan is to provide the means to ensure that the client, and all of their health care providers, are clear about the agreed plan for management and are also able to share information freely through the maintenance and exchange of the plan. If designed well, care plans allow for the development of comprehensive management systems which take into account the complexities and nuances of a client's chronic condition(s) and their broader lives.

It is clear that the promotion of PCC as an approach to structured chronic condition management has led to the increased use of care plans. However, this has not necessarily meant a concomitant increase in client control or client involvement in care planning. Recent Australian research has demonstrated that a doubling in the numbers of people who are aware they have a plan in the period between 2006 and 2008 has not changed the level of their involvement in care planning (22). This raises important questions about whether current systems of care planning, particularly in the light of a PCC approach, are meeting the intended aims of facilitating more effective management of chronic health problems.

Prompting even further questioning is the existence of only a small number of prior studies which have explored care planning experiences from the perspective of people with chronic conditions, either from the person's view directly, or from the health care professionals' perceptions of that view (23-26). Instead, the focus has tended to be on quantitative measurement of health care processes and outcomes (27) rather than understanding how, and under what circumstances, within the interaction between health worker and client that good outcomes are achieved. There is also little research knowledge about the system constraints that impact on care planning within the current primary health care context (28).

Despite these gaps in research evidence, Australian governments have invested heavily in primary health care services where care planning for chronic condition management is a primary focus. Many of these services have been designed as locally managed, sometimes co-located, health centres comprising multidisciplinary teams (29). Central challenges for these initiatives are in understanding how health care providers can undertake care planning and PCC effectively across systems of multidisciplinary service delivery.

The value of effective communication and information sharing in meeting these aims is confirmed by prior research. Research undertaken by Little et al (30) highlighted that effective communication is one of the most central components of making care patient centred. In addition, the evidence-based Chronic Care Model (CCM) (11, 31) emphasises the importance of information sharing in managing chronic health problems. According to the CCM, delivery of quality care requires not only determining what care is needed, but clarifying roles and tasks within the healthcare team. It is also necessary to make sure that all the health care providers involved with a client have centralised, up-to-date information about the clients' status. This reflects the need for true collaboration which allows information and communication to flow between clients and health care providers in a way that is consistent with a multidisciplinary, PCC approach. However, we are not sure how information sharing is currently operating in primary care practice in Australia. We also lack research evidence about the barriers and facilitators to effective information sharing within the current context of chronic condition management.

Our research has articulated and attempted to address some of the identified gaps in knowledge. We examined if and how information is being shared through the care planning process for chronic condition management. We also explored what the enablers and barriers are to effective multidisciplinary communication and client involvement.

Research questions

Several questions guided the research. These are:

1. Do structured chronic condition and self-management care planning tools enhance information sharing between health care providers within and across primary health care services and sectors?
2. What are the mechanisms and processes that enable or hinder this process of information sharing within primary health care services that deal with chronic condition management?
3. How do clients who have a care plan for their chronic conditions interact with, and respond to, primary health care providers as a result of their plans?
4. What features of this care planning process enhance or hinder clients' participation and navigation through systems of self-management support?
5. What do people with chronic conditions who have these care plans think about the way the plans are developed, shared and monitored?
6. What do people with chronic conditions say about how these care plans affect the way they manage their conditions?
7. What do clients and health workers suggest as improvements to this care planning and information sharing process?

Methods

To address the research questions a mixed method approach was chosen. This allowed us to investigate information sharing from various angles and perspectives. In particular, we studied the experiences and perceptions of clients who have a chronic condition care plan and health workers who work with these care plans.

Clients and workers from five services participated. The services were located in two states of Australia, in both metropolitan and rural areas. The services consisted of two community based aged care health services (each with different structures and models of service delivery), one Aboriginal health service, one general practice and one community primary health branch of a hospital. Three different care planning systems were used across the services; these included GP Management Plans, the Flinders Program and the Goal Attainment Scale.

Client perspectives were collected through qualitative in-depth interviews with 24 clients at various stages of their care planning journey. We interviewed several clients more than once to examine how their experiences and perceptions developed over time. A total of 47 interviews were undertaken between April and July 2011. The clients who participated had a range of chronic health problems and co-morbidities, such as diabetes, arthritis, heart disease, depression and anxiety.

The insights of health workers were captured during focus groups with care planning staff and during a quantitative national survey of primary health care workers. Six focus groups were undertaken and the numbers in each group ranged from four to 17 staff members. Five hundred and eighty primary health care workers responded to the national survey. All states were represented and the survey was open for 24 days in October 2011.

The equivalent of one week of intensive observations was also undertaken at each service. The observations focused on consultations between clients and health workers, staff meetings and case conferences. This resulted in 56 observation sessions across the five services. Nineteen consultations were also audiotaped to provide data for quantizing.

The qualitative data was analysed using thematic analysis, discourse analysis and quantizing techniques. The survey data also underwent thematic and statistical analysis. Further

information about the methods and the characteristics of each health service is provided in Appendix 1.

Findings

First, an overview of how information sharing operates within the care planning process is provided. The enablers and barriers to effective information sharing are then examined, followed by a summary of health worker and client views about potential improvements.

HOW INFORMATION SHARING OCCURS

Multiple methods of information sharing were identified during the research (see Appendix 2 for a full list). Information sharing occurred through verbal and written means and both formally and informally depending on the particular context of engagement between clients and health workers or among health worker teams.

Sharing of care plans

The sharing of written care plans was found to be a central, and sometimes sole, means of information sharing among health workers about the management of a client's health problems. The 56 observation sessions that were undertaken at the five health services revealed that all services had formal processes which encouraged health workers to share care plans. These included documentation, handover procedures and central electronic or physical storage. However, the extent of the sharing that occurred in each service differed. In three of the services health workers were expected to share care plans with *all* health workers involved in the care of a client, regardless of where they worked. In the other two health services workers were only required to make care plans available to other staff at their service. In one of these services, sharing was particularly limited, with usual practice being that care plans were only shared within the particular section of the service that created the plan (for example the allied health division). Similarly, only half (52%) of the survey respondents who stated that they develop care plans (total N=394) also stated that they share care plans with *all* providers named on the plan.

Multiple methods of sharing care plans were also identified during the research. In the survey, respondents were able to select more than one method to identify all of the methods they use. Figure 1 presents the responses from the 339 respondents who provided this data.

Figure 1 Methods used by survey respondents to share care plans

Method	Number of respondents (%)
Paper copy sent via mail	208 (61%)
Electronic copy sent via email	109 (32%)
Paper copy stored in single location within a service	60 (18%)
Electronic copy shared via electronic database	57 (17%)
Other	153 (45%)

From the observations it was particularly evident that the use of a common store room in health services was an effective method for making care plans easily accessible to all staff within that service. Many instances were also observed where a shared store room became the site of informal, verbal information sharing.

Despite variance in the amount of sharing that occurs between health workers and the particular method used, it was clear that there was a high level of support for sharing care plans directly with clients. Seventy five percent (N=296) of survey respondents who develop care plans (total N=394) indicated that they share care plans with their clients. Support for this was also evident during the observations and focus groups where health workers expressed the importance of, and demonstrated the practice of, providing clients with a copy of their care plan after it had been created or reviewed. During the consultations some clients were asked if they would like a copy of the care plan. This practice appeared to provide health workers with a guide to the level of client awareness about the existence of the care plan and their willingness to engage with it.

Conversely, more than half (N=205) of survey respondents who develop care plans said that they *do not* share care plans directly with the carers of their clients. This finding highlights the possibility that providing a client with a written version of the care plan, or asking if they would like one, is being used in some instances as a substitute for information sharing with carers directly. This reflects findings from the interviews where clients who had a carer or who were a carer themselves reported a lack of information being conveyed between health workers and carers. Excluding carers is problematic given the benefits that can arise when all those associated with the client are familiar with the care plan. Such benefits were identified during the observations, focus groups and interviews. They included ease of transition for the client between multiple services, an absence of service overlap, a reduction in the number of times a client has to recount their health experiences and a reduction in the amount of time that health workers need to spend asking clients about their history. Health workers also expressed that having access to an up-to-date, collaborative care plan increased their confidence in being able to treat the client and to find out about acute events when they occur. These benefits are also supported by previous research (25).

Next we consider what makes the information sharing process work effectively, what hinders its effectiveness and what aspects of the process work as both barriers and enablers.

ENABLERS AND BARRIERS

The findings reveal that there are many factors which influence the effectiveness of information sharing. Figure 2 provides an overview of the factors that will be examined.

Figure 2 Overview of factors that influence the effectiveness of information sharing

Enablers	Barriers	Both enablers and barriers
Valuing of communication	Different perception of purpose of care	Consent
Clients informed about extent of help available	Closed communication	Free visits linked to GP management Plan
Client knowledge about health worker communication	Fragmented communication	Suspicion
Care continuity	Overlapping care plans	Health worker & client relationship
Involvement of clients in decisions	Belittling, sabotage, put downs, snide comments	Knowledge of care plan
Negotiation	Railroading	Role definition within the team
Emphasis used in conversation	Varied understandings of terminology	Team definition
Openness and accessibility of care plans	Time	Client ownership

Importantly, the themes identified in each category are not mutually exclusive. The many interrelationships highlight the complexities that were identified during the research.

Enablers

Valuing of communication

Analysis of the data revealed that it cannot be assumed that information sharing is valued by *all* health workers or clients. During the observations some health workers admitted that they did not actively share information or think it was important to do so. Furthermore, one client explained during their interview that they preferred to deal with their health workers in isolation from each other, rather than have them work collaboratively. The broader findings, however, reveal that when communication is *valued* this is central to its success.

Clients who value information exchange are more likely to be proactive in ensuring that it occurs. For example one client explained that he had checked that each of his health workers had a record of all the other people involved in his care:

It's very important for the health workers to communicate. It means they can interlock, like what one finds out could affect what the other one - what decision the other makes. (61 year old male, client, metropolitan service)

Apart from encouraging communication between health workers, other clients also ensured that they communicated openly with their health workers. Several clients highlighted benefits of this, for example:

It's useful to have them know everything because when I go to my doctor, if I say there's some pain there again, she'll know how I went with that last time. (64 year old female, client, metropolitan service)

Valuing information sharing and understanding its benefits also operated as motivators for health workers:

Researcher: How important is it for you to share information with other workers?

Physiotherapist: Very important so we can make sure that it's all being collaborative with each other, we're all on the same wave length of what's going on with the client.

Nurse: I think you can also enhance the care you give to a patient if for example you're talking to the counsellor or something like that, you can obviously pass on messages from other workers as well and make sure you're all kind of, yeah, on the same wave length. (Focus group at a rural service)

Clients informed about extent of help available

The qualitative findings also suggest that clients who possessed knowledge about the operation of the health system, and the range of services available to them, actively engaged with the information sharing process. Such knowledge facilitated client communication with health workers because it allowed them to request referral to particular services or ask informed questions. Given their high level of health literacy in this area (particularly their knowledge and skills in negotiating the health system (32, 33)) some clients had even approached a health worker to initiate the care planning process. Several clients explained that a benefit of having a care plan was that it provided them with additional information about available health and community services. This increased client satisfaction with their care plan and may have encouraged them to engage further.

Client knowledge about health worker information sharing

The clients who understood that their health workers *should* share information with each other actively facilitated this by reminding health workers of the need to communicate and by checking to see if this was occurring. The following excerpt from a client interview

demonstrates the level of involvement that some clients have and also highlights some of the benefits that are perceived to emerge from this:

They share copies of letters and things. I know that because Dr Gary often refers to the letters that he's received... It's important they keep up to date with each other, especially around the meds to make sure each other knows and that I'm getting the best possible. So yeah, I do ask if they're talking to each other to make sure. (41 year old male, client, rural service)

Care continuity

Continuity of care was also raised as an important facilitator of information sharing by several clients. Health worker continuity allows clients to build trust and to feel comfortable in discussing health issues. Good rapport between health workers and clients also assists clients to feel safe to disclose information, particularly of a personal nature or if a client feels anxious. Such rapport can only be developed over time and with ongoing contact:

If you change doctors then you've got to get back onto that feeling of being comfortable with a doctor again. And I mean my doctor knows how I have been but I most probably wouldn't divulge a lot to another doctor if I didn't know that doctor before (63 year old female, client, rural service)

Involvement of clients in decisions

Actively involving clients in decision making was identified, by clients, as an important enabler for effective information sharing. Active involvement allowed the client to feel like they were being listened to and like they had a legitimate position in determining the direction of their health care.

From the health worker perspective, greater participation by clients in making decisions and plans around their health also allowed a more equal flow of information. This flow assisted in the generation of more relevant goals and strategies and, therefore, more positive outcomes:

It's important to provide an opportunity for the client to participate in their care as well. If it's written down for them sometimes they actually are very proactive and they'll say, 'Well actually I've gone ahead and I've started that next step', or 'I'm going to do that'...they start to self-initiate. (Nurse, rural service)

The value of clients becoming actively involved, and the role of the care plan in facilitating this process, was supported by the survey results. Seventy two percent (N=418) of total respondents agreed or agreed strongly that part of the purpose of a care plan is to engage clients in the management of their condition and 70% (N=401) stated that clients making decisions about their health care is the best indicator of care plan success.

Negotiation

Clients identified negotiation as an important part of working effectively with their health workers, especially when a difference of opinion arose. Negotiation allowed clients to articulate their own goals and preferences, but still keep their health workers 'on side' to achieve the best health outcomes possible. This was central to effective information sharing because negotiation allowed both the client and health worker to feel like their input was *valued* and like they were *listened to* by the other party:

I've gone down to the smaller one [neck collar], yeah. I wanted to try the big one and I did for a while, but it wasn't that comfortable. The physio wasn't happy that I had the big one in the beginning, but I insisted and she gave it to me to try. And when I went back the first time after I'd used it and she said, 'I'd really prefer you to have the smaller one' and she explained how the smaller one might help. So I got a smaller one and I tried that. It was good, yeah. So we got there in the end. (64 year old female, client, metropolitan service)

Emphasis used in conversation

The importance of using emphasis was also identified by health workers and clients. Emphasis is a subtle yet integral part of information sharing which may provide invitations for disclosure or reinforce a statement of need. During an observed case conference a health worker identified the value of emphasis in ensuring client needs were satisfied:

Nurse 1: Is he going to do an x-ray or is he reluctant?

Nurse 2: He was reluctant, yeah I asked. He just said: 'He's got arthritis, you don't need an x-ray, we know that'.

Physiotherapist: Yeah, I think it needs to be put into perspective that that's really what the client thinks his biggest problem is, because I think sometimes without knowing that they just say 'Oh it's just arthritis', but if they actually are aware of the impact that's having on him, they're more likely to get it diagnosed properly so we can start working on it. (Case conference, rural service)

During the interviews a client also highlighted the importance of emphasis in her communications with her general practitioner. She viewed it as a sign that the open sharing of personal feelings was acceptable and justified:

She [GP] might just say to me 'how are you coping' and I think that is a different way than just saying 'how are you?' You know, there's a leading question with coping rather than how are you, it means she wants to know how I really am. (63 year old female, client, rural service)

In addition, emphasis was useful in communication between health workers and clients to highlight what clients understood to be their primary needs, what health workers understood as priorities and in assisting both parties to highlight important achievements and provide encouragement. This was an important aspect of positive communication.

Openness and accessibility of care plans

During the observations it was evident that having care plan files physically available to all staff in a service facilitated effective sharing of information, collaboration and improved communication. Where this was not possible, the co-location of care plans through centralised computer systems or frequent email updates assisted. Therefore, the location and setting of care plan storage can operate as an effective enabler for health worker communication by providing opportunities and space for both deliberate and incidental information sharing. According to the views expressed during the focus groups, maintaining the currency and availability of care plans also encouraged health worker belief in the value of the documents and increased the extent to which they used them.

Barriers

Different perception of purpose of care

Poor communication and lack of collaboration can result in clients having a different view from their health workers about the purpose of their care and/or care plan and this may impede quality information sharing. A client who *did not* value their care plan identified such a difference in understandings as one of the main reasons that the plan was not useful to him. He wanted care that would relieve his pain. However, he felt that his health workers had different intentions and that they spent more time assessing him than effectively helping:

I thought I was going to go there and get a massage, which I could like really use... I got there and the physio said, 'I am not here to give you a massage.' She said, 'I'm here to go through it all', like the care plan thing. So I went through it all with her. She said 'I would like you to walk' and at the time I couldn't walk. And anyway she kept insisting that I walk and so I walked from the front reception desk out to the far wall, then along the passage and then

along the front veranda. By that time I was stuffed... She came and helped me back in, she goes, 'Oh no!' because I go grey and green when I get like that. She says, 'I am sorry.' I said, 'Yeah you didn't believe me, did you? I can't walk!' I never saw her again. (60 year old male, client, metropolitan service)

The problems expressed by this client highlight the potential effects of ineffective information sharing and a lack of effort to explore the reasoning behind differing perceptions of need. In this case ineffective collaboration and communication resulted in resistance from the client and a lack of willingness on his behalf to engage further with the care planning process.

Closed communication

Clients recounted experiences where they believed that information sharing had been devalued by health workers through their use of closed questioning. Clients perceived that it inferred health workers' disinterest in designing care strategies that were appropriate to their specific circumstances and that it displayed a disinterest in getting to know the client as a 'person':

A nurse asked me these questions, it was almost like A, B or C and she didn't want to hear anything else. She said, 'Are you looking for a hip replacement?' I said, 'Well not particularly'. I mean it's just something that I've wanted to know how it works. So she did a few tests and she went down the list of questions, you know, she was wanting to tick A, B or C. When I started to say - 'No, no' she said 'I want an answer, I want A, B and C' but I don't really fit in with that... we don't all fit in a box do we? (80 year old female, client, metropolitan service)

Some clients also highlighted the potential for health worker assumptions to present strong barriers to information sharing by encouraging closed communication and restricting the flow of information. This left important areas unexplored or unquestioned:

Once you say you've got diabetes, everybody gives up, they go, 'Well you've got diabetes, that's what happens.' But Dr Po was the first one that bothered to explore it further. She said the foot problem is not diabetic related, not totally. I mean yeah I've got diabetes but hang on! It's like they assume I've created the problem. (60 year old male, client, metropolitan service)

Three clients also explained that their ability to share information with their health workers had become restricted through the workers' focus on entering notes into their computer rather than maintaining eye contact and encouraging discussion.

Fragmented communication

Fragmented communication was a central barrier identified through this research. Health workers and clients did not talk about fragmentation per se but this term is used to group together instances where there were identified gaps and breakdowns in information sharing, which occurred through a range of different processes.

Ineffective handover

Ineffective handover and a lack of written handover were major causes of fragmented information sharing. This was particularly evident when staff left a service. We observed that if all of the client information accumulated by a health worker during the course of their practice is not documented then it is lost to the service. Furthermore the impacts of fluctuating rosters and part time or casual staffing were evident during the observations and focus group discussions. These presented system level barriers which restricted the opportunities for staff to share information or to attend staff meetings regularly.

Ineffective referral systems and one-way communication

The impacts of ineffective referral systems were particularly apparent when referrals were lost due to ineffective intake processes or when they became misdirected because they did

not contain sufficient information. During the focus groups health workers also identified problems with interpreting referrals due to insufficient information being included:

I just receive a piece of paper that allocates visits to myself, with no accompanying letter, which means I need to search through the patients' notes to gather a picture. (Dietician, rural service)

Conversely, during the interviews, some clients raised concern about too much information being included on referral documentation. Some clients believed that this could encourage health workers to make judgements about their needs before the first consultation. This is potentially compromising to the establishment of an open, collaborative relationship.

Contributing to the potential for fragmentation is the one-way communication that can occur around referrals. This was a central frustration for health workers and the issue arose in each focus group. One-way communication resulted from: a lack of willingness on behalf of health workers to share information once they received a referral; a lack of understanding about the benefits of sharing information; health workers having only limited contact details for other health care workers or having inadequate knowledge about where the referral originated from. Not receiving feedback meant health workers often did not hear the outcomes of the referrals that they made, and therefore did not hear if their referrals were effective:

Often we refer to external agencies and hear nothing back, therefore we are completely unaware if the patient attended or what the outcomes were. Sharing of information electronically would streamline this and make it more time effective for practitioners. (Physiotherapist, aged care health service)

These findings are further supported by data from the survey which revealed that 9% (N=53) of respondents *never* receive feedback from the health workers they refer to. Eighteen percent (N=104) of respondents indicated that they received feedback some of the time and only 7% (N=41) reported receiving feedback often. Frustrations expressed during the focus groups were also replicated in the survey, with 35% of respondents (N=203) indicating that they were dissatisfied when they did not receive feedback on the referrals that they initiated.

Communication silos

Silos of communication contribute to fragmentation. By 'silos' we are referring to instances where information sharing is contained to one discipline or one team within a health service. The analysis suggests that the containment, rather than sharing, of information may result from health workers being unaware of who else is involved in the clients' team, from a reluctance to share information more broadly or from a sense of 'territoriality' (34) which involves protecting one's own expertise or role. A lack of awareness about the usefulness of sharing information across disciplines may also contribute. This is suggested by the survey results, which reveal that 26% (N=149) of respondents do not believe that the input of *all* health workers consulting with a client is important to the development of a care plan.

Ineffective meeting structure

Ineffective structuring of multidisciplinary staff meetings can also contribute to fragmentation. In particular, the potential for fragmentation was evident where staff attendance was only loosely required, which meant that staff may not attend at all or they could leave part way through the meeting. Many staff reported not being allocated adequate time for information sharing during meetings, which they interpreted as indicating the lack of value placed on it at a service level. This interpretation was also made by 20% (N=117) of survey respondents who believed that information sharing was only somewhat or only a little valued by their organisation. Further insight into the potential impact of meeting structure can be derived from the case study presented in Appendix 3.

Overlapping care plans

Another barrier to information sharing is the existence of overlapping care plans. Instead of one comprehensive care plan being developed with each client, we found instances in which clients were receiving multiple care plans; separate plans from each health worker involved in their care. This is problematic because it results in duplication, which was particularly evident where health workers were observed performing similar initial assessments on clients. These were tiresome for clients who reported being frustrated by answering the same questions several times. They are also an ineffective use of health worker time.

Multiplication of care planning creates the potential for the miscommunication or non-communication of important information within multidisciplinary teams. This can lead to communication breakdowns or the sharing of only fragmented information within and between health care teams. The potential for health workers to be unaware of who else is implementing a care plan was highlighted by 21% (N=120) of survey respondents who stated that they never check if their clients have active care plans with other workers or services. Importantly, the current overlaps create confusion for both health workers and clients. This concern is expressed in the following comment from a survey respondent:

The use of multiple care plans is confusing for clients. For those clients with chronic disease for example, and already on a GP Management Plan, this should be THE care plan that is then 'added to' to incorporate self-management aspects - there should NOT be a separate self-management plan. This is particularly relevant for clients experiencing complexity because you are simply making an already complex situation even more complex by adding in more care plans. (Nurse, community health service)

Belittling, sabotage, put downs and snide comments

During the discourse analysis of the recorded consultations (explained in Appendix 1) comments were identified which may belittle or put down clients. Such comments were often implicit and seemingly unrecognised by the health workers involved. The following are two examples:

So how are you going to get in touch with your son and build those, because there's a lot of bridge to build there isn't there? (Nurse, rural service)

Are you cooking more for yourself or are you still relying on pre-fab meals, or Mum cooking? (Dietician, rural service)

The potential effect of these comments in the context of information sharing is significant. They have the potential to discourage clients, reduce their confidence and lead to small gains in progress remaining unacknowledged. They also have the potential to deter clients from asking questions or openly sharing their feelings.

Railroading

Strong health worker guidance, closed communication and a lack of opportunity for open information sharing can also result in clients being 'railroaded'. Railroading is a concept that refers to clients being directed into particular areas rather than taking control of decision making for themselves. Railroading was evident during a case conference:

Nurse: Are you using hot water again?

Client: Nup.

Nurse: Just still in cold water? Because we were talking sometimes you need the hot water to sometimes help get rid of some of the odours that can happen. It's been a bit better.

Client: Oh yes but- I'll use hot water. (Case conference, rural service)

Railroading directly contravenes the principles of the PCC approach. It also operated as a strong barrier to open information sharing by closing lines of communication and directing clients to say particular things to please the health workers. In directing the responses of clients, health workers disabled clients from expressing their own wishes and goals and from developing greater autonomy and self-management abilities.

Varied understandings of terminology

Given the centrality of self-management to policy initiatives around PCC and its prominence as an aim of some of the care planning systems we observed, we asked all clients what they understood self-management to mean. Most responses were positive and consistent with aspects of what clinicians and academics have written about in the self-management literature (11, 18, 35-38). For example:

Take my pills when I'm supposed to take them and keep regular visits to the doctor when I'm supposed to go and get new scripts and so forth. It involves me taking an interest and having a part in keeping me healthy. (80 year old female, client, metropolitan service)

However, some clients viewed self-management in other ways. The following quotes indicate that for several clients 'self-management' makes them think about what they are *not* doing and what they *should* be doing, rather than prompting them to reflect on aspects of their lives where they already self-manage effectively.

I'm most probably a really bad candidate for self-management, if bad candidate is the right word. My sugars just seem to climb, even when I do everything right. So I seem to still have issues with that. (63 year old female, client, rural service)

I'm not an ideal patient. And I think my GP sometimes thinks well if I don't look after her nobody else will. I, sometimes I'm really good and then I'll fall into a slump and then I don't care. So yeah, I do need to be more aware and try more. (63 year old female, client, rural service)

Oh well there's not much I can do. I have changed my eating habits a bit but there's not really much I can do. Stick to right medication. (82 year old male, client, rural service)

This varied understanding highlights the potential for important differences in how clients understand the connotations attached to the concept of self-management. Despite the benefits of establishing a common understanding about the term, we did not observe any health worker ask a client how *they* understood the term.

Similar variance in understanding was evident in relation to the term 'chronic'. This term was used frequently in discussions between health workers and during their consultations with clients. The term also featured on much of the care planning documentation that was used in the five services. During the interviews, however, it became clear that clients may not share the same understanding of this term as health workers. For example, during one interview the client asked how they were identified as eligible for participation. The interviewer explained that one criterion was that all participants must have a chronic condition. In response the client exhibited signs of embarrassment and said "Oh no! I've been labelled as a chronic patient have I?" Upon further probing the interviewer found out that the client interpreted the word 'chronic' as meaning "bad" and she thought she had been labelled as a "bad patient". After clarifying the intended meaning of the term, the client was reassured; however, this highlights an important disjuncture between the clinical terminology and the client's interpretation of it.

Time

The issue of time emerged as a central concern for clients. Insufficient time operated as a barrier to effective information sharing and it resulted in frustration and difficulties during the

development, implementation and sharing of care plans. A detailed list of problems that result from clients and health workers being allowed insufficient time, and the impacts of this on information sharing, is included as Appendix 4.

Elements that operate as both enablers and barriers

Consent

Consent emerged as a central issue across the research. Consent is *necessary* for effective information sharing, yet our findings reveal that it also *hinders* the process and leads to problems for both health workers and clients.

During the interviews it was clear that most clients understood the need for, and benefits of, information sharing between their health workers. However, most clients could not explain how, or how much, their health workers shared information about them. Some clients were also unsure if they had given consent to their health workers to share information. These findings highlight issues associated with the ethics of consent. In particular, they raise questions about how much clients need to understand information sharing in order to provide informed consent, and what potential implications exist for health workers who discuss client details without the knowledge or awareness of a client. Similar uncertainty also exists for some health workers. This is demonstrated by the 4% (N=23) of survey respondents who admitted being unsure about whether they were responsible for gaining client consent prior to sharing their information. While 4% is a relatively low proportion the existence of any uncertainty is concerning given the legal ramifications and client harm that may result from the sharing of client information without consent.

The importance of seeking consent prior to information sharing is highlighted by the finding that some clients did not want their information shared. During the interviews three clients identified aspects of their medical and personal histories that they did not want their health workers to share. These aspects included sensitive information, such as past experiences of abuse. The three clients could not be certain that those parts of their information were not being shared, but rather could only assume that they were not. In addition, two of these clients recounted experiences where their information *had* been shared without their consent, which had resulted in a loss of trust between them and the health workers responsible.

The clients' desire for some information to remain private highlights the value of clients being able to provide selective consent; that is, consent for only *certain* parts of their histories to be shared by their health professionals. In three of the five services we studied selective consent was not sought or made possible for clients. Electronic templates used in the services also made it difficult for full client histories not to be shared because the full history is automatically inserted onto referral letters. Health workers had to manually delete part of the client history from these letters if they did not want to share it. Health workers reported difficulty with this due to time pressures and templates that were difficult to modify. The survey results indicated that while selective consent was available to clients at some services (66%), the services that 15% of respondents worked for did not provide this option and 17% of respondents (N=101) were unsure about whether selective consent was possible.

Adding further layers of complexity were frustrations expressed by health workers about not being able to share information with other health workers even if they had consent. Health workers reported frustration in dealing with other health workers who did not have a clear understanding about what information they had consent to share. This meant that even if one health worker understood what their clients' consent enabled them to share, this sharing could only ever occur one-way.

Clients and health workers also identified convoluted, overly technical language, and poor layout, as being barriers to the effectiveness of the consent forms that clients were asked to sign. If clients cannot understand the language on the forms that are designed to collect consent, then they must seek the assistance of health care staff. This occupies health worker

time, while also raising concerns about whether verbal explanations (in busy service contexts) include sufficient content to enable the client to be fully informed.

Free visits linked to GP management Plan and Suspicion

During the interviews it became clear that clients enjoyed the five free allied health services that they could access if they had a Team Care Arrangement included as part of their GP Management Plan. Clients reported receiving considerable benefits from this aspect of their care plan, such as the opportunity to receive allied health care when they would not usually be able to afford it and a sense of relief that they did not need to adjust their budget to pay for the visits. Two clients, however, reported difficulties in accessing information about how to initiate the Arrangement because they did not know who to ask or how to approach the issue.

Conversely, during the focus groups, several health workers explained that the system of free visits created a *barrier* to effective care planning and information sharing. Nurses at one health service reported client impatience with being asked many questions during the establishment of their care plan because they “just want the freebies”. Furthermore, suspicion about the motives of GPs who put all of their clients on Management Plans was raised during two of the focus groups. General practitioners who attended one of these focus groups said that there are “too many general practitioners who go after the money” that Management Plans attract and, as such, do not view the fostering of coordination within the team as a primary goal. Such suspicion and assumptions may lead to rifts within health care teams and a sense of impatience or reluctance to pursue open lines of communication.

Health worker & client relationship

The relationships formed between client and health worker had a strong impact on the effectiveness of information sharing and the extent to which each party felt able to share information openly. Clients used terms such as “caring”, “comfortable”, “easy to talk to” and “sensitive” to explain how their relationship with their health worker enhanced their care planning and information sharing experiences. However, it was clear that if clients perceived health workers to be “disinterested”, “rude”, “cold” or “bossy” then they were less likely to value the relationship and the care that emerged from it. The following quotes reveal some of the ways that clients interpreted the impact of their relationships on their care experiences:

I find a very good sense of caring from her and I think she knows that I don't cope at times and she's just very concerned about me. She's just very gentle and sometimes I need that. (63 year old female, client, rural service)

I've had a couple of doctors in the clinic I go to and no, I wouldn't go back to them. One fellow is just so bossy. He talks to you like you're two and I don't like that and just won't stand for it. (53 year old male, client, rural service)

Analysis of the interviews also revealed the centrality of trust. Clients who had faith in the ability and approach of their health workers expressed greater ease in sharing information. Underlying this was a confidence on behalf of clients that they would be listened to by the health workers they trusted rather than having their concerns dismissed prematurely.

Knowledge of care plan

Clients reported varying levels of understanding about the existence of their care plan and how it operated. It is clear from the following quotes that client understanding is an enabler for effective information sharing whereas a lack of knowledge can present a barrier and may also signal the impact of other barriers to information sharing already identified previously:

My doctor's made up a health plan for me where I go out to the hospital to get my toenails clipped and all that because I can't reach down because my back is completely gone. When I need to see a surgeon she organises that for me, the whole lot. But my GP and my counsellor, they keep in contact with each other with my mental health. It's good. (53 year old male, client, rural service)

Well I think I got on a care plan. I'm starting to wonder whether I did. She just told me that all it did was write down everything that was wrong with me and what she thinks I should do. I'm not really certain. I think I just took it for granted that it was good for me. I'm not saying I stuck to it real good. (78 year old female, client, rural service)

The findings of the survey also supported the view that a large number of clients are unaware of the existence of their care plan. Fifty five percent of respondents (N=319) indicated that they consulted with some clients who were unaware of their care plan and 8% (N=47) indicated that they found such a lack of client awareness arising *most* or *all* of the time during their practice.

Role definition within the team and Team definition

The findings highlighted the value of clear definition about who is involved in a health care team and what their roles are. Where clarity about these issues was achieved early in the care planning process, we observed that lines of open communication could be established. However, without clear understanding about the composition of the team, communication and information sharing was observed to be fragmented at best. This was due, in particular, to the late transfer of information or a complete lack of transfer. We also observed the effects of this situation in impeding client care and also frustrating health workers by creating confusion. The importance of early role and team definition is supported by the research of Wagner et al (11, 31) in their discussion about the elements necessary for effective practice.

Funding

Funding is essential to allow care planning and health service access. However, the current systems of health care funding present some barriers to effective information sharing. One such barrier relates to the funding of GP Management Plans.

In the current system of funding for GP Management Plans the greatest workload is rewarded with the least remuneration. Our observations revealed that nurses were primarily responsible for developing and updating Management Plans, while GPs usually worked to review the Plans once they were written. Despite this, the item number nurses claim from Medicare provides approximately 90% less remuneration than the item number claimed by GPs. We found that this situation can lead to nurse dissatisfaction. As an example, during our observations, we were told by a nurse that she believed she did most of the work on the care plan and she felt like her role was not adequately compensated by Medicare. She also felt like she did not get respect from GPs, particularly when they did not feed information back to her after they had reviewed a care plan nor answered the questions that she wrote in client files. This perceived lack of respect detracted from her willingness to collaborate.

As highlighted earlier there is also the potential for more than one care plan to be implemented for each client. Current funding systems make this overlap possible and even likely. Within the primary health care system there are multiple layers of potential funding for care planning services and for services that clients can be referred to on the basis of their care plans. For example, during the interviews one client explained that he was receiving podiatry from two different services and that his referrals had stemmed from two different health workers who had each supplied him with a separate care plan. Further investigation by the researcher (with permission from the client) revealed that one of his care plans was funded by a community based care package and one was funded through the free allied health visits that he obtained via his GP Management Plan. The overlap in services was not identified by the health workers involved and it continued until the client questioned why he had to attend two different podiatrists. Importantly, the co-location of health workers who were consulting with this client did not improve their communication about his care. This surprised the client and contributed to his mistrust of the primary health care system.

In addition to overlaps in service provision, the research also revealed that some health care services are not reimbursed for collaborating with others in administering an existing care plan. Staff at two of the health services accepted referrals from GPs and agreed to participate in Team Care Arrangements, yet to obtain funding they had to generate a new care plan for all clients since they were ineligible to claim through Medicare. Overall, these findings highlight excessive overlaps in service provision, inequities in resource allocation and potential waste of resources.

Client ownership

A key enabler for client engagement and effective information sharing is active inclusion of clients in decision making around their care. Active sharing with these clients ensures they are getting the assistance they need and that they are involved in directing their health care. However, if health workers assume that all clients can and should take ownership this can be problematic (39). This became apparent through a disparity between the results of the survey and the findings of the interviews. In response to survey questions about who care plans are shared with and how they are shared, over half (N=296) of respondents indicated that they share care plans with their clients and 34% (N=197) also indicated that they do this by giving a care plan to a client so that they will share it with their other health care providers. While providing clients with a copy of their care plan is important in achieving PCC, assuming that this will encourage client ownership or ensure that other health professionals receive a copy is problematic. This is reinforced by findings of the interviews where several clients reported that they did not understand the care planning document they had received, did not refer to it and did not share it with others. Therefore, while encouraging client ownership of the process offers considerable benefits, assumptions surrounding it may lead to lack of information exchange within health care teams and create the potential for communication breakdown. This ultimately disadvantages clients and reduces the quality of care.

As an extension of the findings that we have presented in this section, during the data analysis we identified some of the key outcomes of the information sharing and care planning processes. Please refer to Appendix 5 for explanation of these. Next we consider the suggestions for improvement that were made by clients and health workers.

CLIENT SUGGESTIONS FOR IMPROVEMENT

Need to consider emotion as part of information sharing

Two clients suggested that emotion should be recognised as an important part of information sharing. Acknowledging the influence of client emotion on their health and interacting with clients in a way that involves an expression of emotion can assist in creating supportive healthcare interactions (40). However, ignoring emotion can result in client dissatisfaction:

The emotional aspect was missing, particularly with gynaecological surgery where you stand to lose your gender just about. And I think that needs some support. (64 year old female, client, metropolitan service)

In America they sat on your bed – that's a sin here – they sat on your bed and talked to you, they put their arms around you and that's a sin here too, not allowed to do that, oh no. So, certainly it could be improved in lots of little ways. (75 year old female, client, metropolitan service)

Change to appointment process

Clients from one health service also expressed dissatisfaction with the current system where the implementation of their care plan occurred over two separate appointments, which were held on different days. Several clients found this to be an ineffective system, especially if they lived a long distance from the health service, and they suggested the scheduling of both

appointments on one day. Making this standard process across care planning systems may assist in increasing client satisfaction, which is likely to increase their willingness to engage.

Expansion of nurse role in GP Management Plans

Some clients who had experience of the GP Management Plan process also expressed dissatisfaction with the current nursing assessment provided to them. They believed that an expansion of the nursing role and an increase in the information exchanged during nursing reviews could be helpful:

Sometimes I have thought why do I go [to the nurse] but then other times she does do the Doppler test on your feet, and she does check other things. A couple of times I've thought that she could perhaps be more informative or talk more about the diet, whether I have been doing things right or how the sugar levels have been or perhaps offer some hints or something like that. (63 year old female, client, rural service)

Further information about care planning process

Clients who had a GP Management Plan also suggested the need for more information about the processes involved. One suggestion for improvement in this area was provided by client who is employed at another GP clinic:

At work we actually do up an explanation sheet, an information sheet we give out to patients because they have - a lot of them have never heard of it, have no idea, like myself when my physio first mentioned it to me, and it explains, yes, what is a GP Management Plan, the steps in preparing the plan and why have a management plan. But what happens at the clinic where I go is still a bit of a mystery to me. (40 year old female, client, rural service)

More information on outcome measurement

Following on from the need for more information, several clients expressed anxiety about not knowing how their progress on their care plan would be measured. Additional information on review procedures may assist clients to feel comfortable that they are meeting the requirements of the plan:

I guess perhaps a little more information just on the expectations of it. So, you know, do they expect a measurable outcome, do they expect some sort of review at the end, and therefore for the average taxpaying Australian, are they getting something out of their money so to speak. I'm aware it all comes out of the Medicare budget. (40 year old female, client, rural service)

HEALTH WORKER SUGGESTIONS FOR IMPROVEMENT

Need to encourage two-way communication

During the focus groups health workers stressed the need to encourage and facilitate two-way communications between themselves and other health care providers. Some suggested particular areas to be targeted which could improve the current situation. For example, staff shared experiences of using strategies such as typing a bolded note on the bottom of all referrals requesting feedback and providing contact details. These methods were both effective in increasing responses. Staff also shared positive experiences of using email since this allowed them to send short communications that were more likely to be read and responded to in busy service environments.

A more consistent care plan approach

Another central theme was the desire to develop a common system of care planning. The rationales for this included a reduction in client confusion and alleviating the need for health workers to learn multiple planning systems. Suggestions from health workers included developing a single care planning system across services, states and even nationally in order to achieve consistency:

One Australia-wide basic comprehensive care plan used by EVERYBODY with additional relevant sections for things like, palliative care, Disability, Indwelling devices, etc. etc. Colour coded so everybody knows where to look for the information they require quickly and easily. So page 1 is who, where, what's wrong, who's involved and their contact details and page 2 is immediate needs, e.g. DEAF, BLIND, etc. allergies and other alerts and page 3 is personal care needs e.g. can walk, can't feed self. (Nurse, hospital)

It is necessary to acknowledge at this point that the Victorian Government has implemented a consistent system of care planning (41). However, our research has revealed that, in practice, multiple systems still operate in Victoria given that many private care organisations do not (and are not required to) use the this system. Furthermore, in practice it is possible that the Government mandated system may be implemented with clients more than once, thereby, still resulting in care plan overlap. In order to reduce variability, a more rigorous, structured approach would need to be implemented which seeks cooperation within both private and public health care sectors and which is monitored closely to ensure the reduction of care plan overlap.

Electronic database

An idea that arose and stimulated interest in three of the focus groups was that of an electronic database that contained the details, history and care plans of clients across service networks, across a particular state or across Australia. The desirability of this was also reflected in the survey responses. The main benefits perceived were the convenience of central data storage, the ability for health workers to collect a full client history, and the ability to easily and effectively maintain care plans so that changes could be viewed by all health workers involved. Concerns were raised during focus groups, however, about the difficulties around gaining consent for the central storage of client information and about the need to build safeguards into the database to protect against unauthorised access and data loss.

Discussion

We now summarise the contribution that these findings make to research knowledge by using each of the research questions as a framework for discussion.

ADDRESSING THE RESEARCH QUESTIONS

1. Do structured chronic condition and self-management care planning tools enhance information sharing between health worker providers within and across primary health care services and sectors?

The findings indicate that, in general, use of care planning tools and the implementation of structured care plans does enhance information sharing between health workers within and across primary health care services and sectors. From the various sources of data it is clear that, *when working effectively*, care planning tools enhance information sharing between health workers by:

- > establishing the expectation that information will be shared with all members of the health care team;

- > providing a structured framework through which a team approach to chronic condition management can be established;
- > providing a set of documents for use by each member of the team which can be distributed easily and effectively through multiple means such as email, mail and the sharing of client files;
- > providing document templates which can reduce the time health workers need to spend on sharing information;
- > providing a common system of referral and systems through which health workers who are new to the team can access client records kept by other workers;
- > creating scope for multidisciplinary review of a clients' care plan, such as by a nurse and then a GP in a two stage review process, and allowing for each stage of this process to be funded; and
- > allowing health workers access to all information obtained through holistic assessment of client needs, such as financial situation and family relationships.

Although it is evident that care planning tools do facilitate information sharing, the current situation is more complex and some of that complexity has been explored throughout this report. In addition, it must be acknowledged that the current tools and processes do not always work as effectively as possible. This means that while information sharing may be occurring to some extent, information is not shared effectively in all cases and sometimes the processes do not achieve the intended results.

2. What are the mechanisms and processes that enable or hinder this process of information sharing within primary health care services that deal with chronic condition management?

The research has revealed that there is no consistent model or process of information sharing that is being implemented across primary health care services. Instead different practices are used and expectations vary about how and whether information will be shared. The lack of consistency is problematic given that a multidisciplinary approach to care planning for chronic condition management relies upon effective collaboration and information sharing across services and professional disciplines. For this reason several of our recommendations (refer to conclusion and recommendations section) focus on the need for greater integration of policy and practice in this area and for further investigation about the practicality of centralised care planning and information sharing systems. Introducing greater consistency may assist in overcoming some of the barriers to effective information sharing that we have identified through this research.

Fragmented communication was identified as one of the strongest barriers to effective information sharing. Fragmentation leads to information being misinterpreted or lost and, ultimately, to gaps and delays in client care. This, in turn, leads to health worker frustration and, in some cases deters them from actively following up and exchanging information, particularly in the context of repeated experiences of one-way communication. Importantly, our findings reveal that fragmentation is a deeply entrenched problem that cannot be resolved easily. The depth of the problem is highlighted through the examples of miscommunication that we identified, even in places where health care services or health care workers were co-located. These findings challenge the emerging assumption in primary health care literature (42) that co-location is necessarily effective in improving or increasing information sharing.

The effects of fragmentation also interact with other aspects of the information sharing process and, potentially, reverse the positive effects of factors that facilitate information sharing. This is particularly evident in terms of the potential impact of fragmentation within the relationships of health workers and clients. Problems such as a lack of trust may develop

if referrals are not followed through for example, because clients may perceive this to be the fault of health workers. Such a loss of trust is a significant impediment to effective relationships in health care (43, 44). Clients may also be judged by health workers if they do not attend appointments or 'comply' with other advice, even though they may be doing so because they did not receive appointments or because their needs are not being met.

The findings also reveal that complex, multi-level funding systems exist, which provide the potential for the ineffective use of resources and which create the potential for miscommunication or non-communication. Given that different models of funding operate within and across services this encourages health workers to develop several separate care plans for a client in order to ensure that they attract maximum funding for the particular services they provide. Therefore, a shift in funding requirements may be necessary to make it possible for health workers to collaborate on single care plans.

In terms of specific enablers, the findings demonstrate the importance of valuing open communication within multidisciplinary teams. The valuing of information sharing is central to its success both at the broader system level and in the context of one on one practice. In order to attribute the necessary value to information sharing, adequate time and resources must be allocated to health workers. This is required to provide adequate opportunities for information sharing and to promote the message that this is an important and respected aspect of care in chronic condition management.

Overall, through examining factors that operate as facilitators and barriers to information sharing throughout the report we have highlighted that the current systems produce particular advantages and disadvantages for the different parties involved. Questioning who benefits from the current systems that are in place is important, particularly in the context of factors which may seemingly operate to produce positive effects but, also at the same time, operate to disadvantage clients, health workers or health care services. Such questioning is vital in interrogating the complex operation of information sharing in order to achieve understanding about the various implications that are produced and the multiple effects that these may have on the people and organisations involved.

3. How do clients who have a care plan for their chronic conditions interact with, and respond to, primary health care providers as a result of their plans?

Analysis of the data suggests that clients value the improvements in information sharing that they have observed or that they assumed had occurred after implementation of their care plan. The perception of improved information sharing and the valuing of this by health workers appeared to have a positive effect on clients' overall willingness to engage with the processes of care planning and the open sharing of information. In particular clients benefited from the perception that they would receive better care if their health workers were communicating regularly with each other.

Health workers reported changes that they had observed in client behaviour after gaining experience with the care planning process. These changes were positive and they allowed clients to engage more fully with the management of their conditions. Health workers also commented on some clients becoming more proactive, both in terms of their own behaviours and also in ensuring the active collaboration of their health workers.

In response to this question it is important, however, to look at the basis from which clients and health workers are currently engaging. During our observations we rarely witnessed clients and health workers engaging in discussion about preventative health care. The only discussion of prevention occurred at the secondary or tertiary levels (45), that is, around issues of preventing the progression of chronic health problems that had already been diagnosed. There was little discussion about how clients could participate in the promotion of their overall wellbeing. Where this discussion did take place it was in the context of doing so to assist in the management of existing conditions rather than to prevent chronic conditions

from developing in the first instance. This is problematic and it suggests scope for broadening the current exchange of information during contact between clients and health workers in order to promote clients' wellbeing more holistically and to prevent further decline in population health status. Given the findings of this research, however, system change is necessary to support further information sharing around prevention. In particular, this would need to be factored into calculations of required funding and consultation time. The potential benefits of greater engagement with prevention, are considerable, both in providing assistance to individual clients and in limiting the anticipated burdens on the health care system.

4. What features of this care planning process enhance or hinder clients' participation and navigation through systems of self-management support?

In addressing this research question we took the approach of first finding out how clients understood the concept of 'self-management'. Some of the findings that emerged were surprising. The potential for clients to have varied understandings of this concept (37), and understandings which may differ from those of health workers, emphasises the need for more open information sharing around the meaning of particular terms (39). The development of shared understandings will facilitate more effective information sharing (43).

In relation to this question it is also relevant to note that the aims of the care planning systems that the five services use are not necessarily consistent. In practice, the care planning processes that are implemented in three of the five services appeared to be closely aligned with the goal of encouraging client self-management. This was reflected in the goal setting processes where clients were asked to identify their own goals and how they could work towards achieving them. At two of the services clients were also encouraged to take control of managing their health care team and for making decisions about who they will see for particular aspects of their health care. However, the GP Management Plans used at the two other services did not appear to be as strongly orientated towards encouraging self-management. Instead we observed that the central aims of these Plans were to improve the coordination of how clients' chronic conditions are being managed as well as better facilitating the management of the health care team involved. Furthermore these Plans can be used to enable clients to get access to free health services. This does not mean that encouraging self-management is not a focus of practice around GP Management Plan practice, but it does not appear to be a central focus and this is reflected in how the staff at these services measure success with clients. In these services the measurement of success revolved mainly around encouraging clients to follow the instructions of their health workers, whereas at other services greater focus was placed on achieving goals around client engagement and proactivity.

Adding to the complexity of addressing this question are the findings from the discourse analysis of consultations which suggest that, in some cases, efforts to encourage self-management can result in the construction of client dependence¹ and reliance. This suggests the need for careful and regular review of care planning strategies and outcomes in order to facilitate the flow of information, and from this, encourage further discussion about whether the processes being used in the area of self-management are having the desired effects.

Overall, the care planning processes that we studied in this research have some clear benefits in facilitating self-management. The elements that assist most centrally in encouraging self-management appear to be the active collaboration of clients with their health workers to come to mutually satisfying decisions and the role of the health worker in listening to client concerns and aspirations. This can facilitate shared decision making and contribute to increased client and health worker satisfaction.

¹ Refer to Appendix 5 for research findings which reveal how dependency is created and expressed.

The barriers that have been discussed in this report have the potential to compromise care planning relationships, however, and lead to problems which impede self-management. These are problems such as one-way communication, client dependency and unwillingness for clients and/or health workers to actively collaborate in healthcare partnerships. The existence of fragmented, judgemental and ineffective communication may also reduce the opportunities available to clients to develop effective health literacy, which is imperative for self-management. A supportive relationship between a client, their health workers and the health system is vital to allow clients to develop the capacity to manage their health and to make health enhancing choices. Without such support, the health system becomes just another structural barrier (46) to improved client health and wellbeing.

5. What do people with chronic conditions who have these care plans think about the way the plans are developed, shared and monitored?

Most clients were satisfied with the ways that their care plans were being developed, shared and monitored. All clients reported deriving at least one benefit from their care plan (see Question 6) and two clients reported no areas of dissatisfaction at all. However, for the remaining 22 clients there was at least one area of frustration, difficulty or uncertainty related to the development, implementation, sharing and monitoring of their care plans. These issues have the potential to impede the effectiveness of client engagement and their willingness to share information openly.

Inadequate time with health workers emerged as a central source of frustration for clients. Insufficient time was shown to have an important influence on information sharing, not only because it limited the amount of information that can be shared but because it also influenced the willingness of clients to communicate openly.

The need for clients to (still) have to navigate the health care system to achieve the outcomes they desire was also evident. This has the potential to impact on the effectiveness of care plan implementation and also has the potential to reduce the effectiveness of care planning through the lack of a clear path for clients to take in their efforts to improve the management of their chronic conditions.

Apart from issues of time and client navigation, frustrations around the inappropriate sharing of information also impacted on client experience. The sharing of client information without permission and the lack of opportunity for clients to provide selective consent in some services are issues that must be addressed.

6. What do people with chronic conditions say about how these care plans affect the way they manage their conditions?

All 24 clients identified at least one benefit that they had experienced as a result of their care plan being implemented. Some of these benefits included improved access to health services, increased knowledge about the services available and the opportunity to participate in the management of their health and health care.

Apart from reporting benefits, clients also reported anxieties and frustrations which may impact on how they manage their chronic health problems. One source of anxiety came from clients feeling as though they were obliged to continue with the care plan and with the strategies that had been suggested for managing their health problems. This indicates the ineffective sharing of information with clients about the possibility for them to take a greater role in selecting the strategies that are most appropriate to manage their chronic health problems and in deciding how their care plans operate. This may hinder the prolonged and active participation of clients.

Given the early stage that some clients were at when they participated in their interviews, some could not be sure of the extent of benefit that they would derive from the care plan. For these clients the main benefits were thought of as being potentially realised in the future

rather than at their current stage, which highlights a potential influence of the methodological design of this research on the data that we collected.²

7. What do clients and health workers suggest as improvements to this care planning and information sharing process?

Findings from the interviews, focus groups and the survey reveal that there are several aspects of the care planning and information sharing processes that could be improved. The main areas of focus that were defined by health workers and clients included centralising data storage, expansion of the nursing role, delivering further information about the care planning process and expanding understandings of what constitutes information sharing beyond that of clinical information to include emotion.

It was clear that health workers and clients valued the opportunity to voice their opinions about the need for improvements as part of this research. This suggests a benefit of their participation but it also reconfirms the importance of including people as valid contributors of knowledge. Doing so assists in engaging individuals and in conveying their value as partners in the development of contextually appropriate strategies for change. This is similar to the potential effects of inviting and facilitating the active participation of clients through a strong and ethical approach to information sharing. Some of the suggestions made by the clients and health workers are incorporated in our recommendations to policy advisers.

Conclusion and recommendations

Through this research we have explored processes and practices underlying the sharing of information within multidisciplinary teams around care planning for chronic condition management. Our use of multiple methods and approaches means that our findings are relevant to the current context of primary health care and that they are inclusive of the perspectives of those most centrally involved. The findings demonstrate that information sharing has a key role in the management of chronic conditions. Therefore, ensuring its effectiveness is central to optimising the benefits of the PCC approach. While there is certainly effective information sharing practice already being implemented, there is scope for further improvement since many practices still do not achieve the desired outcomes of client involvement and multidisciplinary collaboration. Such improvement may be achieved through developing new policy or by implementing strategies at the practice level that promote the rhetoric of collaborative care that is already present in existing policy. To meet these aims we recommend that the following strategies be considered.

ACCREDITATION AND REVIEW

- > As part of primary health care reform, assessment of care plan use and effectiveness should be built into formal accreditation and performance review process.³

² Refer to Appendix 6 for an overview of the limitations associated with the research design.

³ Creating formal criteria and assessing adherence is vital to improve the effectiveness of care planning and information sharing processes at the practice level. As identified in research by Checkland et al (47) resistance to change is a characteristic of organisational culture that can become a strong opposing force in efforts to identify and address (other) barriers to improving systems and processes. Resistance is usually not intended to impede client care but it may have this effect as well as lead to a waste of resources (47). Developing formal criteria and assessing adherence to these can overcome resistance and encourage implementation of changes in a timely manner. Therefore, initiating formal assessment as part of any policy led changes that are decided as part of the primary health care reform will assist in the realisation of positive change.

- It is particularly important to assess whether care plans are being used and whether they are being used effectively rather than only identifying if they exist.
- It is also important to identify whether multiple care plans are operating for the same client within and across health services and, if so, whether these care plans are being coordinated.

IMPROVING CARE AND COMMUNICATION

The following strategies may be used to inform the accreditation and review criteria used to assess the effectiveness of care planning and information sharing. These strategies may also be implemented by individual health services to improve current practices.

- > At the point of client intake and/or care plan implementation all health workers who are involved with a client should, routinely, be informed that a new care plan is being implemented. Clients should, however, be asked to consent to this in case they do not wish some health workers to know they are accessing a particular service.
- > At intake, all new clients should be asked, routinely, if they have existing care plans.
 - Initial contact with other health workers involved in the care of a client should also include questions about the existence of active care plans in case clients are not aware of the care plans they have with other services.
- > Clients and their carers should be given time to reflect on the content of care plans and standard referral letters. Follow up conversations should be encouraged so that clients and carers have the opportunity to identify gaps, errors or inappropriate content.
- > Information should be routinely provided to clients and carers early in the care planning process to explain the aims of care planning and to identify the processes involved. Consultation with the client about when they would like to receive the information and how they would like to receive it may be useful in determining how it can be conveyed most effectively. All information must also be kept current and relevant in order to ensure that it meets client needs (48). Non-written formats such as an audio recording may suit clients with low literacy levels. Providing such information will improve client literacy (49) around care planning and reduce client reliance on health workers. The preparation of standardised information in various formats will also provide health workers a means of conveying the necessary detail in a time effective way. To ensure usefulness, this information could be prepared in consultation with clients who have experience of the process and who come from different social and ethnic backgrounds (22, 44).
- > Adequate time for information sharing needs to be provided to staff, with meetings scheduled at the times when most staff are able to attend. This may require some prior planning in regard to rostering.
- > Health workers should provide clients with an opportunity to explain how they understand their care plan and the terminology that is used.
- > Primary health care consultations should include the exchange of information about how chronic health problems can be promoted and how wellbeing can be enhanced.

CONSENT

- > There is a need for consistent guidelines about what information health workers can share if they have full consent from a client.

- National policy frameworks should provide clear guidance in this area to ensure client privacy and confidentiality and to protect health care providers from professional liability.
- > Clients should be provided with information about what their provision of full consent entitles health workers to share.
 - Clients need time to reflect on this information before they are asked to provide written consent. This acknowledges health professionals' need to understand and acknowledge clients' health literacy needs.
 - Clarification of terminology contained within this information should occur through joint discussion and during health worker follow up with the client.
- > All clients should be given the option of providing selective consent, rather than full consent.
 - Alerts should be displayed on the files of clients who have given only selective consent along with a list of information that may be disclosed.
 - The list of information that can be disclosed should be distributed to all health workers involved in the care of the client.
- > Clients should be given the option to withdraw consent and/or amend the list of information that they permit their health care providers to share.

FUNDING

- > Those claiming Medicare funding for care plans should be required to produce plans for ensuring their effective implementation and sharing before funding is provided.
- > A review of funding for care planning is necessary to identify areas of current overlap in service provision.
- > A funding review is also required to ensure that all health services that collaborate in the care of clients through care plans may derive funding benefit from that collaboration.
- > Funding systems should be modified to ensure that the greatest amount of funding is linked with the greatest amount of work in care planning systems.
- > Practice nurse positions should be dedicated to the management of client care plans. This would allow practice nurses to take on a dedicated role, similar to that of a case manager to ensure greater continuity for clients and to facilitate collaboration within multidisciplinary teams.
 - Freeing up practice nurses to dedicate their time to managing care plans may relieve some of the burden on general practitioners whose workloads often preclude them from spending the time necessary to establish effective lines of communication with other members of multidisciplinary care teams.
 - For the full potential of this arrangement to be realised, however, funding arrangements would need to be modified to ensure that the work of practice nurses could be recognised and that health services using this system could be remunerated accordingly.

INTEGRATED GOVERNMENT SYSTEMS

- > Medicare Locals should identify areas of possible service overlap in their regions.

- > Medicare Locals should be involved in the development of systems which facilitate the coordination of services within a local network and which enhance information transfer between these services.
- > To ensure the most effective approach to enhancing integration, cooperation and consistency must be present at a policy level. This is imperative given the range of new initiatives that are being implemented, such as Medicare Locals and the GP Super Clinics. These initiatives are currently managed by several Government branches which makes coordination across these branches necessary to avoid further service overlap and to optimise the benefits of future resource input.

TRAINING

- > Leadership training needs to be routinely provided to all health care providers.
 - This training should equip health care providers at all levels of the system to communicate effectively and to take an active role in conveying ideas and information to colleagues, clients and carers.
 - Modules in inter-professional communication should be offered as core components of university training for all new health professionals. This should be a focus that each University Vice Chancellor ensures.

E-HEALTH

- > The findings of this research should be considered by those involved in the Government's various e-health initiatives. This research identifies areas within current systems where clients are excluded rather than being involved as active partners in care. The research also highlights the benefits of creating stronger electronic links between services. These issues are relevant to e-health initiatives and may provide evidence to support the broader implementation of e-health as a cost-effective means of fostering collaboration within multidisciplinary teams.
- > The research highlights the potential benefits that may be derived from providing clients with hand held records in an electronic form. Clients can share these records with all health care providers they see, allowing them to be updated during consultations. Providing clients with electronic records of their care plans also allows them, and their carers, to take greater ownership over those plans and to access them whenever they want to check their content.

FURTHER RESEARCH

- > Further research is required to explore how a more centralised system of care planning could operate in order to reduce the impact of the current multiplication in care plans. This centralised system should provide guidelines for how information can be shared most effectively. A more centralised approach may discourage the current siloed approach and allow full realisation of the benefits that care planning can produce in optimising care outcomes. If such systems are implemented, strategies for ensuring consistent use should also be developed.
- > Further investigation should be undertaken to examine the feasibility and practicality of a centralised electronic database for the storage of client information. Any plans for electronic data transfer or storage would need to ensure security of information and that consent was obtained from all clients before their information is entered (50, 51).

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Appendix 1 Detailed explanation of methods

Throughout this appendix we provide detail about the health services that participated in the research and explain each of the methods that we used to undertake the research.

SELECTION OF HEALTH SERVICES

To undertake the various aspects of data collection it was necessary to access health care services where care planning for chronic condition management takes place. We purposefully selected five health care services and liaised with management to gain permission to undertake research with their clients and staff. We selected organisations with which members of the research team already had working relationships and which would provide us with a diversity of characteristics and experience. In particular, we selected sites that were located in rural and metropolitan areas across two different Australian states, which used different care planning systems and which dealt with a variety of client groups. The five services consisted of:

- > two metropolitan community based aged care health services;
- > one rural Aboriginal health service;
- > one rural general practice; and
- > one community primary health branch of a rural hospital.

Once the sites had been identified, we worked with the contact person at each organisation to select which clients would be observed and interviewed, what practice events we would observe and to establish the processes through which the interviews, observations and focus groups would take place. Each service had a different structure and mode of service delivery, as explained next.

DETAILS ABOUT EACH HEALTH SERVICE

Community based aged care service (1)

Structure: Co-located with a residential care facility. Provides allied health services and manages Government funded aged care packages for clients living in their own homes and in residential care.

Referral: Clients are referred by General Practitioners (GPs), hospitals and other health professionals.

Care planning system: In the chronic care division where we undertook the observations and recruited clients, all clients are assessed and provided with a self-management care plan using the Flinders Program for Chronic Condition Management. This is meant to be a collaboratively developed plan with agreed issues, agreed goals, and agreed care. After initial assessment clients have regular consultations with allied health staff or phone contact as necessary. Upon reaching desired goals clients are discharged. Clients and health workers continue to use the Flinders Program until discharge.

Community based aged care service (2)

Structure: Provides allied health services and manages Government funded aged care packages for clients living in their own homes and in residential care. Nursing outreach service works with the allied health staff to provide home visits. Not co-located with any other service.

Referral: Clients are referred by GPs and can also self-refer. Before referral is accepted client information is directed to a customer service centre and they are placed on a register until a place becomes available or until they are referred to another, more suitable service.

Care planning system: At intake basic assessment of needs and prior history is completed. Then a Goal Attainment Scale (GAS) is completed through negotiation between client and health worker about the goals that are intended to be reached through treatment. The majority of information about client progress is documented in clinical notes rather than on the GAS document. Clients have regular consultations with health workers for three months or until they reach 10 visits. After this, clients are discharged, re-referred or referred to another service.

Aboriginal health service

Structure: Provides nursing and GP services to Indigenous Australians and non-Indigenous members of their families. Not co-located with any other service.

Referral: Clients self-refer to the service.

Care planning system: GP Management Plans are provided to selected clients and the Management Plan documents are tailored to their particular condition. For example, the Management Plan for a diabetic client will include boxes for routine eye and foot checks. The GP decides whether clients should be offered a GP Management Plan, however, clients may request that they be considered. Some clients are also put on a Team Care Arrangement, which entitles them to five free allied health visits per year at other services. Clients have regular consultations with the GP as necessary and their Management Plan is reviewed every six months. Clients are not usually discharged from this service; instead the Management Plan is ongoing.

General practice

Structure: A large general practice with more than 10 GPs. Provides basic nursing services. GPs and nursing services are co-located.

Referral: Clients self-refer to the service.

Care planning system: GP Management Plans are offered to clients with diabetes and chronic heart disease. Clients may also request a Plan if they have diabetes or chronic heart disease. Management Plan is drawn up by clinic nurses and monitored by the nurses and the client's GP. Some clients are also put on a Team Care Arrangement. Clients have regular consultations with their GP as required and meet with a nurse every six months for review of the Management Plan. After meeting with the nurse, clients have an appointment with their GP to finalise the review. Clients are not usually discharged from this service; instead the Management Plan is ongoing.

Community primary health branch

Structure: This service is co-located with several other health services which provide allied health and general hospital treatment. During the research we worked with a team that administers a hospital avoidance program to clients who live in their own homes. The team is comprised of nursing staff.

Referral: Clients can self-refer or be referred by the co-located hospital or GPs.

Care planning system: The program is administered through a care planning system that is based on the tools and philosophies of the Flinders Program for Chronic Condition Management. However, the documents are branded with relevant institutional and government logos. Clients have an initial assessment over several appointments and a care plan is then negotiated between the nurse and client. Regular consultations and phone contact is had until clients have reached the goals they define. After this, the nurse completes a risk factor assessment with the client and recommends further services before discharging the client.

ETHICS APPROVAL

Before we began research at each of these services, ethics approval was obtained from the four human research ethics committees that oversee research at these sites. We adhered to the ethical standards set by the National Health and Medical Research Council (52) and ensured the confidentiality of the clients, health workers and health services. In order to preserve confidentiality pseudonyms are used throughout this report and identifying information has been removed.

PROJECT TIMELINES

The fieldwork for the research began in March 2011 and ended in July 2011. Analysis and data collection proceeded simultaneously. A core analysis of the data was completed in September 2011 but is still being reworked and refined as papers are written from the data.

CLIENT INTERVIEWS

To guide the approach that we applied when seeking client perspectives, we developed a theoretical framework based on the perspective of phenomenology. Phenomenology is about understanding lived experience. Research that is guided by a phenomenological approach focuses on exploring the meaning of every day events from the perspective of those who experience those events (1). The aim is to delve deep into the understandings of participants to gain insight into what a given process, event or phenomenon is like for them. The descriptions provided by participants then form the basis for data analysis with the findings representing the essence of their experiences (53).

Consistent with a phenomenological approach, open ended, in-depth interviews were undertaken with clients at various stages of their care planning process using a semi-structured interview guide (Appendix 7). Twenty four clients were recruited. Nineteen of the clients were interviewed several times. The five clients who participated in a single interview did so because their deteriorating health or family commitments made it difficult for them to commit to subsequent interviews. A total of 47 interviews were undertaken between April and July 2011. The majority of the interviews were undertaken face-to-face, but where distance made this difficult, interviews were undertaken over the telephone. The interviews had an average duration of 40 minutes and all participants were reimbursed for their time with a \$25 department store gift card after each interview.

The open ended, semi-structured format allowed the clients to speak about issues that were important to them while still being prompted by the questions that were asked by the interviewer. The clients were recruited with the assistance of the contact person from each of the five health services. The contact people assessed whether clients were eligible for inclusion before requesting their participation. The inclusion criteria for the semi-structured interviews were as follows.

- > Over 18 and can speak and read English;
- > Existing chronic condition(s) and have or are getting a care plan implemented for their health care management;
- > Current client of the designated service; and
- > Able to provide informed consent as determined by health worker key contact person at the designated service

Client demographics

The clients who participated had a variety of personal characteristics. They ranged in age from 40 to 89 years, with the majority being between 55 and 70 years of age. Eighteen clients were born in Australia with the remaining six born in various parts of Europe. Four of

the clients identified themselves as being an Indigenous Australian. Nine of the clients had private health insurance, 17 owned their own home and the remaining seven lived in rental accommodation. The clients had between one and seven chronic conditions, with the average across the sample being 3 to 4 chronic conditions. Five of the clients were engaged in paid work at the time of their interview(s) while the other clients received income from superannuation, income protection, the aged pension or a disability pension. One client also received a carer's payment for her care of relatives who also had health problems.

The clients were asked to assess their own health status at the end of their first interview. Most indicated that they had good or fair health as shown in Figure 3.

Figure 3

How do you rate your current health?



NON-PARTICIPANT OBSERVATIONS

To supplement the phenomenological approach that guided the interviews, we used interpretive ethnography as a basis for the observation component of the research. Interpretive ethnography focuses on understanding the *culture* of a group, or in other words, the structures and processes that guide and make sense of people's actions within a given group (1). In order to derive such understanding, ethnographic research requires the researcher to become immersed in the culture which they are studying through frequent engagements over a period of time. Stemming from ethnographic study is the ability, and need, for the researcher to provide detailed and substantive descriptions of their learning. Such descriptions in qualitative research are referred to as 'thick' descriptions (1). In order to provide such 'thick' descriptions a researcher spent the equivalent of a week within each health service undertaking non-participant observations of health care practice and consultations.

During the observation sessions the researcher observed interactions between clients and health workers, client exercise groups, staff meetings and impromptu conversations where information was exchanged between staff (such as in the lunch room). Notes were taken after each observation using a guide that was prepared in advance. Consistent with the emergent nature of qualitative research, however, the observation guide was not used as a rigid tool. Instead, when new aspects of information sharing processes were observed, new

categories were added to the guide so that it remained flexible and relevant to the emerging data. During the observation sessions the researcher maintained a distanced position, which is described as akin to being a “fly on the wall”. This was done so not to influence the interactions through actively participating. However, it should be acknowledged that even the presence of a non-participating observer may influence the people or events being observed (1). At times this influence was evident, particularly when health workers expressed signs of nervousness as a result of being observed and when clients tried to engage the researcher in their conversations during consultations with their health workers. To overcome some of the bias produced from this approach we sought and gained permission to audio record consultations between health workers and clients in two of the services. Audio recording meant that it was not necessary for a researcher to be physically present in the room to hear how information was exchanged. The lack of physical presence did, however, prevent collection of information about the non-verbal aspects of the consultation, such as body language and the sharing of printed materials.

FOCUS GROUPS

Consistent with both the ethnographic and phenomenological orientations of this research, focus groups were also undertaken at the conclusion of the observation periods in each of the five health services. The purpose of the focus groups was to delve deeper into the findings of the observations and interviews, to elicit insights into the clinical culture and care planning practices within it.

In preparation for the focus groups at each health service, invitations were sent to all staff involved in the care planning process, in either a clinical or administrative capacity. Following receipt of the invitation staff replied stating whether they would be interested in attending. Information sheets and consent forms were then forwarded to all staff who stated that they would be interested. After receipt of this information staff then accepted or declined participation. A catered lunch was provided during each focus group in appreciation of staff time.

The focus groups were well attended at each service with a total of 41 staff participating in six focus groups during the study. Two focus groups were undertaken at one of the health services due to the inability for all interested staff to attend one session.

Questioning during the focus groups was open ended and the participants were invited to raise any issue that they believed to be relevant to the topics of care planning and information sharing. On average, the focus group discussions lasted for 40 minutes and the end of discussion was followed by the researcher highlighting some of the main findings that were emerging from the client interviews and observations. Staff often engaged with this and supplemented the researchers’ explanation by recounting experiences of their own. This supplementation provided further data for the study and also provided a means of engaging staff in the initial findings of the research.

ANALYSIS OF THE QUALITATIVE DATA

Consistent with the principles of qualitative research, as well as the need to provide an account of emerging findings after each focus group, it was necessary for data collection and analysis to proceed simultaneously.

Note taking

The first stage of the analysis began immediately after each interview and observation session via the documentation of detailed notes. The notes contained observations that the researcher made during the interviews, for example, the non-verbal communication that had occurred (such as body language and the emotions expressed by the participants). The researcher also wrote notes about the particular issues that appeared to be central to each interview or observation session and about any themes that emerged strongly. As part of this

initial stage of the analysis the researcher also reflected on the interview and observation processes and made notes about aspects of, or emphases within, the interview schedule and observation guide that should be changed. Making such changes to the interview schedule and observation guide allowed the researcher to remain attuned to the main themes that were emerging as data collection continued.

Thematic analysis and NVivo 9

The second stage of the analysis was undertaken after the data from each observation had been entered into digital file and after the audio from each interview had been transcribed. The software package NVivo 9 was used to organise, categorise and manage the data during this second stage, which was based on the method of thematic analysis. The thematic analysis began with a researcher coding quotes and examples into categories. Further reading of each transcript and collection of notes was then performed to check the categories that had been used and to further categorise the data into new categories as the depth of the analysis increased. When a new theme emerged in the data, other transcripts were re-read to determine if instances of the new theme also existed in the data previously analysed. Selective coding was then used to identify the core codes and central stories in the analysis (54). Detailed explanations of each theme were written and examples were included as the themes were organised under the research question(s) to which they related.

Discourse analysis

A subset of the qualitative data was also analysed using a discourse analysis approach. We decided to undertake the discourse analysis because it was noticed, during interviews, that clients from one health service appeared to have difficulty in thinking beyond the personality of the health worker to consider the care planning *process*. From talking with staff at the health service the researcher found that they had related concerns about their clients becoming dependent on them. Staff also reported difficulty in assisting some clients to become more independent in the management of their health. These findings prompted discussions within the research team about the extent to which clients understood that there was a care planning process underlying the care that they were receiving from this particular health service. Rather than understanding this, the clients seemed to believe that the improvements stemmed only from the personalities and care of the individual staff and that it was *their* ideas and support (rather than the processes of collaboration and open communication) that were fundamental to improvements in the clients' health.

To explore these ideas more deeply we undertook a discourse analysis of the consultations that we had observed and recorded from this particular health service. This enabled exploration of the language being used, to see if and then how dependency was being expressed. Furthermore, this approach enabled exploration of how strongly clients were guided by the staff, how the processes of care planning and information sharing were working in a way that created dependency and what information was not being shared that, may have, conveyed power or control and encouraged dependency.

During the discourse analysis attention was focussed on the presences and absences in the data. We considered the implied values and concepts that emerged from the communications rather than only those specifically mentioned (55-57). The discourse analysis was commenced by asking the following broad questions.

- > What is dependency in the context of these consultations?
- > Where is dependency evident?
- > How does dependency occur?
- > How is dependency encouraged or discouraged?
- > Who takes control?

- > Who has the power to make decisions?

By exploring the data around these questions, we began to categorise the discourses that were evident using the NVivo 9 software.

Quantizing

To analyse the consultations that were audio recorded, a different approach was used. This allowed capture of the various elements of information sharing that occurred and it added further depth to our qualitative analysis by producing data in numerical and thematic forms. A quantizing approach was used to transform interview transcriptions into a numerical translation using the Verona Medical Interview Classification System – Doctor (VR-MICS/D) (58). This enabled a numerical comparison of information sharing that occurred between healthcare professional and client across two of the healthcare services. Quantizing is a recognised analysis approach in mixed method studies (59) and has been used successfully in similar studies by members of the research team (60-64).

Following consideration of numerous classification systems that are available to analyse information sharing and patient centeredness, the Verona MICS/D classification was chosen. This analysis framework comprises 22 scoring categories and one additional category of unclassifiable verbal units. The types of evidence sought include information gathering, patient facilitation, patient involvement, patient support, and patient education. Twelve of the 22 categories are patient centred categories and these, therefore, were relevant to our research questions. The first five recorded interviews were analysed independently by two researchers, and then the outcomes were compared and contrasted to ensure rigour and agreement in classification decisions.

Discussions about emerging findings and cross-validation

As the analysis of all of the qualitative data proceeded, initial findings were presented to the project Steering Committee. The Steering Committee, which was comprised of the research team, key representatives from each health service and consumer representatives, convened regularly during the project. Presenting initial findings to the members of the Committee was useful in seeking their insights and for stimulating discussion and debate about the key themes. This, in many instances, opened up new parts of analysis or gave the researchers ideas of how they could present the data in ways that made sense to clients and health workers.

The members of the research team also collaborated during team meetings at regular intervals. During these meetings all researchers read parts of the transcripts and notes to discuss the ideas emerging from them and to cross-validate and deepen the analysis. Collaborative analysis allowed the team to offer their different disciplinary perspectives. This strengthened the rigour of the research and contributed further to the triangulation already achieved through the use of multiple methods.

QUANTITATIVE SURVEY OF HEALTH WORKERS

As a supplement to the other data sources, the insights of health workers were captured during a quantitative national survey of primary health care workers. Five hundred and eighty primary health care workers responded to the national survey. All states were represented and the survey was open for 24 days in October 2011.

Processes involved in survey design

Upon completion of the qualitative data collection, the research team completed an initial draft thematic analysis of data from the interviews, observations and focus groups. The most common issues arising from this preliminary analysis were then summarised. The research team reviewed these themes and identified and prioritised the issues to be explored in the survey. This priority list was then discussed with a representative from APHCRI who joined

the research team for a meeting. This representative provided additional input with regard to priority areas for informing policy and practice agendas. The following were then defined as target areas for the survey questions.

- > Client awareness of care plan and process;
- > Consent;
- > Fragmented communication;
- > Overlapping care plans;
- > Withholding information;
- > Care planning documentation;
- > Accessibility of care plans;
- > Decision making;
- > Self-management;
- > Influence of values and assumptions; and
- > Potential improvements.

Having established the priority areas, a draft set of survey questions were generated, where possible, basing items on actual wording extracted from the qualitative data. This set of items was then used to generate an online survey. The survey document was developed using Survey Monkey (refer to Appendix 8 for a list of the survey questions).

Once available online, the draft survey was distributed to a small group of individuals, similar in occupational positions and experience as the target population. This represents the piloting phase of the survey design. Based on feedback from these individuals, wording of items was revised and response options were reviewed. Thereafter the survey was launched on the internet for public access through a hyperlink.

In order to encourage participation, we sent information about the survey to more than thirty organisations which catered to, or are in some way associated with, primary health care workers. Twenty-one of these organisations agreed to distribute the link with information about the survey. Means of distribution included display of the link on their website, direct emailing via their mailing lists and inclusion of information about the survey in their newsletters. These organisations were from all states of Australia. Given the wide distribution of the link and the fact that several organisations could not tell us how many people received their emails or newsletters, it is impossible for us to calculate how many people received the hyperlink to the survey.

Survey sample

The survey attracted 580 responses. Responses were obtained from health workers in every Australian state and territory, with the largest number of responses coming from health workers in Victoria (29%) and South Australia (27%). The survey captured responses from a range of different professional groups; with 48% of respondents being nurses and 8% GPs. Professionals from various other health fields also responded, including occupational therapy, physiotherapy, nutrition, respite and social work. In addition, the survey attracted responses from health service managers and case workers who work with clients to coordinate care across multiple services.

Eighty-three percent of survey respondents were female and 64% of all respondents had been practicing for 15 years or more. This suggests considerable experience within the sample. Seventy percent of the respondents also reported that they create care plans for

clients while the remaining 30% receive and use care plans without being involved in their creation.

The majority of respondents reported having received some training in the creation and implementation of care plans, however, 33% indicated that they had received no training at all. The open ended responses also indicated that some health workers who had received training had felt that this training was insufficient to meet their practice needs.

ANALYSIS OF THE QUANTITATIVE SURVEY

After the survey was closed, participant responses were downloaded into an excel spreadsheet. All responses to open questions were then reviewed by a new researcher who had no previous involvement in the project. This researcher reviewed all responses to the open questions and developed an initial coding frame for these responses.

The coding frame was then reviewed by the main research team, who after applying it to a sample of responses, revised the coding frame. Thereafter, the new researcher (funded by the University of Tasmania), conducted an initial coding of all open question responses. A sample of responses was also coded by one member of the research team to establish reliability of coding.

Once all coding of open responses was completed, the data file for the survey was then cleaned and screened. Initial analysis involved simple descriptive statistics of responses to each item (frequency distributions, measures of central tendency and dispersion). Thereafter, the relationships between variables were explored. Differences in responses across sample characteristics were tested using t-test and analysis of variance for continuous data and using Mann-Whitney, Kruskal Wallis and Chi-Square inferential statistics for ordinal and nominal data. Relationships between items were tested using Pearson's Product Moment, Kendall's Tau and Spearman's Rho correlation coefficients, depending on the level or monotonicity of the data.

This account of the methods and processes involved in the research design, data collection and data analysis for this project upholds the validity of the mixed method research that is presented here (3). In addition, the weaving together of the qualitative and quantitative data, combined with the presentation of findings from existing literature, contributes to the depth and quality of the analysis that is presented. These strategies also, in turn, extend the validity of the findings and increase the extent to which they can be considered accurate and trustworthy (3).

Appendix 2 Methods of information sharing

The following lists present findings from the observations that we undertook to identify how information sharing occurs within primary health care services around care planning for chronic condition management.

METHODS OF INFORMATION SHARING BETWEEN CLIENTS AND HEALTH WORKERS

- > Verbal discussion during consultations about topics such as symptoms or treatments;
- > Provision of printed information by health workers to clients;
- > Case conferences involving a client and their health care worker(s);
- > Physical assessment of client by health worker and the discussion of results;
- > Verbal assessment of clients by health workers during care plan reviews;
- > Provision of printed version of care plan to clients;
- > Sharing and joint viewing of information or results via DVD or CD;
- > Clients or health workers drawing pictures to supplement verbal explanations;
- > Health workers providing clients with a diary or other schedule of future appointments;
- > Conduct of a medication review in the homes of clients and subsequent discussion;
- > Clients providing health workers with letters from their other health workers or relevant government departments to provide holistic insight into their current situation;
- > Follow up by health workers after a client has been discharged; and
- > Spontaneous contact, such as in shopping malls, where client progress is discussed.

Information sharing *between health workers* also occurred through some of the methods in the previous list; particularly through case conferencing and the sharing of test results via electronic media. However information is also shared between health workers through some other, more distinctive methods. These are identified next.

METHODS OF INFORMATION SHARING BETWEEN HEALTH WORKERS

- > Multidisciplinary team meetings held within services where staff review client lists, discuss client progress and initiate verbal referrals to other staff if necessary;
- > Referral letters sent between health care workers via email, fax, mail or databases;
- > Health workers asking questions of each other verbally, via letter or via email;
- > Informal discussions, over lunch or in the office for example;
- > Joint review of client care plans; and
- > The sharing of written client care plans.

Appendix 3 Case study to highlight the potential impacts of ineffective meeting structure

The impact of ineffective meeting structure was particularly apparent during a meeting that we observed within a rural service.

Upon staff arriving at the meeting they greeted each other but there were no formal openings to the meeting. A client list was provided to all staff in attendance and the meeting commenced with a nurse starting to discuss the progress of the client at the top of the list. The staff then worked through the client list progressively and each client was discussed by the health worker who had the most contact with them. While each client was being discussed one of the nurses made notes in their file. The notes were basic; in some cases only indicating that the client had been reviewed and was progressing “well”. For clients who had received a recent referral, an update was given by the health professional to whom the client had been referred. The meeting ended following discussion of the last client on the list.

There are several aspects of this meeting which have the potential to contribute to fragmented information sharing. First, the referral system that was used is inconsistent. On the client list there was a column for discharge plans where some referrals were written. However, not all referrals were written there. Instead some referrals that were made during the meeting remained verbal. From speaking with a staff member who attends regularly we found out that after the meeting a written referral *may* be made but a written referral may also never eventuate. This creates the potential for referrals to be forgotten and not followed up. The clients who attend the health service also do not know they are being discussed. This creates a situation where the health professional has to approach a client on the basis of the verbal referral often without the client’s knowledge that they have been discussed or referred. This highlights existing gaps in the sharing of information with clients about the processes used at the service. Furthermore, during the meeting when a health care worker suggested that a client be tested for her sodium levels, she was told that the doctor had not asked for that and the impression was given that it was not necessary. There were no notes made of this suggestion or any plans made for querying the necessity of this test. Some clients on the list were also listed as needing/receiving care from a dietician, yet a dietician does not usually attend the meeting. This creates the potential for communication breakdown in the treatment of these clients.

Similar issues were also observed in the multidisciplinary meetings held in the other four services.

Appendix 4 Time as a barrier to information sharing

The following is a list of issues that emerged as the consequences of clients having insufficient time with the health workers, particularly their GPs.

- > Clients reported having to book appointments with GPs long in advance. This made their GP Management Plan unresponsive to immediate needs and created anxiety for clients who were trying to have their conditions managed effectively.
- > Standard GP appointments are too short to allow multiple issues to be addressed (despite care plans being designed to cover a range of conditions/issues). This creates difficulties for clients given that they need to book (and pay for) double appointments or rush their discussions with their GPs. Some clients reported being set a 'one appointment/one issue' rule, which restricted the amount of information they could share with their GP and created an overall impression that the GP did not value open information sharing. The 'one appointment/one issue rule' also created difficulties for clients with complex health needs and complex care plans because their concerns often remained undealt with and undiscussed. The need to contain discussion to one issue only also creates the impression that the GP is not a reliable support person for the client when they feel the need to openly discuss issues.
- > Several clients explained that they felt rushed when visiting the GP and carefully monitored the time to ensure they got their full appointment while also trying to fit in as much discussion with the GP as possible. This created a sense of tension for the client rather than being able to have the consultation in a relaxed, open environment.
- > Some clients reported being given printed materials as a substitute for verbal explanations during GP visits. This maximised the information they could receive from the GP in a short time frame. However, it only worked as an effective system of information exchange when there was follow up on the written information at the next consultation. This follow up did not occur in all cases.
- > Long waits in GP waiting rooms discouraged clients from attending, encouraged them to rush their own consult and/or made them feel that the system was not working well for them.
- > Clients also commented on the insufficient time that they believed GPs devote to following up on referrals. The lack of follow up can result in delays in the clients receiving the services they are referred to or in GPs being unaware about whether a referral has been acted upon.
- > Clients appreciate the longer consultations made available to them in community based health services. However, clients found the set time periods that apply to service provision in community based health services to be problematic. For example, at one of the metropolitan services clients can only receive 10 treatments or 3 months treatment (whichever is reached first) before they need to cease treatment. If they require ongoing treatment they must obtain a new referral from their GP, re-join the waiting list and/or seek treatment from professionals outside of the service. This is due to funding systems which allocate funding on the basis of how many clients reach their goals within a given time period. To ensure funding allocation we observed staff setting client goals at a limit lower than the client wanted, or lower than the worker believed was achievable, so that they could ensure the client would reach the set goal within the allocated time period and, subsequently, secure the maximum amount of funding.

Health workers also raised the issue of insufficient time as being a barrier to effective information sharing. With more time health workers believed they could provide a better service but current systems make this impossible, which operates as a source of frustration:

Much more time - to do this effectively you need to have time to build rapport and get them to be honest with you, to counsel, to listen, I can't do that and the other tasks the GPs want in 30 mins! (Nurse, general practice)

Appendix 5 Outcomes and consequences

In this appendix we present additional findings to supplement our explanation about how information sharing operates and what outcomes it produces. First, some of the most salient positive outcomes of collaborative, multidisciplinary care planning are identified. We then shift our focus to explore some of the unintended consequences.

POSITIVE OUTCOMES

Client perception of effective sharing

Most clients reported that the development of a care plan had increased communication between their health workers. Some shared examples of this communication. Others expressed their assumption that their health workers were communicating on the basis that one health worker had referred them to another health worker or that they all knew which health workers were involved so they “must be” communicating with each other. When asked *how* their health workers share information several clients were able to explain the processes used (for example referral letters, emails and telephone calls) while others did not know how the communication occurred. Two clients stated that the increased communication within their team had led to a better experience of health care because they felt that all their health workers were well informed and that they didn’t have to ask too many questions before being able to provide effective treatment.

Greater confidence

Health care workers also reported changes that they had observed in client behaviour after gaining experience with the care planning process. Such changes are explained here by a health worker who believes that the care planning process had assisted her clients to develop greater confidence. She believed strongly that increased client confidence had facilitated the open exchange of information in her relationships with them:

They’re definitely more confident and they’re definitely more empowered to maybe just not accept appointments or processes. They will actually start questioning the necessity and they’ll also question the timing. So if they’ve got three appointments scheduled across the week you’ll start finding that they’ll start trying to coordinate them to be all on one day or similar things. That’s been my experience. So they definitely become a lot more empowered and confident in controlling their health care. It’s not such a passive role anymore. (Nurse, rural service)

Client proactivity

Health care workers also reported their clients becoming more proactive in managing their health and identifying symptoms. They believed this to be a result of the education and confidence that clients derive from their experiences of having a care plan and from actively collaborating with their health care team. Client proactivity also had positive outcomes for the information sharing process by increasing the engagement and participation of clients:

I’d say, yeah they start to observe their symptoms and they will get on the phone and ring up the doctor and say, ‘Look I’m starting to get changes. I think there’s something going on’. (Nurse, rural service)

UNINTENDED CONSEQUENCES

Dependency

Despite self-management being a central goal of the systems implemented in one of the health services, in practice some of the processes used there may also be working against

the goal of encouraging self-management and client independence. A discourse analysis of consultations that we observed while at this service revealed the following processes which may lead to client dependency.

In particular there is a high level of health worker guidance provided to clients during their consultations. This is expressed in the following ways.

- > Health worker direction of topics during discussions;
- > Clients not responding to a particular question and the health worker proceeding to make plans anyway:
Nurse: So shall we go ahead with that?
[Client provides no verbal or physical response]
Nurse: I'll chase that up and get an appointment (Consultation, rural service)
- > The use of 'we' rather than referring to the client as an individual. For example when a nurse said "There's been lots of habits we've had to get into" her language inferred that the health care providers and client are one and the same. This means that these are not habits that the client has themselves learnt and these are not habits they have sole responsibility for learning or implementing.

Several aspects of the *information sharing processes* that are implemented at this particular health service also have the potential to encourage dependency. These include:

- > Health workers going with clients to appointments to tell the consulting health worker what the client needs:
Nurse: Would you like me to ring up and ask the GP if they could schedule some appointments for you and we can write them in your diary? I'm more than happy to.
Client: Yep.
Nurse: Ok I'll do that right now. (Consultation, rural service)
- > Planning for the future in a way that indicates the prolonged involvement of health workers despite also saying that client independence needs to develop, which reveals a contradiction in verbal direction and directions inferred through actions.
- > Health workers suggesting the need to withdraw or modify services that the client receives yet remaining vague about this so that it has the potential to stimulate client anxiety.
- > The warm, very active helpful approach of the nurses combined with the drop in like service, the home visits, the way the staff inform clients about their work schedules and the extent of their holistic care all contribute to the formation of a friendship like relationship that can encourage dependency and blur the boundaries between health worker and friend.

What was not being said or expressed in the consultations may also encourage dependency. This is particularly evident because no formal time limit is set on the duration of a clients' care planning work with staff. Given the holistic nature of care provided at the service, there are also no boundaries set to limit the extent of help that can be provided or the number of areas of life that the client can seek health worker involvement in.

There is, however, also evidence that strategies to limit and discourage dependency are being implemented by the staff. For example, health workers were observed deliberately trying to give control to the clients to make decisions. However, in some cases the strong guidance provided by the health worker created a situation where the client was already being guided down a particular path so when it came time for them to make a decision their range of options had been limited by the relatively closed discourse being used through the

health workers guidance. In other cases the health worker made decisions without actively consulting the client and just assumed that was what they wanted (see previous quote).

In resistance to the dominant discourse of health worker control, however, there were two clients who we had contact with at the health service who were very directed in their beliefs. These clients actively overrode the direction of the health worker. These cases were, however, limited to clients who were quite knowledgeable about how the health system works and the range of options that is available to them.

All of these findings from the discourse analysis highlight the potential for very close relationships between health workers and their clients, a lack of boundary setting and high levels of guidance to hinder client's participation and independence. These findings also reveal the potential for ineffective information sharing to contribute to the development of dependency, particularly through the impacts of what information is *not* shared as part of the relationship between health workers and clients.

No help in terms of self-management

While all clients identified at least one benefit that they had experienced as a result of their care plan being implemented, there were mixed feelings expressed about the extent to which the care plans facilitated self-management. Some clients suggested that the care plans had encouraged them to self-manage through making them take more notice of their health, giving them strategies to manage/address their health problems or by creating a team approach which made them feel more equipped to manage their health problems. However, despite recognising some broader benefits that had arisen from their plan, several clients outwardly rejected the idea that the plan was helping them self-manage. For these clients, self-management had to be self-directed and, therefore, a care plan or health worker could not assist regardless of the particular content of the plan or the processes that were used:

I think a lot of it really is up to me too. And I think it's up to me like to, when I wasn't, when the sugar levels kept climbing and nothing I seemed to do was right I did go to Di and then she set it in motion that I went and spoke to Alli and then I had to go back to her to see. But I did that myself because I knew that I should have. So I suppose I took control then. (63 year old female, client, rural service)

This, again, highlights the importance of considering how clients think about self-management rather than imposing pre-defined definitions on them.

Other clients explained that the care plans had not been as helpful as they could have been. This is due to some anxieties and frustrations that had developed for clients, which may impact on how they manage their chronic health problems.

Safety risks

Ineffective information sharing leads to safety risks. This was made clear through the experiences of one female client who had gynaecological surgery between her first and second interviews and who had tried to ensure that her health workers were well informed about her medication allergies:

I said, 'Here I've got a listing' and she said, 'Are you allergic to anything else?' and I said, 'Yeah, two years ago, Dr Mick did prescribe two things and they were morphine-based and narcotic-based and I reacted allergically to that.' And she said, 'I'll check it out. I'll check it out.' (64 year old female, client, metropolitan service)

The client never heard any more about this issue and assumed that the hospital staff had knowledge of all her allergies. Immediately following the operation however the client was prescribed a drug and had a severe reaction which resulted in hallucination and aggressive behaviour. Upon seeing her mother's symptoms the clients' daughter inquired about the drugs she had been given and found out that she had been given a morphine based drug

which she had an allergic reaction to previously. This delayed the clients' recovery and release from hospital as well as making her feel what she described as "trauma" given that she felt she had unnecessarily lost control of her body after the surgery because she had not been listened to by care staff.

Discussion about another threat to safety arose during an observation session where a health worker was explaining the client filing system and the stickers that are used on the files to indicate various alerts. One alert sticker was used within the service to highlight concerns about staff safety when visiting the home of a client. The health worker, who had only been at the service three months, had experienced an instance where she attended a home visit and met with an aggressive individual who refused her entry to the home. Upon returning to the health service the worker reported this to a manager who asked for the name of client concerned. In response to the worker saying the name the manager explained that another health worker had the same experience previously and the decision was made for the client only to be seen on premises rather than in the home. The worker questioned why she was not informed of this and the manager flicked through the notes to find a small entry about the incident several pages back from the current notes page. The manager stated that an alert sticker should have been placed on the file but it had not been. This breakdown in communication had the potential to risk the safety of new staff given that they could not rely on the 'insider' knowledge possessed by staff who had been working at the service for several years.

Clients still have to navigate systems of care planning and information sharing

Despite the general perception that information sharing had increased, most interviews contained examples of instances where clients remained responsible for navigating the health care system in order to get the care they needed or to facilitate the action and monitoring of their care plan.

The need for client navigation of the system was only mentioned explicitly by two clients. One recognised that he had taken control in order to compensate for deficiencies in the system that were impeding the effectiveness of his health care and the effectiveness of information sharing within his health care team:

Well I didn't think it was my job to be reminding everyone of who else I'm seeing but obviously, you know, just with that instance I've told with you the Clinic, all the health workers are close to each other but, you know, and the clinic next door - like, they're all within 20 yards of each other, about 15 services, and no one knew what each other was doing for me and I'm thinking, gee they're all that close, surely they talk- wouldn't you? ... That's why I'm glad that I'm getting it sorted. If the system was in place right where the info just goes to the person's GP too, it would be great wouldn't it? (61 year old male, client, metropolitan service)

The other client who made explicit mention of the need for him to have taken responsibility for managing his health care did not phrase this in such negative terms. Instead he viewed this more positively as a means through which he was able to gain greater control over how and by who his health was being managed. For this participant, taking control involved the following.

- > Talking with friends about the specialists who they see and comparing their experiences of care with his own;
- > Seeking a referral to a new specialist and arranging to meet with that specialist; and
- > Transferring his care (and care plan) to the new specialist at a time when his regular review tests were due so that the new specialist could easily obtain the required information about his current health status.

While the remaining 22 clients did not mention explicitly their need to navigate the system, their efforts in doing so were evident. These efforts were made in response to frustrations and difficulties that had developed for the clients in the management of their health care through their care plans. Such efforts included the following actions.

- > Clients feeling the need to check and recheck that each health worker had a current list of their allergies because they were not confident that this information had been shared consistently or accurately;
- > Mentally collating the advice that they had received from the variety of health care professionals involved in their team to be selective of the advice that they would follow given that they did not perceive all advice to be relevant to their particular circumstances and/or health problem;
- > Taking referral forms to be signed by relevant health workers because these professionals had not responded to faxed, emailed or verbal requests to provide signatures;
- > Identifying and reporting 'double-ups' or overlaps in the services that they were receiving;
- > Making a point of giving each health worker a list of all other professionals in their team and asking for them to share information;
- > Reminding health workers to share information with other relevant health workers;
- > Asking when the next review of their care plan was due and scheduling an appointment on that date; and
- > Feeling obliged to make regular appointments with the GP to report on the progress made with other health workers in the team.

Importantly, it is evident that some health workers believe that it is part of the client role to navigate the system and they find the care plan helpful in encouraging and equipping a client to do so:

I think I agree with Anya in both those counts as well I think. Simple things like my cat needs feeding or something like that maybe the doctors don't need to know about, that sort of intervention or, you know, as your glucometer but I think as a whole we need to work as a team and it doesn't matter if we're in private practice or public practice or wherever we are, we actually need to start integrating, and the person to do that is the client. So if we start putting all of that together for them then naturally they'll start ensuring and I've had clients say to the podiatrist, 'Make sure you send my nurse a letter about things' or they start wanting their team of professionals to actually know about other interventions. So they start doing that themselves as well which is good and I think it's important, it seems to help. (Nurse, rural service)

Duplication in information exchange, lack of detail and the problem of irrelevance

Furthermore, despite improvements in information sharing following the introduction of the care plans, two clients explained that some health workers required them to verbally recount information even if it was included in referral letters. From the client perspective this has the potential to create frustration about having to repeat explanations about their health and their social backgrounds. From the perspective of service provision this could also be viewed as a waste of resources given that time is spent on sharing the same information multiple times. However, this practice may also be beneficial in ensuring that information is not missed and in ensuring that health workers new to the team are able to gain an accurate understanding of their clients' experiences and perceptions.

Uncertainty about care plan process

Clients also expressed uncertainty about several aspects of the implementation, sharing and monitoring of their care plans. This represents an unintended outcome of insufficient information sharing. In particular the following areas of uncertainty were identified.

- > Clients felt uncertain about the logistics of the care plan review. They felt under informed about the appropriate interval between reviews, who was responsible for scheduling the review appointment and whether all health workers included in the care plan needed to undertake a review.
- > Clients were unsure about how their progress was monitored and reported. This led to apprehension for some who felt the need to “live up to” the expectations of their health workers. There was a willingness expressed by clients to act in accordance with the requirements of their care plan yet many were uncertain about what meeting these requirements involved.
- > Two clients also reported feeling uncertain about the validity and necessity of the plan after they had consulted with health workers who were supposed to be partnering with the GP on their Management Plan. The other health workers they saw spoke negatively of the merits of the Management Plan and this made these clients feel unsure about its worth and also like they were causing an inconvenience to their health workers by making it necessary to fill out (potentially useless) additional paperwork.
- > One client was uncertain about whether her action plan was still current given that it was implemented by her previous GP. The GP who now consulted with the client had not mentioned the Plan or scheduled an annual review. This represents a failure in information transfer upon staff leaving a health service.
- > It was apparent that some of the uncertainty experienced by clients may have been the result of them being new to the process. Several clients who had been on their care plan for twelve months or more expressed more comprehensive understanding about the review and other monitoring processes since they had already experienced one review. However, some uncertainty still persisted after the first 12 months for some clients. This suggests that experience does not necessarily compensate for poor information sharing.

Appendix 6 Potential limitations of the research

If positivistic criteria are applied, it may be argued that the findings of the qualitative components of the research cannot be generalised because the participant cohorts are not representative. However, in terms of the qualitative methodology that we have employed this is not a problem. The aim of the observations, focus groups and interviews was *not* to provide population-based data. Instead our aim was to explore the complexity of information sharing and care planning processes as they operate in practice. The various components of qualitative data collection complement and supplement each other in order to, together, form a deeper, more holistic approach than would have been possible if we had used a single method or only positivistic methodology. The combination of qualitative and quantitative approaches in this study also assisted in overcoming the biases that are inherent to each methodology and in providing both a macro and micro view of how information sharing operates across Australia.

It can also be argued that potential for bias exists in the processes that were used to recruit the interview participants. Asking a member of staff at each health service to decide client eligibility and to approach clients in the first instance creates the potential for the selection of clients who have had good experiences with the service and who are likely to reflect positively. However, this did not appear to be the case. Several clients recounted difficulties with the service they were recruited by and not all of the clients reflected positively on their experiences. Furthermore, two of the people who assisted with recruitment told us that they had tried to select clients with a variety of characteristics and experiences so that the research could provide relevant findings rather than produce overly positive findings which did not reflect the actual context of practice.

In addition, some of the methods that we used to design and distribute the survey impose constraints. The methods used to distribute the link to the online survey created difficulties in calculating the response rate that was achieved. The reason for this is that accurate data about the number of people on particular mailing lists or who view particular websites could not be obtained from the organisations that assisted with distribution. However, use of these methods allowed us to achieve efficient and broad distribution of the link, which is likely to have increased the number of responses we obtained. Furthermore, on reflection, it would have been useful to provide clear definitions of some of the terminology we used when writing the survey questions. Clearly defining terms such as 'care plan' and 'care plan training' would have ensured that all respondents understood the intended meaning of all questions and this would have provided us with greater confidence about the accuracy of the survey data.

A final issue relates more to a specificity of the research than a constraint. The data that we collected and analysed relates to the Australian context only. Containing data collection to Australia was necessary in order to produce findings that are relevant to the context of the Australian health system given that considerable system differences exist across the world. Acknowledging this specificity is particularly important because experiences of health and illness are shaped by the health systems, cultures and dominant discourses that an individual is exposed to. Therefore, while the Australian specificity of the research may limit the generalisability of the findings, it also provides some benefit in terms of allowing for a more nuanced and thorough examination of information sharing within the particular health, cultural and political systems that currently operate within the Australian context.

Appendix 7 Semi-structured interview guide

- > Read the information sheet?
- > Study is about understanding the information sharing that occurs in care teams around chronic health problems.
- > Any questions?
- > Open ended interview so I will ask you some questions but please feel free to raise any issue that you think is relevant.
- > Consent forms
- > Permission to record via audio recorder?

Can you please tell me about what's happening with your health at the moment?

How is your health being managed? Who is involved in your care?

Can you describe to me your understanding about the care plan that has been written for your health care?

Can you describe to me a time when your care plan has helped you.

How are issues related to your care plan communicated to you? How do you find out about progress and changes in your management/care plan?

Can you describe to me your how information about your health care is shared between the health professionals who care for you?

Can you describe to me the referrals that you've had while on your care plan?

How involved do you feel in making decisions around your care plan?

Ok thinking a bit differently now, what does the idea of 'managing your own health' mean to you?

How has the care plan changed your ability to manage your own health?

More generally now, thinking about you care plan(s) overall, are there any things that hinder your ability to receive the care that is identified in the care plan? What are these and how have you overcome them?

What assists your ability to receive the care that is identified in the care plan?

Overall, what do you think of the care plan(s) in relation to the way it's developed, implemented and managed?

What suggestions or ideas do you have as to how to improve the care planning process?

Demographic questions

What chronic health conditions(s) do you have?

How long have you had these condition(s)?

How old are you?

Were you born in Australia? If no, what is your country of birth?

Do you identify as an Aboriginal or Torres Strait Islander?

Where are you currently living? Own home Rented home Care facility

What is your main source of income?

Do you have private health insurance?

How would you rate your current health?

Excellent Good Fair Poor

Appendix 8 Survey questions

1. What is your profession?

GP

Nurse

Physiotherapist

Dietician

Podiatrist

Chiropractor

Occupational Therapist

Social worker

Psychologist

Psychiatrist

Rehabilitation worker

Respite provider

Other (Please state)

2. Are you male or female?

Male

Female

3. What state or territory do you work in?

Australian Capital Territory

New South Wales

Northern Territory

Queensland

South Australia

Tasmania

Victoria

Western Australia

4. How many years have you been in practice?

Less than 5 years

5-9 years

10-14 years

15 years or more

5. What kind of organisation do you work for?

- Private practice
- Community Health Service
- Hospital
- Other (Please state)

6. What care planning system do you use in your work?

- GP Management Plan
- Flinders Program
- Goal Attainment Scale
- None
- Other (Please state)

7. What care planning training have you completed?

- Training in the use of GP Management Plans
- Training in the Flinders Program
- Training in a self-management care planning process other than the Flinders Program
- I have received no training
- Other training (Please state)

8. Do you develop care plans?

- Yes
- No

(If answer is yes, then questions 9 and 10 display. If answer is no, question 11 appears next)

9. When you develop a care plan, who do you share a written version of that plan with? – tick all that apply

- All health professionals named on the care plan
- Only some of the health professionals named on the care plan
- The health professionals who work in your organisation or practice
- Client
- Carer of the client (if applicable)
- Other (Please state)
- I do not share care plans

**10. When you develop a care plan, how do you share it with other relevant people?
- tick all that apply**

- Paper copy sent via fax

- Paper copy sent through mail
- Electronic version sent through email
- Shared electronic database
- Paper copy stored in single location
- Patient holds paper copy to share with other professions
- Other (Please state)

11. For clients you provide services for, who do you receive copies of care plans from? - tick all that apply

- GP
- Specialists
- Allied health professionals
- Rehabilitation workers
- Clients' employer
- WorkCover officers
- HACC workers
- Psychologists
- Psychiatrists
- Counsellors
- Clients' carers
- I do not receive care plans (if selected question 13 is displayed next)
- I receive care plans from professionals who are not on this list (please state)

12. When receiving copies of care plan from other professionals, what format does this take? – tick all that apply

- Paper copy sent through mail
- Electronic version sent through email
- Electronic database
- Paper copy stored in single location
- Patient holds hard copy to share with other professions
- Other (please state)

13. Are you responsible for gaining and documenting client's consent to share their care plans with other care providers?

- Yes
- No
- Unsure

14. Are clients able to give selective consent in your organisation to permit the sharing of only SOME parts of their information?

Yes

No

Unsure

15. How often do you check whether there is some information in your clients care plan that they do not want shared with other health professionals?

None of the time

Some of time

Often

Most of the time

All of the time

16. How likely is it that your clients have care plans also developed with other services?

Not at all likely

Rarely

Somewhat likely

Very likely

17. How often do you check whether a client has a current active care plan with another organisation or service?

None of the time

Some of time

Often

Most of the time

All of the time

18. How often do you come across clients with an active care plan who are not aware of its existence?

None of the time

Some of time

Often

Most of the time

All of the time

19. Please rate the following statements. A care plan is:

- > just a tool to provide access to specific services
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a tool to facilitate clients becoming more proactive active in managing their health
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > just what we need to do for the MBS system to enable reimbursements
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a useful means to coordinate care
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a paper exercise for the bureaucrats
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a means to get funding for my service
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a way to help clients manage their condition
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a tool to share information with other health professionals
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > a means to improve coordination of patient care
agree, strongly agree, neither agree or disagree, disagree, strongly disagree
- > something that helps to improve the wellbeing of patients
agree, strongly agree, neither agree or disagree, disagree, strongly disagree

20. Which of these outcomes is the best indicator of whether a care plan is working?

- Client is compliant with prescribed treatment
- Client is listening more and following health worker advice
- Client is making decisions about their health care

21. How valuable/useful is the care plan to:

- > the client
not at all, a little, somewhat, fairly valuable, very valuable
- > the health worker
not at all, a little, somewhat, fairly valuable, very valuable
- > the health care service
not at all, a little, somewhat, fairly valuable, very valuable

22. In your service, how long does a care plan remain active for?

A pre-defined period of time or a number of service events

Until negotiated client goals are achieved

Ongoing with regular review

Other (please specify)

23. How often are care plans usually reviewed in your service?

Every 3 months

Every 6 months

Annually

Other (please specify)

24. How often when referring clients to other services do you get feedback on that referral?

None of the time

Some of time

Often

Most of the time

All of the time

25. When you don't get feedback, how do you feel? – tick all that apply

Happy

Optimistic

Satisfied

Neutral

Surprised

Unsurprised

Apprehensive

Impatient

Dissatisfied

Sad

Pessimistic

Angry

26. How often when you receive a referral do you provide written feedback to the originator of the referral?

None of the time

Some of time

Often
Most of the time
All of the time

27. How do you check your client's understanding of their care plan? – tick all that apply

Ask them if they understand it
Ask them to explain it to you
Describe it to them and assume understanding
Be guided by their verbal responses and body language
I don't check
Other way of checking a client's understanding of their care plan (please state)

28. How important do you feel it is to share care plans with other health care professionals?

Not at all important
A little important
Somewhat important
Important
Very important

29. When someone shares a care plan with you, how often does this require you to take action for the client concerned?

Never
Occasionally
Sometimes
Often
Frequently
All the time

30. How much do you feel your clients contribute to the contents of the care plans that you practice with?

Nothing
A little
Some
Most
Nearly all
All

31. How often do you find that there are aspects of a client's care plan that you choose not to share with other professionals?

- Never
- Occasionally
- Sometimes
- Often
- Frequently
- All the time

32. To what extent is information sharing between staff valued within your organisation?

- Not at all valued
- Valued a little
- Somewhat valued
- Valued
- Highly valued

33. To what extent is information sharing with external agencies and health care providers valued by your organisation?

- Not at all valued
- Valued a little
- Somewhat valued
- Valued
- Highly valued

34. To what extent is uncertainty about confidentiality and consent a barrier to you sharing information?

- Never an issue
- Sometimes an issue
- Often an issue
- Frequently an issue
- Always an issue

35. How important is information from other professional disciplines to the development of care plans with your clients?

- Not at all important
- A little important
- Somewhat important

Important
Very important

36. How often is your ability to work with clients hindered by interdisciplinary information sharing or its absence?

Never
Occasionally
Sometimes
Often
Frequently
All the time

37. To what extent is the final decision making as to the content of a care plan made by the client? – mark a position on the scale

It is the clients' decision.....It is the health professionals' decision

38. To what extent do you agree that all health care professionals' input is equally important when developing care plans?

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

39. What changes could be made to enhance your clients' participation and navigation through the care planning system?

SPACE FOR OPEN ENDED RESPONSE

40. What do you suggest as improvements to the care planning and information sharing processes?

SPACE FOR OPEN ENDED RESPONSE