



**AUSTRALIAN PRIMARY HEALTH CARE
RESEARCH INSTITUTE, AUSTRALIAN NATIONAL UNIVERSITY**

**PRIMARY CARE RESEARCH UNIT,
DEPARTMENT OF GENERAL PRACTICE,
UNIVERSITY OF MELBOURNE**

ARRANGING GENERALISM IN THE 2020 PRIMARY CARE TEAM

Report prepared by:

Dr Victoria Palmer
Dr Ami Thies
Professor Jane Gunn

February 2010

ACKNOWLEDGMENT

The research reported in this paper is a project of the Australian Primary Health Care Research Institute, which is supported by a grant from the Australian Government Department of Health and Ageing under the Primary Health Care Research, Evaluation and Development Strategy. The information and opinions contained in it do not necessarily reflect the views or policies of the Australian Government Department of Health and Ageing.

The investigating team acknowledges the ongoing financial support provided by the Australian Primary Health Care Research Institute (APHCRI) and our participants in the project. During September 2009, the study team benefitted significantly from an International Visiting Fellowship awarded to Professor Kurt Stange by APHCRI with additional financial support from the Royal Australian College of General Practitioners (RACGP). Professor Stange participated in a number of data analysis sessions and attended one of the professional workshops held for the study. We acknowledge his ongoing support and contributions to our developing research, and the contributions and attendance of his colleagues Mary Ruhe and Caroline Carter to the data analysis sessions. For information regarding this report or project please contact:

Dr Victoria Palmer

vpalmer@unimelb.edu.au

Citation:

Palmer V., Thies A., Gunn J. 2010. *Arranging Generalism in the 2020 Primary Care Team*, Unpublished Final Report, Australian Primary Health Care Research Institute: Canberra.

Acknowledgement of Study Team Roles and Contributions:

Kate Johnston Ata-Ata provided research assistance for this study from February to September 2009 she was responsible for conducting interviews with patients, preparation of the patient stories and completed a preliminary literature search. Ami Thies joined the project in August 2009 to January 2010 funded by the General Practice Education and Training (GPET) organisation to complete her academic registrar study. Ami completed an additional literature search and review of the literature with a focus on professionals' views of teams in primary care. Aspects of her literature review are included within the introduction of this report. Ami also completed a secondary data analysis of interview transcripts with GPs and allied health professionals as part of her registrar project, a separate report is in completion of this but elements of her analysis are drawn on in the professional interview results sections. Ami also attended the workshops with professionals and data analysis sessions with visiting researchers from the United States. Both investigators, Dr Lucio Naccarella and Professor Jane Gunn also attended workshops and analysis sessions. Dr Victoria Palmer was responsible for project coordination and designed the methods of data collection and interviewed GPs for the project. With Professor Jane Gunn she co-facilitated the professional workshops. Professor Gunn has provided mentorship and guidance for the project. This final report was prepared by Dr Palmer, Dr Thies and Professor Gunn.

Australian Primary Health Care Research Institute (APHCRI)

ANU College of Medicine and Health Sciences

Building 62, Cnr Mills and Eggleston Roads

The Australian National University

Canberra ACT 0200

T: +61 2 6125 0766

F: +61 2 6125 2254

E: aphcri@anu.edu.au

W: www.anu.edu.au/aphcri

ACKNOWLEDGMENT	1
ACKNOWLEDGMENT	2
INTRODUCTION	5
APPROACH	7
RECRUITMENT	8
primary care professionals	8
patients	10
METHOD – DATA COLLECTION	10
PATIENT INTERVIEW # 1 - BIOGRAPHIES	10
the brim method explained	10
PATIENT INTERVIEW # 2 - PERSPECTIVE ON CONCEPTUAL MODEL	12
PROFESSIONAL INTERVIEWS	13
PROFESSIONAL WORKSHOPS	13
METHOD – DATA ANALYSIS	15
patient biographies	15
profesisonal interviews	15
professional workshops	15
RESULTS	15
PROFESSIONAL PARTICIPANTS	15
PATIENTS	17
PATIENT PERSPECTIVE ON CONCEPTUAL MODEL	20
PROFESSIONAL INTERVIEWS	24
PROFESSIONAL INTERVIEWS	24
PROFESSIONAL WORKSHOPS	29
workshop one	29
workshop two	35
workshop three	38
CONCLUSION	39
REFERENCES	41
APPENDICES	43
APPENDIX 1 PATIENT BIOGRAPHY INTERVIEW SCHEDULE	43
APPENDIX 2 SEMI-STRUCTURED INTERVIEW SCHEDULE (GENERAL PRACTITIONERS)	44
APPENDIX 3 PATIENT FEEDBACK ON CONCEPTUAL MODEL	45
APPENDIX 4 EXAMPLES OF TWO PATIENT BIOGRAPHIES	49
peter dumus	49
judy page	67

List of Tables

Table 1	Overview of Contents of Professional Workshops
Table 2	Professional Participants in the Study
Table 3	Patient Characteristics and Health Conditions
Table 4	Patient Perspectives on features of the Conceptual Model
Table 5	Professional views of teams and emerging sub-themes

List of Figures

- Figure 1 Diagram of the Arranging Generalism Study Design
- Figure 2 Recruitment Flowchart
- Figure 3 A Conceptual Model of the Essential Dimensions of Generalism

List of Images

- Image 1 General Practitioners Modelling Peter Dumus
- Image 2 General Practitioners Modelling Judy Page
- Image 3 Practice Nurses Modelling Peter Dumus
- Image 4 Practice Nurses Modelling Needs of Complex Patients
- Image 5 Animal figures – Peter’s Ideal Team
- Image 6 Animal figures – Judy’s Ideal Team

INTRODUCTION

Some doctors, if you go in with a sore finger your head could be falling off, and they wouldn't treat the falling off head, they'd treat the finger. Whereas a good GP treats the finger but says, now what's happened to your head and fixes that as well. They've got to be open-minded about what's going on (Helen, Patient, Interview 3, 9).

Primary health care is a site of reform in Australia. Discussion papers released in 2009 by the National Health and Hospital Reform Commission (NHHRC)⁽¹⁾ and The Department of Health and Ageing (DoHA)⁽²⁾ all indicate a preference for greater involvement of primary care in patient care. Accompanying this is a push to organise primary care to deliver multi-disciplinary team care to improve chronic disease management, promote prevention and help address workforce shortages.⁽³⁾ Yet, not all patients will require team based care⁽³⁾ and it is most likely that it will be patients with complex, multiple morbidities with physical and/or mental health conditions that will require a multidisciplinary team to meet their needs in the primary care setting. While team care arrangements have become a focus of chronic disease management, there is less known about the future health care needs of patients with multiple conditions.

The tradition of teamwork in the delivery of healthcare is not new.⁽⁴⁾ For decades effective teamwork has been commonplace in acute hospital settings, as well as the areas of mental health, rehabilitation medicine and many tertiary outpatient services dedicated to addressing complex, multi-factorial health problems, such as chronic pain, diabetes, and falls. In spite of this, the evidence is lacking about who should be in the team for patients in the future, how will teams be coordinated and where will these changes place general practitioners (GPs) in relation to patient care?

Australian health policy and funding structures, through the Medicare Benefit Scheme (MBS) have encouraged the development of a team-based approach to care provision in the general practice setting. The MBS team care and case conferencing item numbers (723, 727, 729, 731 and 734-779) provide financial fee-for-service incentives and remuneration to GPs who formalise team care arrangements and communication for individual patients. These patients are also granted a rebate for their visits to health care professionals on their team, improving financial access to a range of allied health services. When the EPC item numbers were implemented in 1999 their purpose was to shift short-term, episodic care to whole person care integrated with other providers.⁽⁵⁾ In 2005, the Australian government responded to GP feedback and split the care plan program into two. This resulted in the GP Management Plan (721) (completed by the GP alone) and the Team Care Arrangements plan (for cases involving other providers).⁽⁵⁾ Patients and GPs now have a variety of plans available but the question remains as to how much TCAs facilitate 'team care'? In addition, research from the Canadian setting suggests that there is a paucity of evidence about whether multidisciplinary team care does improve patient outcomes.⁽⁶⁾ Thus, there is a need to understand who will need team care, how will it be coordinated, and if team care improves patient health outcomes.

Muddying the waters in this rising debate are the variety of meanings and uses of terms. Team is bandied around quite freely and team care used often, this is accompanied by regular appearance of the terms multidisciplinary teams, inter-professional teams and inter-disciplinary teams within the literature. The words "multidisciplinary" or "multi-professional", and "interdisciplinary" or "inter-professional" are often used to describe a team comprising two or more members from different professional backgrounds. "Multi" and "inter" might be used interchangeably, though at times a distinction is made between the two. "Multi" is said to refer to a group of practitioners working independently, or "in parallel" on the same problem, with limited communication, and "inter" refers to a group of practitioners from different professional backgrounds working collaboratively towards a common purpose.⁽⁷⁾ These definitions represent a shift away from the 'traditional' view of team work.

The Oxford English dictionary, for example, defines teams quite simply as "two or more people working together". If this is the case then general practitioners have always been working as part of a team, however,

'working together' has come to mean something different to 'team work;' particularly when the definitions for multi-disciplinary, inter-professional and inter-disciplinary team are considered.

Hansson et al suggest that teams represent: "a group with a specific task or tasks, the accomplishment of which requires interdependent and collaborative efforts of its members" and "a small group of people with complementary skills who work together to achieve a common purpose for which they hold themselves collectively accountable".⁽⁸⁾ Both of these definitions include more detail that tasks are shared by interdependent and collaborative efforts and people require complementary skills to achieve a common purpose; this is an expansion on the Oxford definition. While the traditional general practice set up with receptionist, practice nurse and GP all working together could easily fit these two definitions, the introduction of other health care professionals into the patient care mix is changing team work in primary care.

Internationally, studies exploring team based care in primary care are really quite limited. This is a surprise given that multidisciplinary teams are so central to the reform agenda; the term appearing 62 times with the NHHRC report. Research to date has examined: team climate and the relationship of this with better chronic disease management, overall patient satisfaction and quality of care;⁽⁹⁻¹²⁾ team training as an intervention to improve team functioning;⁽¹³⁾ the redistribution of work within general practice;⁽¹⁴⁾ interviews with different primary health care team (PHCT) members (GPs, nurses, pharmacists) to identify attitudes to team work, what constitutes a team, the factors affecting team effectiveness, perceptions of working together, understanding of interdisciplinary work and efficacy of health funding reform in facilitating PHCTs;^(4, 6, 8, 15-21) and there has been one small qualitative study to explore patient perspectives on inter-professional care.⁽²²⁾ The patient voice is surprisingly absent in research studies to date and given their important role within the team this needs to be rectified.

Regardless of the push to multidisciplinary team care there is still little evidence that it improves patient health outcomes. Some might prefer that the status quo remains and GPs continue to work with others, but not within highly organised multidisciplinary teams. Research has shown that the sharing of responsibility for patients' needs and overt triage of patients' can present problems that result in the elevation of the general practitioner to "medical expert".⁽¹⁴⁾ Patients with less complex problems are "downgraded" and seen by the practice nurse, and in the team setting, the general practitioner is able to play the role of "pure doctor" focusing solely on the patient's biomedical needs. This view overlooks the important and very fundamental values of the traditional generalist approach and GP as first point of contact.

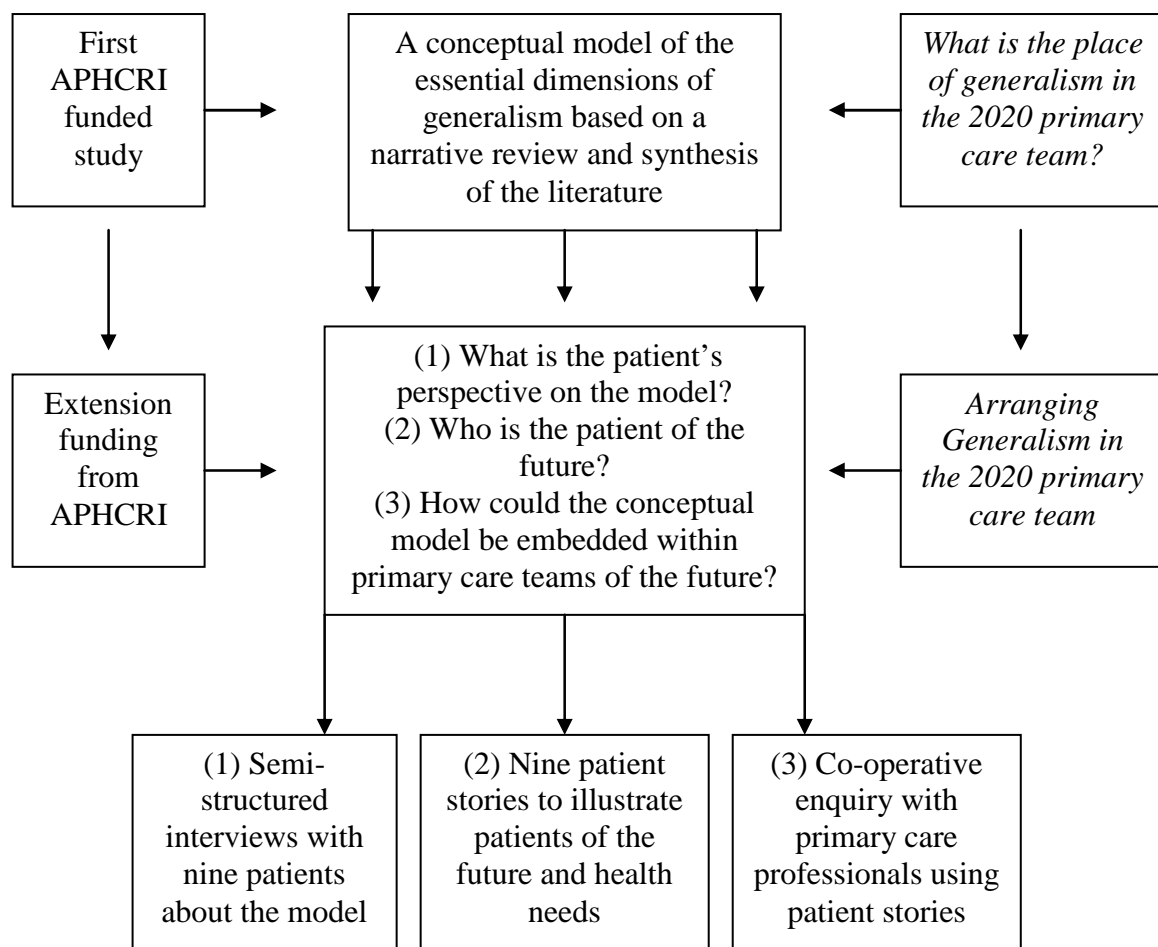
A key question if multidisciplinary teams are to be implemented in the Australian primary care setting -- is how much of the holistic and fundamentally generalist values might be lost? Will there be seamless and integrated care for patients or will more providers increase fragmentation and discontinuity of care. As our first study into the place of generalism found⁽²³⁾, there are unique features of generalist practice that are highly valued by those in the field. Particularly defining features of the generalist were the knowledge of patients over time and the use of the patient's life story and context balanced with technical information to provide holistic care.

As a result of these questions and debates, this study set out to explore the future health care needs of patients with complex and multiple problems; a group of patients that are most likely to receive multidisciplinary care and who currently receive services from a range of health care providers. Our aim was to explore patient's needs and to identify if the features of generalism have relevance for the development of multidisciplinary team care in the Australian primary care setting. Given that the features of generalism were identified from a narrative review and synthesis of literature, working with a group of patients provided us with the opportunity to gather their perspectives on generalism. The following report presents the approach and method used to explore these questions and the results of this investigation.

APPROACH

Our aim in the study was to identify ten patients with complex and multiple problems (who we felt represented patients of the future) and to develop their individual stories. Using these stories we set about to explore their health care arrangements and the role that generalism might play within their health care. We collected qualitative data to achieve this as described in Figure 1 which positions the Arranging Generalism study design as an extension of the narrative review and synthesis completed in 2007.

Figure 1 Diagram of the Arranging Generalism Study Design



To collect these qualitative data sets we recruited primary care professionals first and asked GPs to identify and contact patients suitable for the study.

RECRUITMENT

PRIMARY CARE PROFESSIONALS

Professionals were identified using a purposeful sampling method with criterion added. (24) Purposeful sampling is a common method of recruitment in qualitative research whereby sites are selected to provide information-rich cases that reveal in-depth 'understanding rather than empirical generalisations'. (25) We added three criterion to ensure a good mix of cases could be explored: socioeconomic status (a spread of professionals working within practices of varying socioeconomic status); geographic location (an initial radius of practice location within 30 kilometres of central business district (CBD) was established to facilitate attendance at metropolitan based meetings (this was expanded during later recruitment stages and one rural practice included)); and, organisational structure, (multi-doctor practices with at least one practice nurse, and where possible at least one allied health professional).

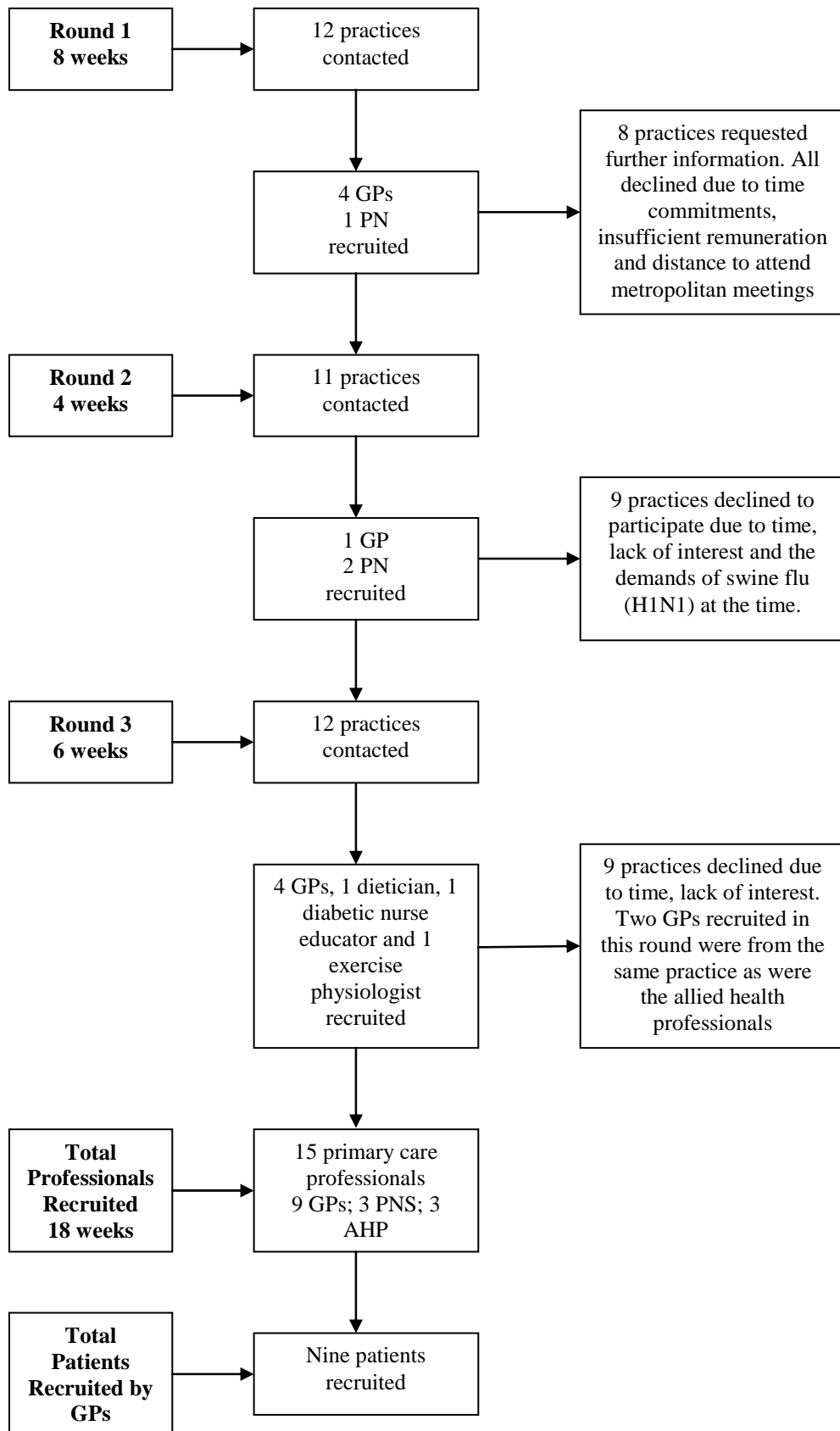
As far as possible we aimed to increase the diversity of sample by adding the three criterion and develop a heterogeneous mix of patients; the aim was not for a representative samples from which generalisable findings could be made. We hoped to recruit 20 primary care professionals (10 GPs, 5 practice nurses and 5 other allied health professionals) with whom we would conduct co-operative enquiry in the workshops as our starting point. We identified GPs by developing a practice recruitment list that included:

- Reviewing a list of member practices from the Department of General Practice's (DGP) Client Record Management (CRM) database (part of the Department's VicREN practice based research network) that were within 30km of Melbourne's CBD and had a prior association with the Department (through teaching or research);
- Further internet searching of the practices from the CRM-generated list to determine which were multi-doctor and had a practice nurse. Where this was not possible (as most practices do not have a website and therefore limited information is available about them on-line) the practices were telephoned and practice managers or receptionists were asked about staffing arrangements prior to making a recruitment call;
- Reviewing the socio-economic Indexes for Areas (SEIFA) information from the 2006 census by postcode, obtained through the Australian Bureau of Statistics (ABS) website. This was to ensure we had a spread of practices located in different socio-economic areas.¹ We used the *index of relative socio-economic disadvantage* which 'focuses primarily on disadvantage, and is derived from Census variables like low income, low educational attainment, unemployment, and dwellings without motor vehicles' (ABS, 2006). Areas within the decile 1 represent those of most disadvantage to those within the 10th being areas of least disadvantage.

Figure 2 provides a flowchart outlining the recruitment process.

¹ Four different indexes make up SEIFA (2006). These include: index of relative socio-economic disadvantage; index of relative socio-economic advantage and disadvantage; index of economic resources; and index of education and occupation. Each index takes social and economic data collected in the 2006 census to summarise a different aspect of the socio-economic conditions of people living in a given area. For each index, every geographic area in Australia (in this case postcode areas) is given a SEIFA score which shows how disadvantaged that area is compared with other areas in Australia – noting that, relative socio-economic advantage or disadvantage as a concept is 'neither simple, nor well defined', and bearing in mind that the SEIFA score represents an average of the total population in a given area – hence the larger the area, the greater the likelihood of variation within that population. Each postcode area is given a score (with a mean of 1000 and a standard deviation of 100), whereby the lower the score the more disadvantaged an area. Every area is then ranked nationally, and grouped into deciles.

Figure 2 Recruitment Flowchart



PATIENTS

GPs were provided with a description for patient eligibility criteria:

...We are looking for a patient with complex, multiple health care needs who represents the patient of the future in 2020. We believe patients with multiple physical and mental health problems are likely to be characteristic of the future – can you think about three patients with such conditions to invite to the study? Each patient's condition, age group, and needs should be different if possible.

In addition to this, we also discussed the nature of the study with GPs by phone prior to their identification and selection of patients. We explained to GPs that the patients would be interviewed in-depth about their health conditions and experiences and this would be formulated as a patient story (biography). We emphasised that the story would re-appear in the patient's own words and we asked GPs to only select patients that they knew would be confident and comfortable with telling the details of their conditions and health experiences.

After this discussion GPs were provided with a letter inviting patients to participate and providing the contact details of the research team. Patients signed consent forms and wrote their phone numbers on them. Completed consent forms were sent to the research team and KJA phoned patients to organise an interview in a location suitable to them. It took GPs approximately 2-3 weeks to identify a patient and book in an interview. In addition to this, when patients were identified by the GP, a researcher asked the GP for their reasons and justifications for selecting the patients. These notes were collated by the team. We attempted to recruit patients in a rolling recruitment style so that we could maximise the possibility of a spread of conditions and illnesses across a range of age groups.

METHOD – DATA COLLECTION

PATIENT INTERVIEW # 1 - BIOGRAPHIES

Patients participated in up to three hours of interviews conducted by KJA and VP. For the first two patient interviews we piloted our interview schedule (see Appendix 1) and refined this as per the iterative nature of qualitative research methods. Initially we used the term 'case profile' to explain the development of the biographies to patients, but we soon discovered that this mis-led GPs and patients. The GPs and patients seemed to expect a more technical and medicalised version of the patient's health history and experiences. As the term 'case profile' did not convey the right meaning, we changed the wording and subsequent patient information to include the term 'patient story' for the remainder of the study. This was also a better fit methodologically for collecting the patient's story which was informed by Wengraf's (2008) Biographic Narrative Interpretive Method (BNIM) with some variation.⁽²⁶⁾

THE BNIM METHOD EXPLAINED

BNIM is a method that facilitates understanding of people's lived experiences and the variety of perspectives they have on these. More than this, BNIM is focussed on "the subjectivity shaped by and perhaps shaping situations; and/or the situation that shapes and is perhaps shaped by subjectivities."⁽²⁶⁾ BNIM is about the "unique subjectivity and biographical specificity of particular people".⁽²⁶⁾ The purpose of the patient biographies was to understand the biographical specificity of people's lives and how this related with their health experiences and conditions.

Usually the BNIM interview utilises an open-narrative structure rather than a semi-structured approach and the interview is conducted in one session taking up to 3 hours. The goal is to produce a whole story or long narration with what Wengraf calls 'particular incident narratives (PINs)'.⁽²⁶⁾ However, we used some semi-structured questions to guide our interviewees as we also wanted to collect data on the patient's relationship with their GP relationships and health care experiences. We included one specific question to elicit the patient's narrative, asking patients to: "please tell me the story of your health conditions, events and experiences of care that are important to you personally; begin wherever you like, I won't interrupt but I'll just take some notes for afterwards"?

Often we modified the wording of this question to suit the interview circumstances. We wanted to hear the patient's story about the health conditions which was naturally embedded within wider stories of their lives. Though we adopted a semi-structured approach we still remained true to BNIM by exploring patient subjectivity through the vocal and embodied expressive in improvised storytelling.⁽²⁶⁾ We allowed patients to talk about the life events and meander through different memories and important relationships, but asked this to be considered by them in relation with their health care. The final biographies reflect this content.

The additional reason we selected the biographic method was due to common medical cases that appear in doctor's training or online medical sites. In these patients are presented as 'cases' that follow a particular formula and plot: the patient name is provided, their age follows, and then a list of complex medical terms follow for various conditions and diseases. The plot outlines when the person presented, the diagnostic formulation and outcomes from the case. Presented all in a quite neat and linear format, these 'cases' all begin similarly, they are told in the second person, they describe symptoms and disease trajectories, and are devoid of subjective information and the person's life experience. Here are some examples of the kind of 'cases' we mean:

A 76-year-old man presented with progressively worsening vertigo, memory and concentration impairment, spatial disorientation and mild expressive dysphasia for 6 months. His medical history included hypertension and a surgically treated abdominal aortic aneurysm. (<http://path.upmc.edu/cases/case608.html>).

The patient was a 16 year old girl with known idiopathic scoliosis that presented for consultation. According to the mother, the patient was a full term delivery, had a normal development and never complained of back pain or discomfort. (http://www.orthospine.com/patient_cases/frame_patient_cases.html).

Such examples of medical cases are common and the narrative style is predictable. We did not want to replicate this approach and overlook the unique, subjective and complicated experiences of patient's lives. Typical medical cases presented like those above ignore the details about the person within the case.

Our aim was to identify if using a biographic narrative approach could assist to re-gain some of the important humanistic dimensions about medical care – an aspect of generalist approaches that appeared to be highly valued in the literature reviewed in our first study. In addition to this, the conceptual model of generalism from which the ideas for this project emerged, had identified an idealised version of the generalist (GP) and the importance of understanding the patient in the context of their life, knowing the person's life story, context, family and social situation and taking into account these family and community relationships. This raises the question of whether the kind of patient presented in typical medical cases is actually played out in practice, or whether this is rhetoric. In reality, most patient cases in the primary care setting are usually highly complex with a high degree of uncertainty. Diagnosis does not happen quite so neatly and the story rarely unfolds in a linear sequence.

PATIENT INTERVIEW # 2 - PERSPECTIVE ON CONCEPTUAL MODEL

Following the completion of biographies, patients were asked to participate in a second interview to gather their perspectives on the conceptual model of the essential dimension of generalism shown in Figure Three.

Figure 3 A conceptual model of the essential dimensions of generalism

Dimensions of Generalism	Explanations: the key features
Ways of Being (Ontological Frame)	Virtuous character: holds ethical character traits of compassion, tolerance, trust, empathy and respect.
	Reflexive: interdependent, reflects on judgments and biases, lifelong learner.
	Interpretive: processes of interpretation are used to understand patient with an emphasis on the contextual factors, use of multiple health systems languages, active listener, autonomous decision-maker, good communication skills.
Ways of Knowing (Epistemological Frame)	Biotechnical: uses scientific and rational evidence, high index of suspicion, bio-medically driven, technically focussed, uses advanced information systems.
	Biographical: concentrates on lived-experience and life-story, family, carers, community and social knowledge all provide evidence.
Ways of Doing (Practical Frame)	Access: accessible, first-contact point, gatekeeper, provides referral.
	Approach: balances individual versus population needs, consultation-based, holistic, comprehensive, flexible, adaptable, acts across clinical boundaries, provides early diagnosis, interdisciplinary team approach, negotiates & coordinates services, integrates knowledge, promotes health through education, prevents disease, is culturally sensitive, provides patient-centred care, minimises service inequities, reduces service fragmentation.
	Time: provides continuity of care over whole of life cycle (longitudinal).
	Context: community-based, uncertain, complex, deals with undifferentiated multiple problems of patients, acute and chronic care.

As the model represents a synthesis of 133 themes identified directly from the literature, we hoped to gather some patient perspectives to determine how much they felt their GP embodied the features of each dimensions and whether patients valued this. Early feedback from some GPs indicated that some of the terms would be technical for patients and would require simplification. We thus reviewed the features of the model to produce a lay list. The list was not used as a ranking exercise but to prompt patients to make comments about the importance or existence of particular features.

Of the 47 key features that appear in the above conceptual model above, we revised this to a lay list of 33. Four features were excluded because we felt these represented features that patient's would find difficult to comment on. Four were deemed systems factors: minimises service inequities, reduces service fragmentation, balances individual versus population needs and consultation based. Autonomous decision-maker was excluded also as we felt only GPs could assess this. Nine features were found to be covered by other lay features so a patient's discussion of the one lay feature was seen to apply to other features. The nine features were: lifelong learner (discussed as part of knowing); cultural sensitivity (discussed as having tolerance and empathy); prevents disease (discussed as providing education and information); interdisciplinary team approach (discussed as works with others); scientific and rational evidence, bio-medically driven and technically focussed, provides early diagnosis (discussed as having medical knowledge); adaptable (discussed as is flexible and adaptable). The lay list of features is provided in Appendix 3.

PROFESSIONAL INTERVIEWS

GPs were also interviewed individually following patient interviews, allied health professionals involved in the patient's from the multidisciplinary team practice were also interviewed. The interviews asked participants about their career histories, use of EPC Medicare item numbers, working with other team members and why the GP had selected the patient that they did (see Appendix 3). Following this, the interviewer then asked GPs to spend some time reading the patient biography to provide feedback and any initial impressions. The purpose of asking GPs to read the biography was to identify any points of convergence and divergence in terms of what the GP knew about the patient and their conditions, and what the patient had told. In particular we wanted to make note of any areas where GPs felt that they had learned new information. A second purpose of asking the GPs to read the biographies was to trial how long each profile took a person to read in preparation for the workshops. Given the busy nature of professional life we were conscious that presenting back the material to people for the professional meetings needed to be an achievable task. The reading of the profile enabled the professionals to become familiar with what the research team would be sending out in advance of professional workshops.

PROFESSIONAL WORKSHOPS

On completion of patient and professional interviews, professionals were invited to participate in three workshops. The workshops were designed using the qualitative action research technique of cooperative enquiry.⁽²⁷⁾ Cooperative enquiry seeks to appreciate the current state of practice within a group, feedback research to test accuracy and impressions, and to encourage participants to decide on areas of investigation as much as is possible. Our goal was to appreciate the current state of practice regarding team work in primary care and feedback our research with patients and on generalism to test accuracy and impressions. Facilitators guided participants to identify areas of investigation within the patient stories relevant to team care arrangements in the future. Participants were enlisted as co-researchers in the process. Table 1 provides an overview of what was provided prior to the workshops and the activities that were set to facilitate co-operative enquiry.

Table 1 Overview of Content for Professional Workshops

Meeting 1	<p>Patient Biographies provided in workbook one:</p> <p>Peter Dumus, Lorenzo Staccato, Nancy Firth, Helen Norton, Judy Page</p>	<p>Group Activity: Modelling team care</p> <ol style="list-style-type: none"> 1) What are the health needs of this patient (Peter and Judy)? 2) Who is involved in this patient's health? 3) Who or what could be added or removed to optimise care?
Meeting 2	<p>Patient Biographies provided in workbook two:</p> <p>Barbara O'Donnelly, Kathleen Delaney, Niamph O'Shannessy, Aalberts and Joan Raymer</p>	<p>Group Activity: Mapping team care arrangements</p> <p>Taking findings from meeting one, participants will model the ideal patient team for Peter and Judy using animal figures provided.</p>
Meeting 3	<p>Arranging Generalism</p> <p>Conceptual Model of Generalism in the context of biographies and the organisation of teams in primary care in the future.</p>	<p>Group Activity: Individual Reflection and conceptual model</p> <p>Participants spend 15 minutes reflecting on stand out cases from workbooks. They provide some reflection and feedback on the use of the biographic approach within the study. Participants are presented with a copy of the conceptual model of the essential dimensions of generalism and asked to reflect on the place of this in primary care teams and meeting the needs of patients in the future.</p>

METHOD – DATA ANALYSIS

PATIENT BIOGRAPHIES

Patient interviews were audio recorded and transcribed using a professional transcription service (Pacific Solutions). Interview transcripts were checked for quality by KJA and de-identified. We provided patient's with pseudonyms that matched their cultural background and age group, and all residential and practice locations were changed.

Interview transcripts were then read and segments of relevant text copied from them to a word document to develop biographies. The categories of chronicity, conditions and health care experiences were used as guides for assessing the relevance of data. Each transcript was read by KJA and VP, and both conducted cross-checking between the patient story and the transcripts. The stories followed the temporal order in which patients spoke about events, conditions and experiences, we used particular incident narratives (PINs) within accounts to flesh out the account. Our use of the order in which patient's responded to questions was based on the idea that recall of particular events indicates importance to the person telling their story. Patients told their accounts of health care, but these also included stories about important people in their lives, social supports, family members and life story information.

Given that our purpose was to develop rich biographic accounts that could still be read by busy professionals, we included as much of this as was possible. A medical chronology was developed for all patients (excluding one) also to provide a detailed health history about each patient and to provide temporal ordering to the onset of conditions and diagnoses. Biographies and chronologies were mailed back to patients for checking after the first draft. Patients were asked to identify any gaps or points of misinterpretation. Once this was completed changes were made to the biographies and final copies were sent back to the patients for their records. The nine patient biographies were separated into two workbooks for use in the professional workshops.

PROFESISONAL INTERVIEWS

GP and allied health professional interviews were audio recorded and transcribed. The transcripts were read to identify key information about the GPs career and history and this was formulated into a smaller biography to accompany the patient's biography. The GP overview also included the reason about why the GP had selected the person that they did. A secondary analysis of GP interviews was completed by AT by conducting a general thematic content analysis, this will be reported on separately. In the results a summary of some preliminary themes about professional views on teams and use of EPC item numbers is provided.

PROFESSIONAL WORKSHOPS

Workshops were audio recorded but transcripts were not made of these. Audio files were listened to and key themes and discussion points were summarised for reporting and drawing conclusions for the study.

RESULTS

PROFESSIONAL PARTICIPANTS

Of 33 practices contacted, nine GPs (39.1%) agreed to participate, including an additional three practice nurses and three allied health professionals (one dietician, one diabetic educator, and one exercise

physiologist). Two GPs the allied health professionals were from the same practice (Hunter Street Medical Centre). Participants are shown in Table 2 with practice distance from metropolitan centre and SEIFA location.

Table 2 Professional Participants in the Study

Name (Pseudonym)	Profession	Gender	Practice (Pseudonym)	Distance from CBD	SEIFA Ranking \pm
Dr Ingrid Harris	GP	F	Freeman Street Medical Centre	8km	7 th decile
Dr Geoffrey Stevens	GP	M	East Banksford Medical Centre	6km	7 th decile
Dr Bronwyn Whitford	GP	F	Lewis Street Medical Centre	7km	8 th decile
Dr Syed Kadir	GP	M	Templeton Medical Centre	31km	7 th decile
Dr Giovanni Aroni	GP	M	McRobertson Medical Centre	34km	1 st decile
Dr Chun-Yan Li	GP	F	East Liverpool Clinic	30km	8 th decile
Dr Edward Kendall	GP	M	Hunter Street Medical Clinic	70km	8 th decile
Dr Rebecca Jones	GP	F	Hunter Street Medical Clinic	70km	8 th decile
Dr Simone Murphy	GP	F	Cameron Street General Practice	6km	6 th decile
Jacky Thomas	Diabetes Educator	F	Hunter Street Medical Clinic	70km	8 th decile
Amanda Spelman	Exercise Physiologist	F	Hunter Street Medical Clinic	70km	8 th decile
Lisa Newell	Dietician	F	Hunter Street Medical Clinic	70km	8 th decile
Rhonda Kernow	Practice Nurse	F	Owen Medical Centre	17km	8 th decile
Michelle Morgan	Practice Nurse	F	McRobertson Medical Centre	34km	1 st decile
Joanne Reading	Practice Nurse	F	Cameron Street General Practice	6km	6 th decile

\pm 1 = area of most disadvantage 10 = area of least disadvantaged

Table 2 shows that the majority of practices were located within the seventh (n=3) and eighth deciles (n=4) on the index for economic disadvantage representing areas of less disadvantage. One practice was located in the first decile (an area of most disadvantage), and one in the sixth decile (just above halfway on the disadvantage scale).

The practices were geographically spread around inner and outer metropolitan Melbourne and one in a regional town. Five practices were located in inner Metropolitan locations, three in outer Metropolitan (but within the 30 kilometre boundary we initially aimed for), and one practice was located in a Regional setting (70 km from Metropolitan centre). The practice located in the area of most disadvantage McRobertson, was located within the Outer Metropolitan area. The practice within the sixth decile was inner Metropolitan, six kilometres from the City Centre. All of the practices with the exception of one (a corporate owned practice)

were privately owned and were medium sized. Five GPs were female and four were male. Practice nurses and other allied health professionals were all female.

PATIENTS

Now, I suppose, when my body began to break down – there's a difference – there's me and there's the body. We're not one entity and Nancy would like to do a lot of things, but the body says no. I'm 97 this year. (Nancy Patient Interview 1)

GPs gave various reasons for selecting and inviting the patients to the study. Common justifications included: that the person was older and older patients would be typical patients in the future; the patient was complex with multiple physical and mental health conditions; the patient had integrated care around them with a case manager, daily visits from council carers, independent and lived on their own, so representing a patient of the future; other justifications included that the patient would be interested in service improvements and so might enjoy participating; and, the conditions that the patient had reflected those perceived to be the most common in the future (for example, diabetes).

Table 3 provides the details of the nine patients. This includes an overview of their conditions and multiple health care needs, including their residential SEIFA location.

Table 3 Patient Characteristics and Health Conditions

Patient Pseudonym	Patient Age / Sex	Patient Health Conditions	Residential Postcode and SEIFA Index \pm
Sister Kathleen Delaney	82 / F	Shoulder injury and replacement, high blood pressure, high cholesterol, twisted bowel, previous breast cancer, haemorrhoids, hysterectomy, gall bladder	3013 8 th Decile
Mrs Helen Norton	65 / F	Migraine, high blood pressure, asthma, high cholesterol, Type 2 diabetes, sleep apnoea, obesity (gastric banding), anxiety / sadness (following deaths of several close family members including 2 sisters, son and husband), back pain	3039 9 th Decile
Miss Nancy Firth	97 / F	Osteoarthritis, osteoporosis, repeat hospitalisations from spinal and pelvic fractures, some memory loss but not dementia, previous bowel cancer, ongoing problems with feet, skeletal changes to ribcage and pelvis	3072 6 th Decile
Mr Peter Dumus	43 / M	Type 2 diabetes, high blood pressure, high cholesterol, sleep apnoea, obesity (gastric banding), carpal tunnel	3029 7 th Decile
Mrs Barbara O'Connelly	60 / F	Post-polio syndrome (weakened muscles and joint problems), osteoarthritis, hip and knee replacements, ongoing problems with feet, lesion on brain, elevated blood pressure, cholesterol and glucose levels	3135 8 th Decile
Mr Lorenzo Staccato	34 / M	Type 2 diabetes, high blood pressure, previous stomach ulcer, hemochromatosis (iron overload disorder)	3201 5 th Decile
Mr and Mrs Aalberts and Joan Rayner	74 / M	Type 2 diabetes, high blood pressure, emphysema, enlarged prostate	3442 8 th Decile
Mrs Niamph O'Shannasy	62 / F	Type 2 diabetes, high blood pressure, previous uterine cancer, arthritis	3429 8 th Decile
Mrs Judy Page	55 / F	Motor Neurone Disease	3055 6 th Decile

± 1 = area of most disadvantage, 10 = area of least disadvantage

Patient ages ranged from 34 to 97 years. Socioeconomically, most were in areas of less economic disadvantage with two patients in the mid-range deciles of disadvantage. Most patients lived within 20km of their practice, though in one or two instances, patients travelled great distances to visit practices. Patients had a range of physical and mental health conditions with four having existing diagnoses of Type 2 diabetes. One patient's condition was terminal.

On average the completed biographies were five to six pages in length with the medical chronology accompanying this and the GP overview. Two biographies are included in Appendix 4 as examples (due to the length we have not included all nine).

The patients range from having three to ten health care providers (excluding the important role of family members and other significant people patients mentioned). On average this group of complex patients have no less than four health care providers involved in their care. Each patient took a range of medications from pharmaceutical, over the counter complementary medicines to vitamin supplements. One patient, Nancy, had 18 combinations of medications while others were taking between four and seven, and Judy taking one as part of a clinical trial.

Most of the patients received care that was coordinated by their GP, who provided referral to specialists and allied health professionals where required. They all talked about the involvement of their family and people close to them in their care. Helen Norton, Niamph O'Shannasy and Aalberts Rayner all had TCA plans completed but there were differences between Helen's care organisation when compared to Niamph and Aalbert's; largely due to the multidisciplinary nature of their care through the organised team practice. Still, the differences were interesting given that all three patients had a diagnosis of Type II diabetes.

A number of the concerns raised in individual stories differed to the health care arrangements patient's received. Niamph in particular talked a great deal about being alone and dying at home, a worry shaped by the traumatic death of her husband while at home, yet her care arrangements were heavily focussed on disease management and it seemed that she might benefit from just having someone to talk to. A strong characteristic of Niamph and Aalberts accounts was their need to be good, compliant patients meeting all their health care provider expectations. This was in contrast to Lorenzo and Peter (also diagnosed with Type II diabetes) who talked about their struggles to remain motivated to exercise and diet for their diabetes management. Lorenzo also expressed a great deal of worry and a sense of fatalism about becoming like his father:

The doctors say that if I keep my weight down and keep everything under control then the insulin will be longer and further down the track. But that's inevitable, that will happen. So I haven't really got much to look forward to...the diagnosis was devastating, it was like a death sentence, at that point my father had already lost vision in one eye. He was already quite sick. He's also got a gastric tube in as well because he couldn't eat...As I said, he's lost half a foot. It's quite confronting (Lorenzo Patient Interview 1, 5).

The patient biographies ultimately represent a mix of social, personal and health information. Many of the accounts draw on life events like the death of a partner, sickness of a parent or fear of a decaying body as primary health concerns. Patient health needs thus vary considerably in terms of needing quite bio-technical care for disease management to highly relational care to support personal fears. The trap of highly organised care is that the relational might be easily overlooked if all of the disease is being attended to. Aalberts wife Joan talked about this during their interview:

Now with Edward (GP) we see him once a month but sometimes, say if anything was happening in between that was urgent, we would have to see another doctor. I don't find that very good, I mean he says, "oh, everything is on the computer and they can look it up". That's fine, they can read what's on the computer but they don't know you personally and the little things for you. With a computer they can't tell a little quirk that say Aalberts might develop, that's not normal, and they wouldn't know that. I think, well being serious, it could be something that Edward thinks Aalberts doesn't normally do, which another doctor wouldn't know and I find that is something that is difficult to deal with (Joan Raymer, Patient Interview 1, 23).

It is difficult to address the relational aspects of patient care given the time required to establish knowledge of the person. This is confirmed by using the biographic narrative approach as it has revealed the importance of the longitudinal relationship for patients with their GP. Even for Niamph and Aalberts who received multidisciplinary team care, the role of the GP was central and a surprise to the GP. For Niamph and Helen they expressed uncertainty about the retirement of their GPs for whom they'd both seen for over a period of 20 years. Only Sister Kathleen and Judy saw this aspect of the doctor patient relationship differently which was shaped by the short time they'd been seeing the GP.

PATIENT PERSPECTIVE ON CONCEPTUAL MODEL

Considers me as a person?Yes...She accepts me as I am on the day of the visit
(Kathleen, Patient Interview 3, 6).

Patient responses to the lay feature prompts are summarised in Table 4 to show points of convergence and divergence and any new features that emerged. It is important to note that nearly all of the patients suggested that all features were relevant before they summarised their views based on what was important to them; many acknowledged that the degree of importance could vary markedly from individual to individual.

Table 4 Patient Perspectives on features of the conceptual model of generalism

Patient	Feedback on lay version of features of model	Emergent Features
Kathleen	<p>Convergence: GP reflected many of the values and qualities and held GP in high regard. GP showed patience, listened to her opinions, told her the truth about the health situation, worked with others, and put her at ease. Patient felt welcomed for an appointment and not like a number, and saw the practice as friendly, did not feel rushed into decisions, and her health care needs were met when needed. Patient suggested GP enquired with others when they didn't know the answer, provided information, was a clear communicator, provided assurance, was respectful.</p> <p>Divergence: did not feel GP 'knows about my life' nor 'an equal partner in their health care'.</p>	<p>➤ Advocacy</p>
Helen	<p>Convergence: GP caring person, a good doctor, investigates further if needed, easy to talk to, not intimidating, provides information, open-minded. Patient felt comfortable, known as a person, listened to.</p> <p>Divergence: nil</p>	<p>➤ Open-minded</p>
Nancy	<p>Convergence: Patient felt known by doctor, respected, GP provided ongoing comprehensive care, was flexible and adaptable, compassionate, sought further information when needed, dealt with multiple problems, ruled out possibilities before a diagnosis,</p> <p>Divergence: did not feel GP was always 'first person I see when I have a health problem,' or 'GP 'asks or talks about my social and community activities'.</p>	<p>No new features emerged</p>
Peter	<p>Convergence: felt GP had patience, provided information and education, communicated in an understandable manner, is the first person seen for health problem, provides referral, listens, is respectful, knows patient as a person, follows up, diagnoses.</p> <p>Divergence: Nil</p>	<p>➤ Sense of Humour</p>

Patient	Feedback on lay version of features of model	Emergent Features
Barbara	Convergence: holistic approach, thinks about patient as a person, GP comfortable not knowing all of the answers, takes time to reflect, communicates well, provides information, someone trusted, refers when needed.	➤ Monitoring
Lorenzo	Divergence: 'is accessible,' and 'flexible and adaptable'. Convergence: felt that GP communicates well, provides information, listens, refers when needed, thinks about patient as a person not just as a condition, provides ongoing care, follows up, rules out other possibilities, is someone to trust, is accessible, deals with multiple problems, sees patient as equal partner. Divergence: 'uses modern information systems,' 'asks about my social and community life'.	No new features
Niamph	Convergence: felt GP knows who she is, is accessible, finds out information, gives out information, provides comprehensive care, is a caring person, compassionate, tries on thing and another to work out the best course of action, is empathic, Divergence: Nil	➤ Reassurance
Aalberts and Joan	Convergence: GP listens, doesn't fob patient off, is tolerant, knows who you are, flexible and adaptable, easy to understand, gives information. Divergence: Nil	No new features
Judy	Convergence: GP is tolerant, communicates well, shares their information with others, gets another viewpoint if needed, gives whole picture of what is happening, coordinates and negotiates other services, knows you as a person, is self-aware, generally first person seen, confident in information being given,	➤ Honesty

All of the patients were in agreement that the dimensions and features of generalism were important to them, although some patients valued more personal aspects of the relationship more highly than others. Key features for the group were being able to trust their GP, for the GP to show empathy, listen to them and moreover communicate information openly and honestly. Judy's discussion about one visit to a health care provider from her biography shows the importance of this:

As far as my doctors go, we used to see the doctors just down the road and there was an incident where I had problems with work, the boss who was a dreadful man causing me a lot of stress...I went to the doctors down the road and they just told me to go back to work and deal with it. I wanted some time off and he said, "you're not going to be able to get time unless you go to see a psychologist". So I said, "maybe I need to?" So he sent me to one in the city and he spent 15 minutes with me. He didn't really ask me any questions and wrote out a prescription. I got the script filled from the chemist, it had, "do not stop taking these unless under medical advice" written on them. I got a bit freaked out and I just threw them out (Judy, Patient Interview 1, 9).

For those who did express divergent views it was largely due to their personal preferences in terms of medical care. For example, Kathleen expressed that she did not feel the GP knew about her life, and suggested that the interviewee knew more about it than her. However, Kathleen's relationship with her GP was a relatively new one established two years previously and she also expressed that it was not all that important to her to have medical people 'sort of knowing or having that knowledge of me' (Kathleen, Patient Interview 3, 11). While being known was not important for Kathleen, most of the other patients saw this as fundamental to their health care. Helen who has seen her GP for 30+ years says:

I'm sure that some of these [values] wouldn't be maintained [with the new generation of doctors] because of the length of time that I've been a patient there, and with the other doctors, even a couple of the newer ones, they don't know me. The history is there with the files, but they wouldn't have time to read it all anyway. So yes I'm very concerned, that's if I'm still here, that the new doctors coming in they haven't got that history and it takes time to establish the relationship with the person (Helen, Patient Interview 3, 4).

Some patients described this relationship as being like 'long term friends' (Helen, Patient Interview 3, 8). Other divergent views emerged around the feature of 'is the first person I see for my health problem'. Nancy in particular felt that she did not always need to contact her doctor and sometimes, depending on what the health problem was, could phone the pharmacist or nurse on call. Two patients queried whether it was important that their doctor ask about the patient's social or community activities.

Patients also expressed divergent views on the topic of is accessible. A number of patients noted the accessibility of being able to see their own doctor was diminishing, however they often stated that if their need was less complicated, like a cold or flu, it didn't matter who they went to. Others made mention of accessibility being limited because of the part-time nature of their GP. Time emerged as a constraint on accessibility, flexibility and adaptability.

Notably one patient, Lorenzo, held particularly strong views about the use of modern information systems. He felt that his practice could provide information in a more accessible format to him via email and other electronic communication forms.

PROFESSIONAL INTERVIEWS

GPs were asked specifically about their use of EPC item numbers for team care arrangements. The responses were quite varied in terms of their attitudes to the item numbers and their use. The EPC item numbers appeared to be widely used by some GPs with diabetic patients and as a tool to provide patients with access to services not normally available. Bronwyn (GP) explained:

I use them extensively with my diabetic population for podiatry. It's just fantastic for your diabetic patients to be able to see a podiatrist..... But there are significant financial benefits for patients. Dental care, that's an enormous benefit. It's fabulous. Dental care just hasn't been available to people on low incomes, and this gives them a chunk of money over two years (Bronwyn, GP Interview 1, 11).

In spite of how the EPC item numbers are meant to facilitate team care for patients, there is a prevailing sense that for some GPs this is in name only. Bronwyn for example outlined how she sent her plan to other providers with a letter to add in information or make changes...she said, "Inevitably they don't change anything, they just fax it straight back. I suspect they don't even read it...Often the plan is the end of the communication" (GP Interview 1, 11-12). Others like Dr Kadir said that they regularly received written reports back from other providers which he felt was sufficient. The providers did not appear to meet face to face and he seemed to be the main point of contact and coordination for his patient.

GPs held different positions on when to use the EPC item numbers. Chun-Yan (GP) for instance suggested that some practices might over use the item numbers because of remuneration rather than it being in the patient's interest. This perspective was also shared by Michelle a practice nurse:

When [TCA] all first started up it was very overwhelming and none of us could get our head around it. I've got a lovely little template now, but I've got it down pat, but I've seen other places and they just produce them for a diabetic -- well that's a waste of my time. As far as I am concerned I produce it for that patient and I go through everything with that individual (Michelle PN Interview 1, 12).

Allied health professionals held a different view to GPs and PNs about TCAs, suggesting that the item numbers enabled them to bill separately from the GP which allowed them much greater autonomy in patient care. Although it appears that this does not resolve the issue of who is primarily responsible for coordinating the patient's care.

While the GPs and AHP from Hunter Medical Street actively talk about an intentional team structure, for the other professionals team work was discussed much more as working together in the traditional practice sense, rather than as a collaborative activity with a shared and common purpose. Table 5 provides some of the sub-themes raised by professionals in the secondary analysis completed by AT. This shows the variety of perspectives on how this group of primary care professionals view 'teams'. It identifies the importance further research to investigate these elements of team work if multidisciplinary teams are to be implemented in primary care. These include: knowing other professionals (social bonds), face to face meetings to encourage communication and team work (meetings), personal enjoyment of working with others (predisposition to collaborate), need for a vision (shared vision), threats or risks to professional identity (GP buy-in), utilising professional strengths to collaborate (roles), scope of practice changes (hierarchy), mistrust of other professionals (trust), communicating about patient care (communication), integrated care (co-location), structures to support teams (systems) and knowing what's available (fragmentation and time).

Table 5 Professional Views of Teams and Emerging Sub-themes

<i>Social bonds</i>	<p>"...let's try and do something to improve those bonds, those relationships...So we all got to actually meet the people that we were speaking to on the phone. So that was really good." – GP 3</p> <p>"She was seeing the physio long before I even knew about it and that's difficult, because it's someone I don't know or deal with or have had any communication with. So she's probably happy about it, but to me I find those situations a bit unsatisfactory." – GP 1</p>
<i>Meetings</i>	<p>"We have a formal meeting. Of course we always pass each other in the corridor and talk about informal stuff, but we have formal practice meetings at least once a month." – GP 6</p>
<i>Predisposition to collaborate</i>	<p>"So I suppose I always enjoyed the team and the collaborative approach to patient care..." – GP 8</p>
<i>Shared vision</i>	<p>"a common vision is always really important and then people can say yep I can share that vision and in that vision, of course, is a commitment to best practice..." – GP 8</p>
<i>GP buy-in</i>	<p>"I think there are challenges at a practitioner level to accept and adopt and support that model and I think that that's a key driver for change." – GP 7</p>
<i>Roles</i>	<p>"I guess that's the way we like to work things as well. Because we have the services available, there's no point me giving exercise or diabetes advice when there are experts sitting in the room next door." – dietician 7/8</p>
<i>Responsibility</i>	<p>"Because we are – we are sort of relinquishing if you like. We are sort of – the buck stops with me doesn't it?" – GP 8</p>
<i>Hierarchy</i>	<p>"Yes, well we work very closely with our nurses. They help us with dressings, immunisations, blood tests and blood pressures and things, so they do do quite a bit for us. However, I think we could probably use them a little bit more than we are now." – GP 5</p>
<i>Trust</i>	<p>"It's my understanding, too, that GPs don't immediately trust people, which is fair enough, so you've got to develop that rapport and that trust..." – dietician 7/8</p>
<i>Communication</i>	<p>"I've been using the local community health centre a bit for diabetes education and that's not often a good communication situation, and the same with the podiatrist. That's not a wonderful – traditionally there hasn't been a lot of good feedback from that group." – GP 2</p> <p>"I think if she was to come to us and the team care arrangements weren't available, we would probably still refer her to those people. I think all the things about communication between them happen anyway." – GP 5</p> <p>"I think they used to write back less. I think now that they're under the team care arrangement or the mental health care plan they're obliged to do it, and I suppose the reports are a bit more detailed." – GP 5</p>
<i>Co-location</i>	<p>"...we are certainly aware that whilst we do some team-based care of people with providers who are outside this building, that it's a different sort of care because the greater the dislocation the greater the risk of perhaps negative aspects occurring within that." – GP 7</p>
<i>Systems and structures</i>	<p>"The point about employing them, although it carries a risk to the company, was that it also enabled us to engage them more in the process of multi-disciplinary care as seen by us collectively rather than their any one individual process." – GP 7</p>

<i>Fragmentation and Time</i>	"I think most of her frustration is at the fact that things are done in bits and pieces. No one really comes and tells her this is what you're entitled to; she has to go out and find out for herself. I think that's a lot of the problems with these things is that I think being a doctor, we don't have time to sit down and do any of this. It would probably take two hours to go through everything and say this is what's available, sometimes we don't even know what's available." – GP 5
-----------------------------------	--

PROFESSIONAL WORKSHOPS

WORKSHOP ONE

Six GPs and three nurses attended the first workshop which resulted in a 81.1% attendance rate. For the first meeting nurses and GPs met separately to encourage participants to speak openly and share their views. Both groups completed the same activity as outlined in Table 3. Each were provided with a patient case and allocated 45 minutes to discuss and brainstorm their responses. Images one and two show the final results of what the GP group presented back. Images Three and Four show the results of the practice nurse group.

Image One GP Modelling Peter Dumus

Organisation / Peter Chronic Disease

Time & Effort

Patient's self-organisation

Characteristics

- ↳ falling off wagon
- ↳ being human
- ↳ opportunities for change
- ↳ "likeable requires"

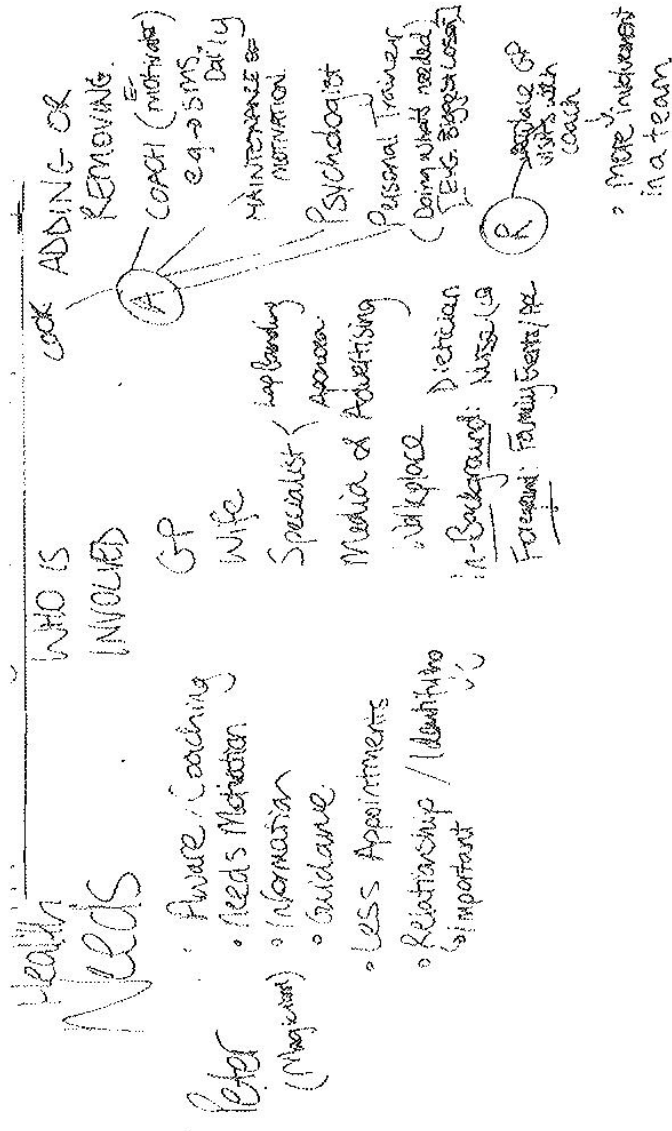


Image Two GP Modelling Judy Page

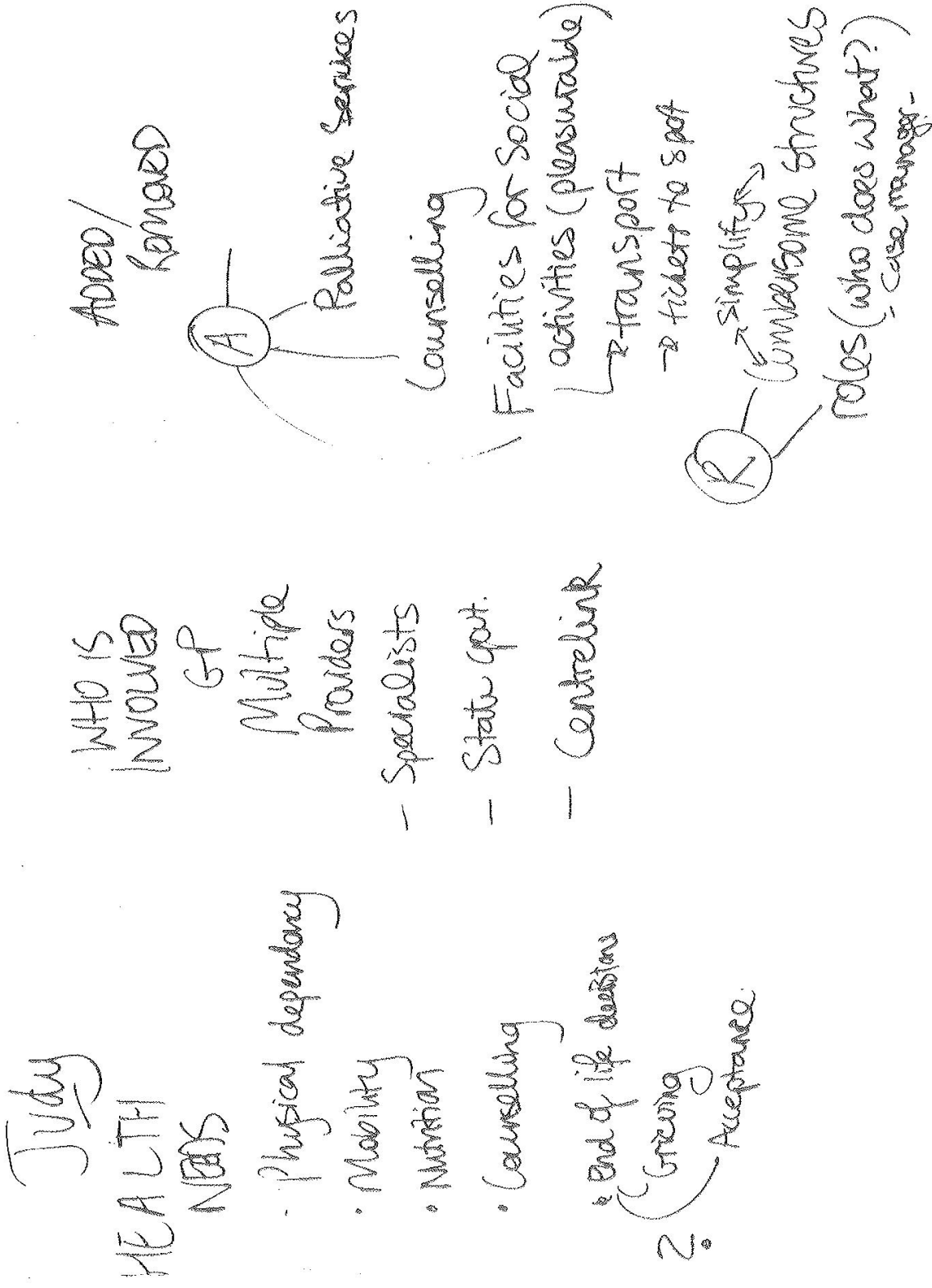


Image three Practice Nurse Modelling Peter Dumus

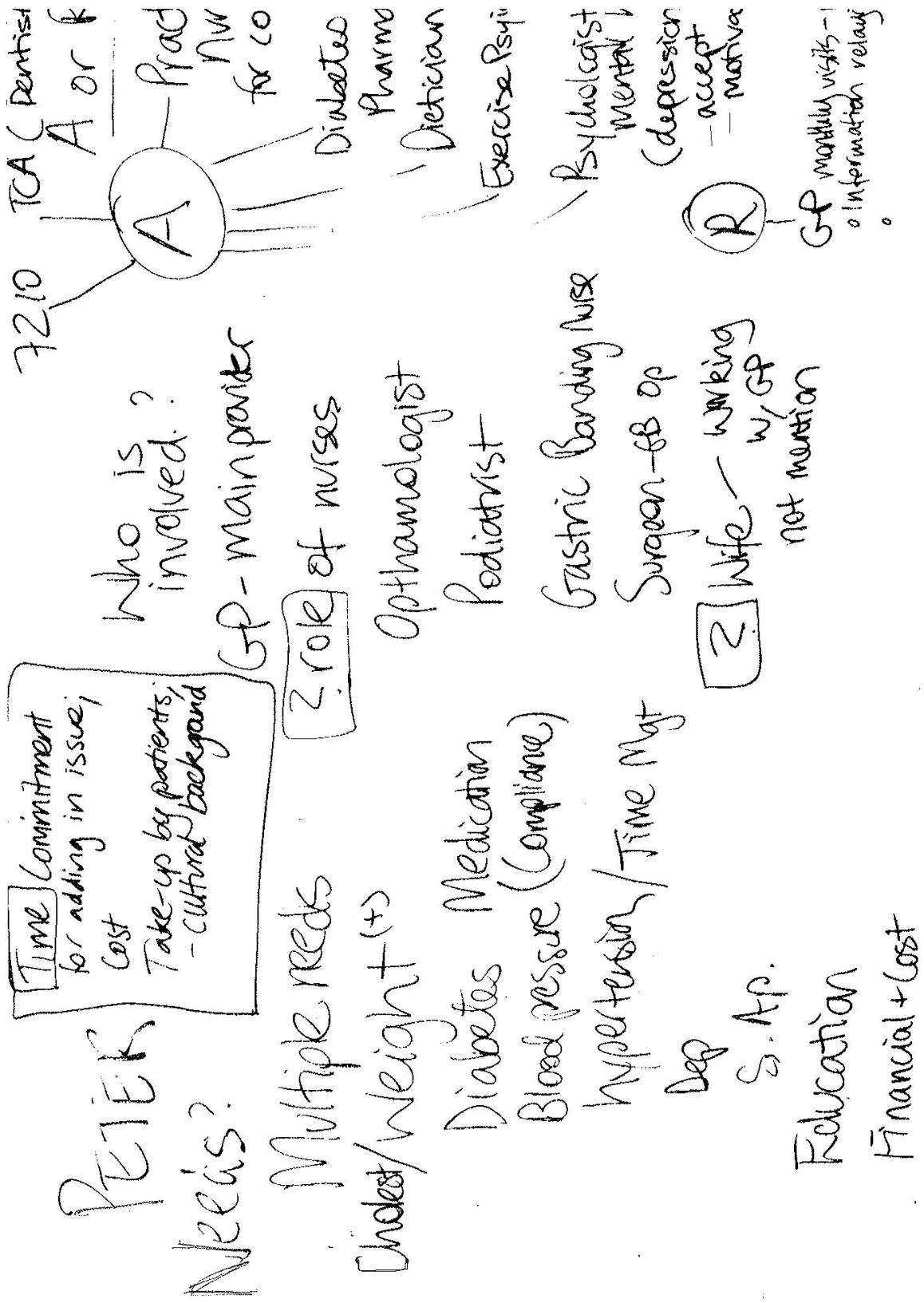


Image Four Practice Nurse Modelling of Needs of Complex Patients

Meeting Needs of Complex Patients

Involving family (- eg. Peter's wife); Judy (Emotion)

Educating family re: risks + support; } Preventive }
 Patient's → stories took doctors to be expert; } Health }
 → loyal to dr's; (praised) } Care. }

→ could be difficult patients (good rapport w/ car)

→ patient's didn't talk about illnesses, measures + how to meet goals;

- Time consuming to meet needs -

Identifying the main problem - Asking patients to identify which one to work on;

All patients - communication issues + information.

Nancy

- o well facilitated

Helen

- o multiple providers
- o No EPC
- o Teamcare wld facilitate communication

Both groups found ways that they could improve Peter and Judy's care but a great deal of this was related to social needs. Practice nurses did suggest that Peter would benefit from a TCA to facilitate his care, a suggestion that GPs did not make. GPs felt Judy needed to be given free tickets for a social outing and more engagement with palliative care services to prepare her for end of life. Practice nurses found Judy to be a well facilitated person. Practice nurses noted that Peter's GP appointments could be reduced and possibly replaced by a health coach who could motivate him for lifestyle changes.

WORKSHOP TWO

5 GPs and 1 practice nurse attended the second workshop resulting in 54.6% attendance. In this workshop, information gathered in the first workshop about the patient's health needs, who was involved in their care and what could be added and removed was presented back to participants. The group was divided in two groups and they were given animal symbols to use. The animal symbols were selected intentionally to encourage participants to think creatively after long days at work. Groups were asked to model the ideal team care arrangement for each patient. Participants were given 45 minutes to achieve this and they presented their material back to one another. The following represent the ideal team developed for patients and what the presenter's said about their mapping: Peter and Judy.

Image Five Peter's Ideal Team



Peter = grey rhinoceros who is positioned on the top of a mountain with a bridge constructed for him to walk down.

GP = Silver back gorilla
(positioned next to PDA and pen)

The dolphin (blue sea creature)
symbol of maybe taking up water
areobices.

The dog – a signifier of a motivator to get Peter exercising.

Another change group are positioned at the end of the bridge cow, camel and emu with dice – special circle of friends expansion to assist in change.

Palm Trees, Grass and horses to the side = place of pleasure and relaxation. The health resort

Other health professionals off to the side – the giraffe, shark (podiatrist and dietician), chicken (surgeon), green animal (GP nurse) and zebra (diabetes nurse educator).

....Bronwyn (GP): This is Peter he He's just staying there.

He's looking at you -- that is about as much as he does. Peter has a great **GP** this is the **silver back gorilla** -- he's big and strong and supportive and looks after the prescribing. We talked about all sorts of

dearest dinosaur, it is a lovely story about a mother duck billed dinosaur and Amy is there protecting the mother.

Facilitator: How would you explain your team to the others who have come in here? How are they working together?

They are working together by phone and fax. We chose the **GP (the rhino, no the hippo)**. The hippo, strong, is bringing them together – they have thick skin! There was a list of multiple services from last time but added to this was palliative care services so we decided that a palliative care team around these people, Judy and her daughter would be really important in instigating that team and staying in touch as you do through phone and fax and we debated how often the GP might visit.

These are the **wild animals - the unpredictable patients!** The **domesticated ones are the trained palliative care nurse** the very reliable creatures are in there but we decided from listening to Judy's story that her home is her castle so as much of their care as possible for as long as possible we would try and arrange in their home, which symbolizes their sanctuary and home. We brought in a practice nurse later on because we felt that the GP might not be in the position to field calls all the time from the palliative care services but we wanted a strong link and maximal accessibility. Of course the specialists over here will hopefully feedback to the GP what they are thinking and doing, and also the patient may need explanation of the specialist's verdicts so that's another role for the GP there. As we said there may be a time when the GP needs to do a visit once every few weeks depending on Judy's mobility she may be happy to come down to the clinic but she would have someone at the clinic, probably the practice nurse who would be well aware, and would know Judy's case so the receptionist and everyone would be worded up to know that if you get a call from Judy it is put through to the nurse. As you are aware palliative care services regularly writes notes. The case notes are there at the home so the GP can read them if they are going to the home but they would often ring and speak with the GP.

We thought that some pastoral care may benefit, whether these people might the **chooks are community chooks** - maybe volunteer chooks that might chook around because this is an independent lady, a very strong lady and she has been busy, he has had tragedy and she may not have strong links with the community. But yes we are relying pretty heavily on the palliative care services. We know that she will need state government housing trying to put a channel there with them with faxing and phoning. Judy may need visits to hospital and re-hab and we are hoping that these people can say that Judy is coming along today try and make those three groups of people all aware that we know what is happening with the patient. We are all really busy GPs and so we are thinking we need the practice nurse.

Facilitator: would you add the receptionist in?

No we haven't...

The hippo is the GP because of being thick skinned. That one is sort of empty (the PDA) we needed to really affirm this lady and that she had done a fantastic job and to say she is a very strong and an independent lady and any care we think of needs to be empowering of her decision making needs and abilities. This was an after thought [tiger territory bit] we were saying at the end of the discussion that this could all dissolve in a heap if she gets a serious infection and sometimes people get more needy and they stretch resources that can't keep pace with what's happening in their care and she might just go into hospital or the hospice. So we said that we hope that what we've set up around her that she has a good system around her and it all a bit of rolling dice and she might just go into tiger territory pretty quickly but hopefully we've got good feedback from the nurses. The state government were bits and pieces and equipment and funding.

WORKSHOP THREE

6 GPs and 2 PNs attended workshop three resulting in 72.7% attendance rate. Reflecting on all of the patients, participants mentioned that they noticed all of the patients had physical, mental and emotional needs in common, and the patients all expressed a high regard for their GPs (for some GPs this was surprising). Nurses felt that the patient almost held the GP in a god-like status. The other striking aspect for participants was the weighting that patients gave to some things compared to the weighting that GPs gave to things. Notable for GPs was that patients focussed on things as making ground and progress that GPs would not consider in this way. GPs also reflected that they begin their involvement with patients largely on medical issues but soon becomes about the complex personal stories.

A final comment was that reading all the biographies gave some GPs a sense that everybody was dealing with complex patients, and they were not alone. The common feature of the cases was that each of the patients had a different solution, which could not be identified in a text book. Individual GP skills need to be used to graph and work with someone to find solutions. GPs also mentioned the challenges of getting to the level of intimacy required for identifying solutions within a small consultation timeframe. These themes all resonate with the sub-themes identified in the professional interviews and these will need further investigation if multidisciplinary team care is to be implemented.

CONCLUSION

Our research confirms that primary care professionals do not use a singular definition of “team”. Rather, when primary care professionals speak about teams and team working they may be referring to a practice team, a uniprofessional team (working with providers from the same profession, sometimes in parallel), an interprofessional team (a mix of professional disciplines working together) or quite often, a unique mix of providers addressing an individual patient’s needs (what could be called conventional referral arrangements). The lack of uniformity makes any comparison of teams and patient health outcomes challenging and also demonstrates that we do not fully appreciate the structure and systems currently in place in the primary care setting.

It is surprising given the Australian government’s focus on multidisciplinary teams that professionals rarely, with the exception of the one practice organised to deliver multidisciplinary team care, mention this as a normative way of working with patients. This includes those GPs who work in group practices where TCA plans are an active part of daily work with patients. Team care is still interpreted and talked about in a variety of ways by professionals. There are some that might see team care rather instrumentally where sending a patient to a specialist, for example, is a task for ruling out possibilities, and determining diagnosis and treatment pathways. Once the task is completed and the written report back no further engagement is required. This is characteristic of conventional referral arrangements but also seems to be mirrored in the practice and processes of TCA. Other professionals though place a good deal of value on relationships and note the key barrier to working with others is not knowing who other professionals are. These perspectives still do not resolve who needs to be in the team and whether these professionals need to be co-located to deliver ideal care.

Interestingly patients, including those receiving organised team care, talk very little about their other health care providers. Certainly other professionals are mentioned as people responsible for different parts of their health management, but their individual stories illustrate the importance of the GP to their care. The GP is the point of check-in, the person who monitors and follows-up and who oversees the whole health picture. Being known by the GP, checking back in with them, feeling comfortable, listened to and communicated to with honesty are all important to patients. If patients of the future are likely to be those with complex and multiple needs as presented in our study, then they will require a range of care providers, from allied health professionals engaged in regular clinical care to specialists who may be required for short-term episodic care. Certainly, to meet patient needs the team will need to be one that is flexible and adaptable, but will patients feel that deep sense of being-known with multiple providers engaged in their care? Have we fully understood the unique aspects of general practice/primary care in Australia where GP is so central to patient care?

This study employed alternative research methods to engage professionals in an imaginative and detailed way. GPs and practice nurses found the use of alternative research methods such as the biographies and using animals for mapping out patient care useful. Outside of these activities helping to think differently about patients, participants found the activities enjoyable. While in-depth reflection on the patient stories was highly valued it was not possible to do this with all of the cases.

Further research is required into how primary care should be organised to best respond to the complex and multiple needs of patients in the future. The kind of practice structure and communication channels required and professional mix are all important elements. There is unlikely to be one elusive model that will meet all of the complexities of patient’s needs, even within our highly organised practice we note that patient’s still have health needs that can be silenced. While we know that patient’s value the essential dimensions of generalism in their health care, the diffuse nature of teams in the current primary care setting means that arranging generalism within this has a considerable way to go.

REFERENCES

1. NHHRC. A Healthier Future for All Australians: Final Report of the National Health and Hospitals Reform Commission. Canberra; 2009 Contract No.: Document Number|.
2. DoHA. Towards a National Primary Health Care Strategy: A discussion paper from the Australian government. Canberra: Department of Health and Ageing; 2009 Contract No.: Document Number|.
3. Yates R, Wells L, Carnell K. General Practice Based Multidisciplinary Care Teams In Australia: Still some unanswered questions. A discussion paper from the Australian General Practice Network. Australian Journal of Primary Health. 2007;13(2):10-7.
4. Dieleman SL, Farris KB, Feeny D, Johnson JA, Tsuyuki RT, Brilliant S. Primary health care teams: team members' perceptions of the collaborative process. Journal of Interprofessional Care. 2004 02;18(1):75-8.
5. Hartigan P, Meng-Soo R, Kljakovic M. Do Team Care Arrangements address the real issues in the management of chronic disease? Med J Aust. 2009;191(2):99--100.
6. Hills M, Mullett J, Carroll S. Community-based participatory action research: transforming multidisciplinary practice in primary health care Revista Panamericana de Salud Pública / Panamerican Journal of Public Health. 2007;21(2-3):125-35.
7. Soklaridis S, Oandasan I, Kimpton S. Family health teams: can health professionals learn to work together? Can Fam Physician. 2007 2007;53(7):1198-9.
8. Hansson A, Friberg F, Segesten K, Gedda B, Mattsson B. Two sides of the coin - General Practitioners' experience of working in multidisciplinary teams. Journal of Interprofessional Care. 2008 01;22(1):5-16.
9. Goh TT, Eccles MP, Steen N. Factors predicting team climate, and its relationship with quality of care in general practice. BMC Health Serv Res. [; Research Support, Non-U.S. Gov't]. 2009 2009 Aug;9:138.
10. Bower P, Campbell S, Bojke C, Sibbald B. Team structure, team climate and the quality of care in primary care: an observational study. Qual Saf Health Care. 2003 2003;12(4):273-9.
11. Harris MF, Proudfoot JG, Jayasinghe UW, Holton CH, Powell Davies GP, Amoroso CL, et al. Job satisfaction of staff and the team environment in Australian general practice. Med J Aust. 2007 2007 Jun;186(11):570-3.
12. Proudfoot J, Jayasinghe UW, Holton C, Grimm J, Bubner T, Amoroso C, et al. Team climate for innovation: what difference does it make in general practice? Int J Qual Health Care. 2007 2007 Jun (Epub 2007 Mar;19(3):164-9.
13. Cashman SB, Reidy P, Cody K, Lemay CA. Developing and measuring progress toward collaborative, integrated, interdisciplinary health care teams. Journal of Interprofessional Care. 2004 05;18(2):183-96.
14. Charles-Jones H, Latimer J, May C. Transforming general practice: the redistribution of medical work in primary care. Sociology of Health and Illness. 2003;25(1):71-92.
15. Shaw A, de Lusignan S, Rowlands G. Do primary care professionals work as a team: a qualitative study. J Interprof Care. 2005 2005;19(4):396-405.
16. Delva D, Jamieson M, Lemieux M. Team effectiveness in academic primary health care teams. Journal of Interprofessional Care. 2008 12;22(6):598-611.
17. Molyneux J. Interprofessional teamworking: what makes teams work well? Journal of Interprofessional Care. 2001;15(1):29-35.
18. Mulvale G, Danner U, Pasic D. Advancing community-based collaborative mental health care through interdisciplinary family health teams in Ontario. Canadian Journal of Community Mental Health. 2008 09;27(2):55-73.
19. O'Neill M, Cowman S. Partners in care: investigating community nurses' understanding of an interdisciplinary team-based approach to primary care. Journal of Clinical Nursing. 2008;17(22):3004-11.
20. Sicotte C, D'Amour D, Moreault M. Interdisciplinary collaboration within Quebec community health care centres. Social Science & Medicine. 2002 09/15;55(6):991-1003.

21. Naccarella L, Sims J. How do general practitioners work together with other health care providers: policy, reality and research perspectives within the Australian context? *J Interprof Care*. [short research report]. 2003 2003;17(3):303-4.
22. Shaw SN. More than one dollop of cortex: Patients' experiences of interprofessional care at an urban family health centre. *Journal of Interprofessional Care*. 2008;22(3):229-37.
23. Gunn J, Naccarella L, Palmer V, Kokanovic R, Pope C, Lathlean J. What is the Place of Generalism in the 2020 Primary Care Team? Canberra: The Australian Primary Health Care Research Institute; 2007 Contract No.: Document Number].
24. Creswell J. *Qualitative Inquiry and Research Design*. 2nd ed. London: Sage Publishers; 2007.
25. Patton M. Two decades of developments in qualitative inquiry: a personal, experiential perspective. *Qualitative Social Work*. 2002;1(3):261-83.
26. Wengraf T. Interviewing for life-histories, lived situations and ongoing personal experience using the biographic narrative interpretive method. London: Berbeck Institute of Social Research; 2008. p. 595.
27. Baldwin M. Working Together, Learning Together: Co-operative Inquiry in the Development of Complex Practice by Teams of Social Workers. In: Reason P, Bradbury H, editors. *Handbook of Action Research: The concise paperback edition*. 2nd ed. London Sage Publications; 2006. p. 221-7.

APPENDICES

APPENDIX 1 PATIENT BIOGRAPHY INTERVIEW SCHEDULE

Patient interviews (Development of Patient Biography) – Interview Guide

Duration: 1 to 1.5 hours.

The following semi-structured questions are designed to guide the patients to share their health information history and care needs. Material will be assessed according to how it describes patients':

- ***Health condition/s;***
- ***Chronicity of health conditions;***
- ***health care arrangements and experiences;***
- ***treatment and management of conditions.***

1. So, perhaps we might begin by hearing a little bit about you. Have you lived here long?
2. Tell us about coming to see your GP. Have you been coming long? Have you always seen the same GP?
3. How often would you say that you see your GP about your mental/physical health conditions?
4. ***** Now, can you please tell me the story of your health conditions, events and experiences of care that are important to you personally; begin wherever you like, I won't interrupt but I'll just take some notes for afterwards?***
5. Are there other important people involved in your care you want to tell us about?
6. Are there any experiences that you've had in the health system that you'd like to tell us about to improve patient care in the future?
7. Is there anything else you think is important that you would like to tell us?

***** It is important when question four is asked that the participant is encouraged to talk through their story – let them know that you are not going to interrupt and you want to hear their health story. This question was not necessarily asked verbatim for each patient interview but in an open ended style to encourage participant's to share health conditions and experiences.***

APPENDIX 2 SEMI-STRUCTURED INTERVIEW SCHEDULE (GENERAL PRACTITIONERS)

1. How long have you been practicing for?
2. Have you always been located at this practice? Can you tell us a little more about your career experiences?
3. Do you have a special interest as a GP?
4. Do you utilise the Medicare Enhanced Primary Care Item numbers (721; 723) very often?

Can you tell me a bit more about the benefits and disadvantages to using these?

5. Can you tell us about the patient case you selected?

We are asking for information on extent of condition/s, treatment to date, contextual and social information used for diagnosis, approaches taken to delivering care, referrals to other care providers (specialists and allied health professionals) and challenges presented by the case.

6. Can you tell us about any particular team care needs that this patient has which have not been met previously and why?
7. Have you thought about having other allied health staff at your practice? What are some of the barriers and advantages to co-locations of other health care providers?
8. Now, read through the patient case profile that has been developed – can you tell us your first impressions and thoughts on this and did you learn anything new about this person by reading the profile?

APPENDIX 3 PATIENT FEEDBACK ON CONCEPTUAL MODEL

Quality of Care and Professional Values

The following pages contain a list of things people say are important about their GP. Please read through the two pages and circle which qualities and values are important to *you*. *This is not a ranking exercise we just want to know what you value about your health care.*

When we meet next we will ask you the following questions:

- 1) Why did you circle the ones that you did?
- 2) Which of those things you circled are qualities that are reflected in your GP?
- 3) Which of those you circled are qualities that describe the health care you receive at your general practice?
- 4) Which of those that you DID NOT circle are qualities you would like to see in GPs and your health care services?

We will ask you to give this page back to us for our data collection purposes when we meet with you next. This information is not given to your GP. It will be collated and presented in a de-identified format.

This will be the last time we meet with you. THANK YOU once again for participating in the *arranging generalism* study to identify the health care team arrangements for patients in the future. We will be in touch later in the year with study information if you are interested.

QUALITY OF CARE & PROFESSIONAL VALUES

Is Tolerant	Provides me with information and education
Communicates well	Negotiates and coordinates other services
Works with others	Information given to me is easy to understand
Knows who I am	Is non-judgemental
Is accessible	Is the first person I see when I have a health problem
Is self-aware	Is someone I trust
Uses modern information systems	Refers me on to other health care providers when needed
Listens to me	Considers me as a person

Provides comprehensive care

Asks or talks about my social and
community activities

Has medical knowledge

Thinks about me as a person and not
just my illness or condition

Is respectful

Follows up with me

Provides ongoing care for me

Deals with multiple problems

Knows my family and other
important people in my life, or knows
about them

Takes time to reflect

Is empathetic

Is flexible and adaptable

Is comfortable not knowing the
answer straight away

Rules out other possibilities before
reaching a diagnosis

Manages my short and long-term
health needs

Sees me as an equal partner in and at
the centre of my health care

Is compassionate

Knows about my life

Knows my personal story

Able to translate health information from
a range of sources

APPENDIX 4 EXAMPLES OF TWO PATIENT BIOGRAPHIES

PETER DUMUS

Mr Peter Dumus

Dr Kadir's strict. But he's good, I can't complain. He calls me a walking time bomb, and he tells me off when I don't do what he says. Sometimes I can't get a straight answer out of him though – when he takes my blood pressure and that, I ask, well has it improved? And he just doesn't say anything and he goes no, it's still no good. So he doesn't tell me whether it's gone better or gone up. Just straight down the line he says, nope, still no good. Then there are medications that I don't take sometimes, and he tells me off. I don't like to pump too much medication. It's no good for the kidneys.

I'm 43, though I'm trying not to think about it. I originally came from Holdgate, from the high rise flats, and then I went out to Avonside with my parents. Then I got married, I moved out here, which was with the first marriage. Then that didn't work out and I got remarried and I stayed down here. Virtually I could say a good 15 years of my life I've been out this side. I've got a daughter with the first wife, she's 20. I got one inside the bedroom there, a boy, 13 years old, and my wife's got two others from her first marriage, a girl, 19, and a 24 year old boy. The two boys are here, though the older one's planning to move out in the next week or so. That will leave just three of us left. One more to kick out and then no more kids! Well, I don't wish the younger one to go early, but when he gets there, 21 or whatever, out the door. I've done my job, now it's your turn to learn the real world. I left home at 17, for about a year. I was in a job for about six months, then I went back home because everything went pear-shaped. Then I got married at 21, young

Use this space to record your initial impressions as you read. What stands out to you? What's happening? What could be different?

and stupid. But I learned my lesson, I mean they always ask, why did you get married the second time? I said, well after the first time you know what to expect now. I was the first one out of my friends to get married. I wouldn't say stupid, but young and it didn't work out. Now I see what the idea is, not to get married at a young age because you haven't lived your life and that.

I've been seeing Dr Kadir since my son was born, so about 13 years. He's the only one I'd prefer to see, any of the rest of them... I'm not saying the others aren't any good, but I'd prefer him. I feel comfortable with him. Look, he's stubborn. About time, I mean – better being stubborn with me than not. He checks you out, if there is something wrong he's thorough. Some people I see – like I've had a couple of other doctors there. They tend to rely on the computer to diagnose whatever problem you've got and that. He's a bit more thorough.

Before him, I never really had a regular doctor. What happened was, he's given me blood tests and that, and found all the high blood pressure. It's over the weight factor virtually, where it's kind of started, and he's done all the tests and found out I had high blood pressure, I found out I'm a Type 2 diabetic, everything under the sun it seems I've got. I particularly, myself, would rather see one doctor because then the record's there with one. He knows my ins and outs, what my problems are. If I go to more than one, things are just going to be all over the place. I felt comfortable with him and just let things take their course. So, and then it led from one thing to another – high blood pressure, diabetes, bad cholesterol, or not the good

What are your initial impressions? What stands out?

cholesterol, but the bad cholesterol. Now I'm on medication. The main factor was the weight, which I had to lose.

I probably see Dr Kadir every month. He only gives me prescriptions for a month and then he likes me to go back again and monitor how we're going. Right now, the first thing I do is hop on the scales and then he sits me down and checks my blood pressure. Usually when I go back I need new scripts and then he checks my blood pressure first, and then if I had a blood test he'll look back on the results and he'll go, you been taking your tablets? No. Why not, he says. Or I'll ask him has the blood pressure gone down, and he'll go, no, still the same. So I said, I'm taking your tablets, but obviously it's not working. I'm just kind of wondering whether he's saying no it hasn't changed, and is just motivating me to keep at it. Some days I just can't get a clear answer out of him, or maybe he just doesn't want to tell me, but just give me the negative so that – well, make sure I'm still losing weight. I said to him I've given up smoking, has it made any difference to my blood pressure, and that – I know I give him a bit of a hard time sometimes, but he can take it. Occasionally I really stir him – every three months he takes blood, I tell him he takes more blood than what I produce. I'm a big baby when it comes to needles. I mean, even when they operated on my carpal tunnel, on my hand, I threatened the anaesthesia bloke – don't muck around, one prick and I'm out. If I'm still awake I'll thump you. I hate it when they – because back in the school days when they used to come to you and you get injections, well they broke a needle in my arm. Since then I just don't get along with them. I mean, I've got tattoos and they say well, how do you put up with the needles and I said, if I

What are your initial impressions? What stands out?

don't see it, I'm fine. When I go to the dentist's and I see the needle going across my face, I shut my eyes.

As well as the blood pressure, the diabetes and all that, there's the sleep apnoea. As I said, I've got the works. That's why Dr Kadir says I'm a walking time bomb, but then I kind of say there's a lot of people that are hugely bigger than me. I'd have to say, well if he'd seen them, he'd probably call them nukes or something like that. I never used to be big like this. I used to do truck driving and it was just drive, eat, sleep. There's no physical exercise. That's where I put on the stomach. Now, I don't know where it started off, but as I said, he's taken blood pressure, my blood pressure was high and I used to weigh 140 kilos and it just led from that virtually, the size, it ended up with high blood pressure. Well, the high blood pressure, I used to have a bit of a temper, I used to be snappy real quick, it didn't take much to trigger me off. Then just led from that, from one after the other, he decided to do a blood test and that's where it led. Then all the higher cholesterol problems, Type 2 diabetes, I used to drink a lot and that. It just led from there, it just snowballed. He reckons it's due to my size. I mean that made me diabetic. Having this lap band, I'll lose the diabetes and – I stopped smoking, I used to smoke a lot, so I've stopped smoking. It all just snowballed from there and just led from one to the other and that's it.

Before that I was just an everyday Joe Blow. Work, eat, sleep, pay bills, eat, argue with the wife. Never really gave a shit about my weight or anything like that. Dr Kadir's virtually woken me up, or given me the idea that, hang on Pete, that's

What are your initial impressions? What stands out?

your problem, now the rest is up to you how you're going to go about it. I still, these days, cut corners. My cholesterol's subsided but I mean I've slightly changed my eating habits. Hopefully it will – because I don't like too much medication. I see people with kidneys packing up and that. I'll take it one thing at a time. I've had to cut back on my waist, I've also got to cut back on the eating, I've got to cut back on the sugar. In a sense you're damned if you do and damned if you don't. You look at something where's there's less sugar, it's high in fat. You look at something low in fat and it's got more sugar. Where do you go from there?

Dr Kadir does the check-ups, he does prescriptions of what I'm going to take and as I said I just had the lap band done in March by Mr Parsons in Alfred Park. That's his surgery and I had the operation at the Eastern General. Now we'll see how that goes. I mean if I lose weight – so far it hasn't been much. I'm supposed to see a dietician, but I got a bit slack. That means another visit to the clinic, so another day off. My situation with making appointments is very hard because I work at the airport. I've got set hours, but then I do overtime, so to get a day off is hard... Even with these blood pressures I've got to either make it – you know because you've got to fast and that, I've got to make it either as early as possible or I make sure I'm not working that day when I can take it. I try to work around my schedule, sometimes it's not too easy though.

Two times in my life I've been in the hospital. I've never been in for broken legs or anything like that, I haven't got any history of hospitals – but as I said, I don't like them. I ended up

What are your initial impressions? What stands out?

going to the Eastern General for a sleep apnoea test there, they reckon I fell asleep, but I don't reckon, I was still awake, but they don't really know if I was asleep or not. Operation-wise, only had a day surgery for carpal tunnel and then the lap band, they're pretty much the only two I've ever been in for. Apart from that, I've never been in hospital. The carpal tunnel was a same-day procedure, as soon as they woke me up from the anaesthesia I was out. I was up and at them, even though I was a bit funny, but I was like, let's go, see you later. They did warn me about the anaesthetic, where you feel a bit light-headed. But to me, bugger the light-headed, I'm up and out – hospitals, forget it. If anything, I was up a bit toey, but I held my nerve and I walked out.

What are your initial impressions? What stands out?

Where the sleep apnoea originated from was my wife was constantly complaining that I snore, or I snore the house down. I didn't believe it, thought she was exaggerating a bit. Then I went and saw Dr Kadir about it and he referred me to get a test done. Apparently I stopped breathing 100 times. I mean I felt tired, I used to fall asleep on my job, I'm the only bloke that could fall asleep standing up. I keep telling them they're liars, what are they talking about, but I don't realise that I fall asleep. Some days in the car you tend to kind of be nodding off and it just got dangerous where you don't know you're asleep. My brother-in-law's fiancée, she used to be a big girl and she had the same problem where she actually ran into a brick wall, with her kids in the car, and that kind of made her wake up and have to use an oxygen mask – they reckon that when you're in the sleep apnoea problem, you don't sleep during the night like you're supposed to, like you can have eight hours, but really you

only had two hours sleep. Where your brain's always ticking, your mind's not shutting down, your eyes are still moving around, when they shouldn't be. With a mask with oxygen, I can have four hours sleep and then I feel great, like I slept eight hours. I use the mask every night but I don't want to rely on it all the time, plus again it comes down to the weight factor as well.

Apart from my wife keeping on my back about my health – at the end of the day it's up to me really, how I tend to push it you know. She's helped with regards the eating factor, that's about all. I mean she's aware of my mood swings occasionally that I get. She's been very supportive the whole way through. I really I try not to – only the eating habits, what I eat and how I eat, that's the only change. Apart from everything else, I really tend not to give it too much thought. Life's too short to worry about it. I've got a gym thing in the bedroom there. I mean, I've been slack for a little while now, but when I get motivated I get on it and do the running and lifting weights. But the biggest part is motivation. After 12 hours a day at work, I don't really have much of a motivation to do a workout. I get enough exercise at the airport. I mean I do enough walking 12 hours a day there. What I do is x-ray bags, I'm at the international. See, I'm a senior there, so I overlook all the other guys at what they do, and then occasionally, about five times a day I make sure I walk the whole airport – I've got to get out of there to see if it's still daylight outside. I get out there and walk from one end of the airport to the other.

What are your initial impressions? What stands out?

With the lap band fills and that, it's only \$120, but 80-something I get back on Medicare, so I lose \$40, but it's not bad. I mean, that's only just until enough has gone in, you know. Later on, I mean, if I lose the weight and I'm quite happy, they'll drain it back. Hopefully losing this weight will bring down the blood pressure and the cholesterol and the Type 2 diabetes, well, end it anyway. As I said, I'm enjoying my life so I don't worry about these things too much. Put it this way, if my number's meant to be, it's meant to be. I've got no family in my history that's gone early, not that I'm going to rely on that kind of report. Apart from that, take life as it comes.

What are your initial impressions? What stands out?

Peter's GP

I graduated in Afghanistan – I did my medical school in Kabul, Afghanistan. It was 1982. I did two and a half years or three years teaching physiology, and then I ran away from Afghanistan, escaped during the war with the Russians and went to Pakistan as a refugee, I was in Pakistan for one and a half years and then I came to Australia. When I came to Australia, I had to learn English, and at that time we had to sit for the AMAC exam. I did my English exam, and I had to sit for my written exam. I did my written exam and my clinical exam. I managed to pass all of them first try, because I was lucky enough, and in the meantime when I was preparing for my exam, my first job in Australia was the production line in Toyota.

My second job was for APM, then, driving a taxi. I got married and my first job was in Alfred Park Hospital. I did my Dip Obs there, and also I did two years hospital work in Robertson, different positions, registrar, and psychiatry and again obstetrics. That's the time I did my training and I joined the training program with the college. It was 1994 when I passed my fellowship exam. I was working as a GP, but then I got my fellowship in 1994. Then I opened up this clinic in 1996, just myself, and now we have six full-time GPs here. We have another clinic which we have four full-time doctor there. So all of us altogether between clinics we have got ten, eleven full-time GP plus about fifteen receptionist, six nurses, and one practice manager.

What are your initial impressions? What stands out?

When I came to Australia and I worked at different places, I thought it's an opportunity if you open your own practice. Of course, first financially it's rewarding. Second, you have your own boss and you're independent. It's not an easy job to own your practice, especially in general practice. It's not the tension, the stress of the work, it's basically the stress of not finding doctors. The doctors get sick, they're away and you have to cover them. So it's a lot of, basically, overtime and plus on top of that your paperwork. If we had more doctors it would be more fun, but we're expecting to get a few doctors hopefully, next year. We're planning to apply another three full-time. We are also accredited for training college for registrars, so hopefully we'll get one registrar next year. That helps us with the workload.

In this practice we have three practice nurses, one Div 1, two Div 2, a practice manager, six, seven receptionists and six full-time GP. We're like small family practice. We have fun, we go out a couple of times a year and we celebrate each other's birthday. So we cover each other when we need. We also discuss the issues, typical issues, we have clinical meetings every four to eight weeks. More so the GPs, at least four of them from the six try to be there plus the practice nurses and the receptionist and, of course, the practice manager.

So basically we work here as a team. With the clinical meetings it depends on how much time we have. I think this area is busy for everyone here in Avonside – the southern suburbs, but there's not enough doctors, and the doctor/patient ratio is the worst in Australia, or second worst in Australia. We use the

What are your initial impressions? What stands out?

EPC item numbers. Two of our nurses are accredited for immunisations, pap smears, and they're also very good with organising care plans. One of our nurses is in the middle of becoming a diabetic educator. We also do refugee health check here in southern suburbs. It's a lot of work involved, but it's something different to see different – it's a different medicine from refugees. It's not like all this, probably high blood pressure, cholesterol, it's something different.

So we have refugee health system check-up, diabetes we're very good at that, the care plan and also diabetes check. We have psychologists here onsite, we have a dietician onsite, also have physiotherapist. I'm trying to do some dermatology. You just tend to forget about it and it's always a dilemma, you know, these tiny skin lesions, you don't know what to test, but also, of course, it gives us confidence. It makes us more confident about our diagnosis and management. So I'm planning to do dermatology a bit.

I chose Peter because he met the criteria - he's male, he's 42 years old, probably he is a typical Aussie male, which is overweight, very overweight. He has sleep apnoea, he has high blood pressure, he has diabetes. I think diabetes is getting better after gastric banding, and he has high cholesterol, so he has everything. On top of that he is depressed, but he denies it. I've tried to put him on an antidepressant a few times. It helped him and he stopped it and he says, I'm better, but when he's here with his wife I know that he's not good. He has a touch of depression. It's not a very bad one, but he has.

What are your initial impressions? What stands out?

Mr Peter Dumus – A Chronology and Brief Medical History

Year	Age	Life event	Health condition / event	Treatment
1966		Born in (then) Yugoslavia		
1970	4	Migrated to Melbourne, Australia, lived in Portsmouth then Holdgate		
1981	15	* Moved to Avonside * Commenced cabinet-making apprenticeship		
1983	17	Moved out of home for 12 months for work		
Mid-80s	20s	* Left cabinet-making after finishing apprenticeship, worked as a forklift driver and truck driver		
1987	21	* Married first wife (later divorced) * Moved to Lexton		
1988	22	First child born (daughter)		
1995	29	Married second wife (who had 2 children from her first marriage)		
1996	30	* Second child born (son) * Templeton Medical Centre opened by Dr Kadir, started seeing him as regular GP		
1998	32	Started driving semi-trailers locally and interstate	Carpal tunnel syndrome	Surgery
2000	34	Left truck-driving, started working in security	Beginning of weight gain	
2004	37	Started current job at airport (security role)	* High blood pressure * High cholesterol * Type 2 diabetes * Overweight	Medication, lifestyle changes (diet, exercise)
2007	41		Sleep apnoea	Oxygen mask
2009	43			Gastric banding surgery, 4 saline fills to date

(ii) Medications and supplements

Currently taking four different medications / supplements:

Medication / supplement	Dose	Condition
Karvezide	1 tablet per day	High blood pressure
Perindo 8mg	1 tablet per day	High blood pressure
Diaformin 1000	3 tablets per day	Type 2 diabetes
Vitamin D supplement	1 tablet per day	Low Vitamin D

N.B. Was also taking Lipidol for high cholesterol but this has recently come down and so Peter has ceased this medication.

Care arrangements

(iii) Current care providers

- GP – since 1996, every month, for monitoring of blood pressure, glucose levels, cholesterol, blood tests (3-monthly), general health
- Nurses at bariatric surgeon's practice – for saline fills following gastric banding surgery
- Eye specialist – for monitoring of eyes in relation to hypercholesterol
- Podiatrist – for monitoring of feet in relation to diabetes

JUDY PAGE

Mrs Judy Page

I've been living here in this particular house probably about 28 or 29 years. My husband and I moved here to rent it and it went up for sale probably about six months after we moved in. We decided it was a pretty good location and we were lucky enough to be able to buy it. My GP thought that I'd be a good study and although she didn't mention what the other people in the study had as an illness, she thought that mine was the most serious and that perhaps you needed someone at that end of the medical scale. My illness has an end period and it's not far off, so rather than only having people with diabetes who can be managed to live a relatively healthy life, there's nothing that can be done for me. At the moment I don't see my GP very often but she has rung at times to check on me. I've seen her to get a flu and pneumonia shot. So, I don't see her that often but that may change as my condition progresses.

Most of my medical care has been done by the St Paul's team out at Foster or a group visiting the Namadgi Medical Centre. It's mainly a medical team including – the people at St Paul's, the neurologist, a physio, an occupational therapist, a respiratory specialist and a speech pathologist. I might need speech therapy down the track too, but at the moment it's okay. Because St Paul's is so far away I've got a more localised team through Smithfield Health Services including an occupational therapist. I've also seen a physio a couple of times.

Use this space to record your initial impressions as you read. What stands out to you? What's happening? What could be different?

Alberton Health finally approved, after five months, that I have a serious illness, (motor neurone disease). I've got a case manager through Smithfield Health Services who set up home care visits to utilise the funding that Alberton Health has provided for me on an annual basis. This service is to help me by giving me medicines or taking me to the toilet, dressing me, bathing me, or just sitting with me or taking me to a shop.

St Paul's have been great in providing me with all sorts of medical aids, a bed, trolley, hospital table, wheelchair, bath seat and they're all on loan which is great because my illness is short term. So all this is on loan and it will go back to the hospital when I'm not around anymore. I think that's great for someone like me who has something that's terminal and short-term. It would be a shame to have to also put a financial burden on families because you've got enough worry as it is; having to deal with the fact that you're not going to be around anymore. And, all your family having to deal with that fact -- which is probably worse for them, having to deal with that loss in the future. But it's very satisfying to know that there's a group -- the Motor Neurone Disease Equipment Library providing such a service.

The people out at St Paul's have been absolutely fantastic in providing care. Centrelink on the other hand, absolutely dreadful and I wonder whether some of the staff down there have any more than two brain cells because they say the dumbest things, and you just think, are they kidding? Are they seriously kidding, the questions they're asking? They've got all your information there but they don't even seem to

*What are your initial impressions?
What stands out?*

check the file before they go and open their mouths. It's very frustrating when you've got enough to deal with as it is, then to have to deal with people who just obviously are not really checking their work before they go and make the telephone call. They ring up and say, you haven't provided this and haven't provided that. I'm sorry, we're going to have to cancel your application and it will have to all start again. That means that you don't get paid for all that time going back. This happened after we had already provided the required information! You wonder whether they're counselled into really helping people or trying to shift them away; bit of non-service really and very frustrating. My husband had been my full-time carer until May 6 2009 when he died of a massive heart attack. We were waiting for months and months. We started our application for the Centrelink assistance probably around about mid to late November and it didn't come until after he died in May. Now to me, that's not proper help. You might not want to hear about this side and prefer more about the medical side, but all these things affect the mental health of the patient and their family – and our time having to get it all happening. The point is I think some of those government services take too long to give people help when they really need it. As far as my husband's concerned, he died waiting, and I'm pretty annoyed about that.

As far as my doctors go, we used to see the doctors just down the road here and there was an incident where I had problems with work with this boss who was a dreadful man causing me a lot of stress. Almost the whole college knew about him. I worked directly with him and it really messed with my head. I

*What are your initial impressions?
What stands out?*

went to the doctors down the road and they just told me to go back to work and deal with it. I wanted some time off and he said, you're not going to be able to get time unless you go to see a psychologist. So I said, maybe I need to? So he sent me to one in the city and he spent 15 minutes with me. He didn't really ask that many questions and wrote out a prescription. I got the script filled from the chemist, it had "do not stop taking these unless under medical advice". I got a bit freaked out and I just threw them out. I decided to change doctors because I needed help and they made some judgement about me and were totally wrong. I've never been a person to have shirked work. For goodness sake, when I left work I had something like well over 150 sick days, 65 annual leave days, and 22 weeks of long service leave. So I was a workaholic. I was passionate about my job. I worked until I found out that I had motor neurone disease. As soon as they told me I think you've got motor neurone disease, I rang up and said I've had dreadful news. I'm not coming in and I never went back.

I changed my doctors and went to Cameron Street to where Dr. Simone Murphy practices, but I haven't seen her for very long. Often you make an appointment to see the doctors and you see a different doctor because it's a clinic of doctors. When I realised I had motor neurone disease, Simone told me, but I had already figured that it was probably going to be something serious. Mainly because of the way the physio had acted, she looked like she was stunned when she couldn't fix me and horrified, and said, "no, no, I'm not even going to charge you for the appointment". I thought hello, what's going on here. I thought that perhaps Simone would be a

What are your initial impressions? What stands out?

better person to be my doctor through the illness because I'd be able to verbalise things with her more than with Dr Taylor who I'd seen a few times – I don't know, it's just hard to judge with Dr Taylor, because he was one of those pensive types that keeps his thoughts to himself, just writes you out the prescription or says try this and if it doesn't work come back. Maybe for some people it's good to have a doctor like that. They don't want to know what the matter is but I wanted to know. I've been seeing Simone since I've known that I've had motor neurone disease – she actually told me that I had motor neurone disease. I had a guess in August last year and it took until the end of that year to go through numerous tests for a definite diagnosis.

Amy, my daughter, is now my main carer and she's just got a job at Murdoch working Tuesday to Friday from 10 'til 4. Since my husband died she's been here all the time as my carer. She was made redundant two weeks before my husband died. So I have to reassess the care that I am needing; which will have to be reassessed on a weekly or a fortnightly basis because I'm deteriorating. I'd say in a couple of months I won't be able to feed myself because my right hand's on its way out and the left hand has already gone. Even my body's getting tired to lift itself up. I don't want to dwell on the fact that I am going to die but the annoying things like not being able to scratch or move my body in bed or get a drink when I am dry are on my mind. I'll have to plan things on an as-needs basis. I'll have to have someone dropping in here every couple of hours or something. Alberton Health has approved an annual package that is reviewed. When reviewed we need to

*What are your initial impressions?
What stands out?*

seek more funds for more regular care. That's just the nature of this type of illness -- it gets worse, not better. As long as all the medical needs and the help is easily available, it makes everything else a lot easier because you know you've got that support. You know that your family's got that support.

It's been a very big burden on Amy. She's had to take over the whole responsibility and I'm glad she's got this job. Amy feels like she has been in her tracksuit pants and PJs for the last three months and needs something other than just looking after me and to engage with others. However, she's been achieving a lot for me. When someone passes away in the family, there is their estate to deal with and the funeral to cater for. My husband had power of attorney for me and had re-done my will. There were a whole lot of things to organise there, and then, when my husband passed away we had to do it all over again. I had to make a new will. There was just so much to do, organise the funeral and make sure that he had a good send-off. Amy has excelled in achieving this with help from my son.

As far as other help, I've got carer help funded by the Alberton Health through Silver Service, one of the care agencies that we selected. I have two ladies coming. We met them first. We had a meet and greet. They tried to find people that were similar to us and matched with our personalities. It's hard to adjust to the fact that I can't even dress myself. It's hard losing your independence and frustrating that you can't do things. I'll go to the toilet and I've got a bidet seat, they're great, but I can't turn on the tap even though we've

What are your initial impressions? What stands out?

had a plumber to fix it to make them easy to open -- I still can't turn the tap on. I hope I'm not going to get to the stage where I will not be able to even get out of my room. It's frustrating but I try not to dwell on such things. I may as well try and think positively rather than negatively. Sure I could think of it negatively, get into the doldrums, get all maudlin and sad. But I try to look at it on the positive side. I will enjoy my time that I've got as much as I can. Also that makes it easier on all the people that are around me.

I've got a couple of friends, a really good group of friends who are giving me lots of support, by doing things like dropping into the Alberton Market. They do that for themselves so they ring up and find out what we want and drop it in. Another friend she's got Thursday off work so she doesn't spend the whole day with me, but she can if I want her to, and another friend that comes on the weekends and drops in and sees me. I've got my sister-in-law who is now working for St Paul's Silver Service. She's coming and actually helping me and getting paid for it. I haven't got to the stage yet where I need nursing help, but that probably could be soon, especially if I can't get myself to my toilet. I might have to have a catheter etc. I'm not going down the peg or the breathing path assistance at this stage. When my time's due to go I may as well just go because it's not like if I wait it's going to be all sunny and lovely down the track. It's just going to get worse. I think the system tries to leave people in their comfort zone as long as possible but I can see that that's going to end down the track. By the end of the year I might not be here anymore. I don't know how quickly it's all going to happen. Yeah, so I

What are your initial impressions? What stands out?

won't look forward to that day. But when I get to that stage the family will really need for me to be gone because I'll be too hard to manage. So that's how it stands at the moment.

In this left arm for instance, all the muscles have withered away. I really have nerve twitching all over my whole body, but this left arm was the first to be affected. I've noticed it in the shoulder and the hand. I used to ride to work and I could feel a dull ache and loss of strength when I was going over speed humps in my hand. I just thought I was holding onto the bicycle handles too hard. But anyway both arm's on are on the way out. I have to wear splints or my wrist will just hang limp and there's no strength in them. I need that aid to be able to use a spoon to support my hand. I can feel my legs getting much weaker. I can't walk normally anymore. It's like a bit of a shuffle and I can feel one foot bending in a bit. I can feel my toes aching. You feel that dull ache first, a bit like an arthritic pain and then later you lose more movement. It can happen to your arms and legs, you can lose your speech. Some people with MND have lost their speech first. In the end it attacks your breathing and of course that's what gets you. It attacks your swallowing. So some people agree to have pegs so they're fed by a tube in their stomach. That's the future, it's not terribly bright. It's not bright for me and it's certainly not bright for all the people around me.

What are your initial impressions? What stands out?

Judy's GP

I graduated in 1989 or 1988 and did my intern years and graduate years in Corinder. Then I went to general practice, having had experience both in the country and in town, I then signed up at the Community Health Centre in 1992, in Brookefields. I was there for 15 years. I left last year and joined my current practice in June last year. So I've been there a year. Why did I join general practice? I think that it possibly chose me. I think that the acute setting never suited me. It's a very bullying environment, in the hospital setting. I don't think I truly appreciated how distressing it was, until about 10 years later. I didn't necessarily think that I would have an ongoing career in medicine, or in general practice. I always thought of other ways of getting out of it, I initiated a Masters in social health, initially in anthropology, so I actually was going to move --that was about four years ago. But I'm probably very good at general practice in a wider way, taking that lateral step made me realise that I'm actually quite good at what I do. There are times when it's busy and I think, maybe I'll do something else! I think I'm good at giving information to patients in a way that they can understand, and good at understanding that there are many other ways of thinking about health and health solutions besides the biomedical model. I think general practice lends itself to that.

At Brookefields, I did heaps of antenatal care. That was probably the largest component of my practice. I am still doing lots, and being a generalist still, I never necessarily chose to sub-specialise. To some extent it's quite true that in

What are your initial impressions? What stands out?

general practice you tend to get the patients that find you, and suit you, and you develop a rapport in that way. General practice has changed, even in my short career of 15 years, from being a very episodic kind of illness-driven experience to much more of relationship-driven. In the 15 years I've seen that relationship become critical to ongoing care, rather than just episodic care. I sought people out with similar values to mine to work for. Interestingly, both the principals have spent time at Community Health, so I think they very much have a...team probably isn't the right word...probably a team approach to healthcare, and that suits my values as well. There's an enormous understanding at our practice that the patients are patients of the practice, and not individual patients of individual GPs, we encourage the patients to actually move between us. Certainly there's very little ego involved when it comes to providing patient care. There may be many days when you are sitting alongside people and you don't actually know what's going on -- it's a very solitary profession. I think the aid of an electronic record means that you can see what's been going on for that patient as well, and understand that your care for that patient will be critiqued by others within the practice. I work part-time, so if I'm in the practice four days, they're short days, so it has to be that their care has to remain within the practice not with me.

We have five GPs, two practice nurses and a mental health nurse. There are physios that visit who have their own private practice outside, but they come and provide care particularly to some of the elderly patients. The diabetes nurse comes by the risk management program at the acute hospital. There

*What are your initial impressions?
What stands out?*

was a psychologist that visited, but mostly the rooms are pretty much filled with us now. So there's a space imperative now, which is awkward. We do use the Enhanced Primary Care item number. The nurses are really good at doing all that coordinating the paperwork for patients. Basically we select the patients for them, but they might initiate it as well, so it doesn't always come from us. Nurses might decide that that patient would benefit from extra care particularly those patients with a lot of complex mental health issues.

I selected this particular patient...it was one of those very busy days, where I met her for the first time with a medical student. She had a profound diagnosis that was obvious at the first time of meeting. I think it's always a challenge to give bad news to someone right at the first time of meeting, then, having to facilitate her diagnosis, which needed to be made fairly promptly, in the setting of teaching. It was probably one of the most challenging experiences that I've had. I think I chose her because she represents a demographic that might be missed in chronic disease, where she in fact does have a terminal diagnosis, but a part of that is pretty much a chronicity that still needs to be managed, both in the acute and in the community sector. She's also very articulate, but also has great challenges, both grief and loss, and also still having young children who have to face her diagnosis. She represents to me, particularly from a female perspective, all those complexities of a chronic disease, but also with the added distress of having a terminal disease as well.

*What are your initial impressions?
What stands out?*

