

# Implementing care coordination plus early rehabilitation in high-risk COPD patients in transition from hospital to primary care

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# Glossary

**CCQ:** Clinical COPD Questionnaire

**CDSM:** Chronic Disease Self-Management

**COPD:** Chronic Obstructive Pulmonary Disease

**CRQ-SAS:** Chronic Respiratory Questionnaire – Self-Administered Standardized Format

**D12:** Dyspnea-12 Questionnaire

**ED:** Emergency Department

**FP<sup>TM</sup>:** Flinders Program

**GOLD:** Global Initiative for Chronic Obstructive Lung Disease

**GP:** General Practitioner

**GPMP: General Practice Management Plan**

**INSCOPE:** Integrated Multidisciplinary Specialist COPD Programme

**MBS:** Medicare Benefits Schedule

**NP:** Nurse Practitioner (respiratory specialist)

**PFT:** Pulmonary Function Test

**QOL:** Quality of Life

**RPT:** Research Assistant Physiotherapist

**TCA:** Team Care Arrangement

**2MWT:** 2 minute walk test

## Project at a glance: Main messages

This pilot study implemented care coordination plus early rehabilitation in people with chronic obstructive pulmonary disease (COPD) at the time of transition from hospital to home.

### Key results

- This pilot intervention generated a positive experience of both the *process* and *outcomes* of transition for COPD patients and their carers.
- Patient-centred problem identification and goal setting was followed by significant and meaningful progress toward achieving those goals.
- Patient-centred care planning by the care coordinator was highly comprehensive and valued by patients, carers and general practitioners
- This intervention avoided adverse events including emergency department presentations by patients in the early post-transition period.
- Only 1 in 10 (10%) of patients in the intervention group were readmitted within 28 days for a respiratory reason compared with 6/19 (32%) of controls.
- Objectively measured physical activity increased (time spent standing and walking) and time spent sitting decreased as a result of early rehabilitation in the context of transition care coordination. These improvements were not seen in the control group.
- Commitment of this program to gain collaboration with the patient's general practitioner (GP) proved challenging but did effectively prompt care continuity at the time of transition. Evidence for this lay in the generation or review of GP management plans by the patient's usual practice resulting from the intervention in all cases where a current plan had not previously existed (9/10 cases).

### Recommendations:

1. Based on the positive results of this pilot project, care coordination plus early rehabilitation in people with COPD at the time of transition from hospital to home should be implemented in a larger controlled study that is adequately powered to determine a difference in readmission rates between the intervention and usual care.
2. The team of specialist respiratory Nurse Practitioner and physiotherapist demonstrated ability to implement all planned components of care coordination and early rehabilitation in this population and also to expand scope to meet further identified and previously un-addressed needs. This workforce combination is indicated to implement the intervention.
3. Implementation of early rehabilitation could take place utilising physiotherapy workforce in "rehabilitation in the home" services that currently exist to facilitate discharge from acute care. Implementation of the specialist respiratory nurse practitioner role, with ability to work across acute and community care is essential to coordinate care in transition, facilitate access to specialist services and to hand care over to general practice/community care.

## Executive summary

**Background to the problem:** Hospital admissions due to worsening of symptoms in people with chronic obstructive pulmonary disease (COPD) are associated with poor outcomes, high costs and frequent re-admission.<sup>1,2</sup> Problems identified with the transition between hospital and primary care in people with COPD include:

- Patient and carer dissatisfaction with experience<sup>3</sup>
- Poor identification or concern for patient health goals<sup>3</sup>
- High incidence of adverse events including re-admission<sup>1,4</sup>
- Declines in physical activity, function and quality of life (QOL) after hospitalisation.<sup>5,6</sup>

Care coordination at the time of transition has demonstrated reduced hospital readmissions and improved QOL for people with heart failure<sup>7</sup> but there is minimal evidence in people with COPD. In addition, early rehabilitation in people with COPD after hospital admission with an exacerbation of symptoms is safe and effective,<sup>8</sup> but implementation is low due to barriers associated with attending centre-based programs during this challenging early period.<sup>9</sup> The combination of care coordination and early rehabilitation has the capacity to directly address the costly problems associated with transition from hospital to home in people with COPD.

**Aim of this project:** To pilot the implementation of care coordination plus early rehabilitation in a COPD population in transition from hospital to primary care. We examined the effect of care coordination plus early rehabilitation on

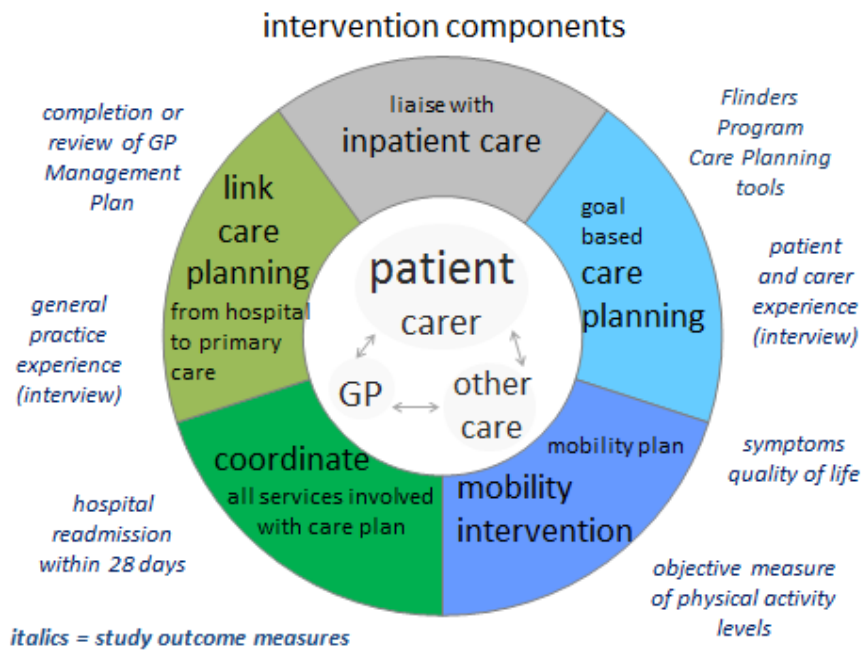
- Patient and carer experience of transition
- Progress toward agreed patient health goals
- Collaboration with patient's general practitioner/primary care
- Hospital readmission and physical activity levels compared with a control group

### **The care coordination plus early rehabilitation intervention**

The intervention was home-based and flexible, usually 1 visit/week by each practitioner for 4-6 weeks. The intervention incorporated patient-centred care coordination plus early pulmonary rehabilitation with two unique and innovative foci: (1) patient and carer goals, and (2) effective transition to primary and community care, by use of existing Medicare Benefits Schedule (MBS) items.



Figure 1 Intervention components and outcome measures



### Results achieved by this pilot project

#### A positive patient and carer experience of transition

The intervention was perceived as highly valuable to participants and their carers, delivering a positive experience of both the *process* and *outcomes* of their transition from acute to community-based care.

**"It's really helped me along, step by step."** patient

**"You can really sort it out with one another and work on it"** carer

#### Significant progress toward achieving patient goals in transition

The intervention created opportunity for patients to articulate goals. In the intervention group overall, a significant reduction in perceived severity of patient problems, and significant progress toward their self-selected goals was achieved between 4 – 6 weeks at home after discharge from hospital.

#### Participant quality of life

Improvements after the intervention in fatigue, emotional function and mastery subscales of a standardised, validated health related QOL tool (Chronic Respiratory Questionnaire) were greater on average than the minimal difference reported as clinically important.

#### Effectively linked transition care planning to primary and other care

The intervention enabled collaboration with the patients' general practitioner or practice nurse, resulting in the review or generation of a GPMP and/or TCA in all cases. General practitioners reported a positive experience of the program for both themselves and their patients.

**"I think it is a fantastic initiative and would definitely recommend it for other patients"** GP

### **Early rehabilitation increased physical activity and reduced sedentary time**

Patients who participated in the intervention demonstrated significant changes in their patterns of physical activity at 4 weeks after discharge from hospital compared with during their admission, including:

- % of awake time spent in prolonged sitting (sitting 30 mins or more without interruption) reduced by 31%, from 81% during hospital admission to 50% at 4 weeks after discharge
- % of awake time spent standing increased by 12%, from 6% during hospital admission to 18% at 4 weeks after discharge. *This represents an average improvement for the patient of 200% on their standing time in this period.*
- % of awake time spent stepping increased by 3%, from 1% during hospital admission to 4% at 4 weeks after discharge.

**No** significant changes occurred in activity patterns between hospital admission and 4 weeks later in the control group.

### **Positive trend toward fewer readmissions for respiratory reasons in 28 days after discharge**

Although this study was not powered to detect a significant difference, readmission within 28 days for a respiratory condition occurred in **32% in the control group** and only **10% of the intervention group**.

**Implications of these results:** This pilot data suggests that care coordination and early rehabilitation provides a positive and effective transition from acute care in people with COPD, with benefits for the patient and carer, for primary and community care and for acute care services.

Based on the positive results of this pilot project, care coordination plus early rehabilitation in people with COPD at the time of transition from hospital to home should be implemented in a larger controlled study that is adequately powered to determine a difference in readmission rates between the intervention and usual care.

### **Methods of this study**

We conducted a controlled pilot study in patients admitted to hospital with a primary diagnosis of COPD.

**Control group (n=19):** recruited Mar-Dec 2013 (prior observational study). Received usual care

**Intervention group (n=10):** recruited Jan-April 2014. Received care coordination plus early rehabilitation intervention.

Outcome measures were conducted at hospital discharge and repeated at four weeks after discharge from hospital, in both intervention and control groups. Other measures were conducted at the beginning and end of the intervention only. Post-program interviews exploring patient, carer and GP experiences of the intervention were conducted by independent practitioners not involved with delivery of the program.

## Introduction

This pilot project was made possible with funding awarded by the National Lead Clinicians Group (NLCG) of the Australian Primary Health Care Research Institute (APHCRI). The Integrated Care Working Group (subgroup of the NLCG) examined the literature regarding transfers of care at the interfaces of primary, acute, sub-acute and residential aged care in Australia. The group identified gaps in transition care and recommended the funding of pilot projects that addressed one or more of the following areas:

- Identifying and targeting high risk patients
- Exploring transitions of care managers/teams based in the community, and
- Support for family members/carers to effectively move patients through transitions of care.

Our application was awarded funding for a 9-month pilot project to **address identified gaps in the transfer of care of people with chronic obstructive pulmonary disease (COPD) from hospital after an acute exacerbation of symptoms, to home.**

## Background

COPD is a common and disabling condition with high personal and public health costs.<sup>10</sup> Due to progressive breathlessness on exertion, people with severe COPD endure a poor QOL with a symptom burden comparable to that of palliative cancer patients.<sup>11</sup>

### **Problems faced by people with COPD in transition from hospital to home**

Most of the high costs of COPD care are associated with hospitalisations for worsening of symptoms or function.<sup>10</sup> Hospital admission due to a worsening of symptoms (or exacerbation) in people with COPD is associated with further declines in lung function,<sup>12</sup> loss of QOL,<sup>5</sup> and physical inactivity.<sup>6</sup> Readmission is very common in people who have been hospitalised with an acute exacerbation. Studies indicate readmission rates of >50% within 12 months, with highest risk in the first 3 months after hospital discharge.<sup>1,2</sup> A retrospective study in a regional hospital in south eastern Australia found diagnosis of COPD to be an independent factor associated with frequent readmission (3 or more admissions/year) in a multivariate model (odds ratio for frequent readmission=8.8, 95% CI 3.9, 20.1, p<.0001).<sup>13</sup>

Beyond hospital readmission, consumer and provider dissatisfaction with transitions of care from hospital to home are well documented.<sup>4,14</sup> Patient experience of transition is negative and there is little involvement of older people in their care. Communication between health care professionals, and between professionals and patient/carers can be inadequate, and adverse events are common.<sup>15</sup> A recent South Australian qualitative study in people with COPD and health professionals caring for them reported ongoing difficulties around access to care, lack of continuity of care, poor care co-ordination and poor communication. A COPD care co-ordinator was suggested as an effective strategy for ensuring best-practice care.<sup>16</sup>

**Potential benefits of care coordination in COPD at the time of transition**

Care coordination at the time of transition has been proposed as an effective way to overcome these problems, but the addition of care coordination responsibilities to current workload is beyond the scope of many busy general practices and acute care facilities.<sup>4</sup> A meta-analysis of 18 studies (n=3304) investigating comprehensive discharge planning plus post-discharge support services in people with congestive heart failure found reduced hospital readmissions and improved QOL with same or lower medical costs than controls, over an 8 month observational period.<sup>7</sup> A subsequent successful care transitions program in patients with chronic conditions (n=750 but included only 5% with COPD) cited important components as assistance with medication self-management; a patient maintained health record; timely follow-up with primary/secondary care and “flags” indicative of worsening along with information about how to respond.<sup>17</sup> To date transitional care coordination programs have demonstrated efficacy for people with heart failure but there is minimal evidence in people with COPD, and only one study reported in the meta-analysis included any physical rehabilitation.

**Early pulmonary rehabilitation: another missing component of COPD care**

Pulmonary rehabilitation is an integral aspect of care in people with COPD that is effective to reduce admissions<sup>18</sup> and improve QOL<sup>19</sup> but remains underutilised.<sup>20</sup> Early rehabilitation immediately after discharge from hospital due to an exacerbation is safe and effective, improves functional exercise capacity, health-related QOL, and reduces unplanned hospital admissions and mortality.<sup>8</sup> However a South Australian study found that while 57% of patients had been referred to rehabilitation at some point in their disease course, only 18% had ever completed a program, and only 8% had done so within the 2 years prior to their hospital admission.<sup>21</sup>

**An intervention to address these gaps**

Our model of transition care incorporates patient-centred care coordination plus early pulmonary rehabilitation delivered at home with two unique and innovative foci: (1) patient and carer goals, and (2) effective transition to primary and community care, by use of existing Medicare Benefits Schedule (MBS) items. The aim of this study was to pilot this intervention and describe outcomes in terms of feasibility and fidelity of this approach; patient and carer satisfaction; demonstrated progress toward achievement of patient goals, and involvement of general practice in care planning through use of MBS items. We also compared effects of care coordination and early intervention on rates of hospital readmission and physical activity levels at four weeks after hospital discharge with a control group of people with COPD who received usual care.

## Aim and Hypotheses

The **aim** of this study was to pilot the implementation of care coordination plus early rehabilitation in a high-risk COPD population in transition from hospital to primary care.

### Study Hypotheses

(a) Implementation of the pilot intervention (care coordination plus early rehabilitation) is feasible, satisfactory to patients and carers and can be delivered with fidelity.

(b) Care coordination plus early rehabilitation will result in (i) documentation of agreed patient goals and (ii) demonstrated progress toward them assessed by the four major Flinders Program™ (FP™) care planning tools: Partners in Health / Cue and Response / Problems and Goals assessment and Self-Management Plan<sup>22</sup> in at least 85% of cases.

(c) Care coordination plus early rehabilitation will involve collaboration with the patient's GP/practice nurse with generation of a General Practice Management Plan (GPMP) or Team Care Arrangement (TCA) in at least 85% of cases.

(d) People with COPD who participate in care coordination plus early rehabilitation will have lower hospital readmission rates at 28 days and greater physical activity levels at 28 days after discharge than a control group of similar patients.

# Methods

## Ethical considerations

This study was approved by the Human Research Ethics Committees of the Royal Adelaide Hospital and the University of South Australia prior to commencement.

## Study Design

We conducted a non-randomised study of intervention vs control. Allocation to control or intervention group was determined by date of admission; consecutive eligible patients admitted in 2013 were allocated to the control group and those admitted in 2014 were allocated to the intervention group.

## Participants

This study included patients admitted to hospital with a primary diagnosis of COPD, confirmation of COPD diagnosis by previous pulmonary function testing and length of admission at least 48 hours. Potential participants were excluded if they:

- (a) had insufficient English language or cognition to give informed consent;
- (b) had been unable to walk during the previous 3 months;
- (c) were rapidly approaching death at the time of hospital admission;
- (d) lived outside the area serviced by Central Adelaide and Hills Medicare Local (CAHML).

**Usual care control group:** Patients who met the above inclusion/exclusion criteria were recruited between March and December 2013 to an observational study “Time spent in sedentary and physical activity in people with COPD during and after a hospital admission”, which also formed the control group for this study.

**Intervention group:** Patients who met the above inclusion/exclusion criteria between January and May 2014 were all recruited to the intervention group for this study.

**Sample size:** This pilot study was limited by a pre-determined project timeframe (Sept 2013 to July 2014). Sample size for the intervention group was determined by number of patients who met inclusion/exclusion criteria and were able to be recruited from the study site during the available data collection period (4.5 months).

## Care coordination and early rehabilitation intervention

The care coordination plus early rehabilitation intervention (Figure 2) was of flexible duration (1-2 months) and implemented by a specialist respiratory Nurse Practitioner (NP) and a research assistant physiotherapist (RPT) and included the following components:

- (1) Liaison with existing Integrated Multidisciplinary Specialist COPD Programme (INSCOPE) inpatient hospital COPD coordinator and Respiratory Physician for streamlined transition into INSCOPE as required.
- (2) Care coordination by weekly home visit (NP) to patient with additional

phone contact as required.

- Needs assessment, problem identification, goal setting and care planning with the patient (using the FP™). The patient’s carer was invited to participate in care planning discussions.
- Facilitation of referrals across all health sectors in collaboration with the patient/carers and relevant members of the health care teams involved.

(3) Early rehabilitation by weekly visit (RPT) with flexibility for additional visits as required.

- Walking program: flexible depending on the individual, commencing at 2 x10 min walks/day prescribed at approximately 40% of peak speed in 2 minute walk test prior to hospital discharge,<sup>23</sup> or using appropriate cut off on modified Borg scale<sup>24</sup> to determine intensity and duration of walking; optimal walking aid prescription
- Interrupt daytime sedentary periods of >1 hour with sit-stand/short bursts of mobilisation.
- Upper and lower limb resistance exercises, including use of free weights and resistance bands

(4) Collaboration with patient/carers, local primary care practice nurse and GP to integrate care using existing MBS items (GPMP/TCA).

Figure 2 The care coordination plus early rehabilitation intervention.

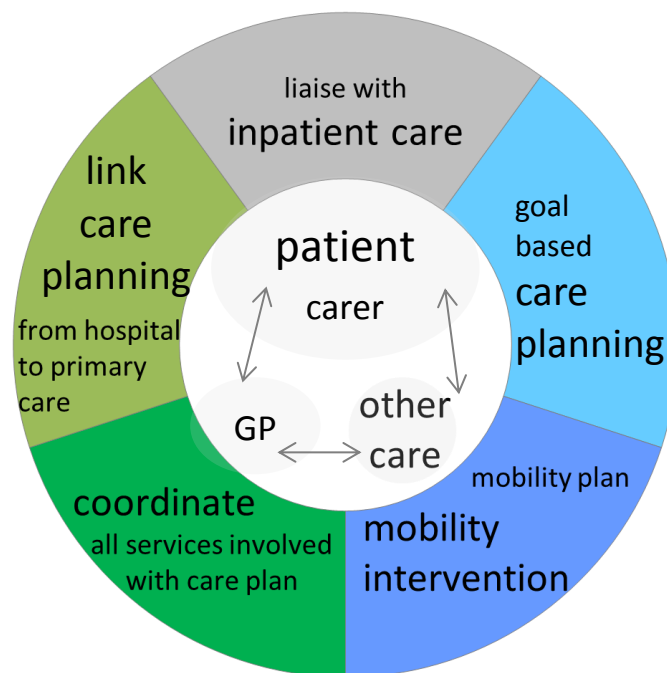


Table 1 details how the components of this intervention were delivered.

Table 1 Care coordination and early rehabilitation intervention

<b>Before hospital discharge</b>	
<ul style="list-style-type: none"> <li>• Liaison with existing INSCOPE hospital COPD coordinator</li> <li>• Liaison with patient's GP/practice nurse re:               <ol style="list-style-type: none"> <li>a) Existing (GPMP)/(TCA)</li> <li>b) Obtaining support from the patient's GP for future involvement with developing a care plan where one does not exist</li> <li>c) Sending the GP/practice nurse project information</li> </ol> </li> </ul>	NP
Liaison with NP re patient's mobility and outcome of discharge walk test	RPT
<b>Intervention Week 1</b>	
Conduct NP Visit 1 within 2 working days of patient's discharge, including: <ul style="list-style-type: none"> <li>• Needs assessment, problem identification, goal setting using the FP™ tools</li> <li>• After visit, liaise with RPT re patients' mobility problems, needs and goals</li> </ul>	NP
Conduct RPT Visit 1 within 1 week of patient's discharge, including: <ul style="list-style-type: none"> <li>• Assessment and prescription of mobility plan* incorporating findings of in-hospital assessment</li> <li>• Supervised practice of exercises comprising mobility plan</li> <li>• Provision of sheet detailing mobility plan, and activity diary if appropriate</li> </ul>	RPT
Conduct NP Visit 2 within 1 week of patient discharge, including: <ul style="list-style-type: none"> <li>• Development of care plan (FP™ tools) with patient and carer</li> </ul>	NP
Communication between NP and RPT re initial goals, incorporating findings of both initial assessments	NP ± RPT
<b>Intervention Weeks 2-4<sup>#</sup></b>	
Conduct weekly (or as required) NP home visits/phone contacts/GP liaison to <ul style="list-style-type: none"> <li>• Facilitate care planning</li> <li>• Coordinate all health services involved in care plan, including RPT</li> <li>• Facilitate additional service referrals in conjunction with GP/Practice nurse</li> <li>• Provide ongoing support with individual goal attainment</li> <li>• Support independence and behaviour change through education and risk factor management, symptom monitoring and problem solving.</li> <li>• Facilitate direct patient care in the event of a patient exacerbation during this time by supporting the patient with self-management, linking the patient initially with their GP and if not responding to treatment, negotiate shared care with RAH INSCOPE Rapid Respiratory Response team.</li> </ul>	NP
Conduct weekly (or as required) RPT visits to supervise practice of mobility plan, progress mobility plan <ul style="list-style-type: none"> <li>• Facilitate sustainability of mobility plan by patient, carer, support network and primary care services by 4-6 weeks</li> </ul>	RPT
<b>Intervention Weeks 5-8<sup>#</sup></b>	
<ul style="list-style-type: none"> <li>• Book appointment with the patient's GP/Practice nurse for development of new <i>or</i> review of existing GPMP/TCA</li> <li>• Meeting with GP/practice nurse to establish GPMP/TCA if required</li> <li>• Provide recommendations from FP™ tools to inform establishment of <i>or</i> review of GPMP/TCA</li> </ul>	NP ± RPT
<b>Transition completed</b>	
<ul style="list-style-type: none"> <li>• Patient goals and care plan/recommendations integrated into GPMP or TCA ensuring sustainability</li> <li>• Referrals actioned</li> <li>• Patient has a copy of their care plan</li> <li>• Patient is demonstrating progress towards achieving their goals</li> <li>• Activity monitors collected after 4 week assessment completed</li> </ul>	

\*refer to detail of mobility plan

<sup>#</sup> if required, NP ± RPT may continue in these roles until Week 8



## Care coordination

A key recommendation of a recently completed NHMRC funded study in Adelaide was the implementation of the role of a COPD care coordinator to address the unmet needs of people with advanced COPD.<sup>25</sup> The COPD care coordinator was intended to work across health care sectors, having the knowledge and capacity to give appropriate advice and co-ordinate a response either in the community or by accessing hospital services. Care coordination formed part of the scope of practice of a specialist respiratory NP, following the framework for care delivery recommended by Burgess et al.<sup>16</sup> The care coordination component of this study intervention provided an opportunity to pilot this role.

The main foci of NP care coordination were goal setting and care planning following initial needs assessment; building a partnership with the patient and carer to support independence and problem solving; providing clinical expertise to intervene with more specific assistance when needed and to ensure effective communication with all members of the health care team regarding the patient's treatment and care plan.

## Early rehabilitation

Exercise prescription for the early rehabilitation component of the intervention was based on pulmonary rehabilitation programs implemented during a hospital admission for COPD<sup>23</sup> and shortly after an exacerbation.<sup>8</sup>

The mobility plan had 4 components (walking program, lower limb strengthening, upper limb strengthening, and breaking up sedentary time), which were individualised, based on patients' goals and ongoing assessment by the physiotherapist (incorporating findings of in-hospital assessment). Following an initial assessment of each patient, a visual plan was generated that incorporated all four elements at a level suited to the individual. If the patient was amenable to it, an exercise diary was used for them to record their daily activity. Pedometers were also provided to patients for whom this was seen to be a potentially-useful method of promoting increased activity levels. Appendix 1 outlines the components of the mobility plan.

## Data collection and project evaluation outline

Evaluation measures were put into place to test each hypothesis. Specific outcome measures and goals/criteria are discussed in relation to each hypothesis.

Hypothesis 1: Implementation of the pilot intervention is feasible, satisfactory to patients and carers and can be delivered with fidelity.

Outcome	Outcome measure	Key Criteria
<b>Feasibility</b>		
Recruitment rate	Number of patients recruited per month	Recruit 18 patients in 7 months
Retention rate	Number of patients completing the intervention.	Complete intervention in ≥80% of all recruited patients
Resource capability	Workload of intervention staff: hours/patient/week	Workload within 1FTE
<b>Satisfaction</b>		
Participant satisfaction Carer satisfaction	Post-intervention interview conducted by independent consumer advocate	80% of participants satisfied with intervention

Fidelity of intervention		
Care coordination component delivered as planned	Execution of planned elements of care coordination as outlined in Hypotheses 2 and 3	As outlined in Hypotheses 2 and 3
Early rehabilitation component delivered as planned	Occasions of early rehabilitation at home service data collected	Services conducted as planned in ≥80% of all patients
Participation in planned home exercise/activity	Participant diary	80% of all planned home exercise/activity completed

**Hypothesis 2:** Care coordination plus early rehabilitation will result in

- documentation of agreed patient goals and
- demonstrated progress toward them

assessed by the four major FP™ care planning tools: Partners in Health / Cue and Response / Problems and Goals assessment and Care Plan<sup>22</sup> in at least 85% of cases.

Outcome	Outcome measure	Key Criteria
Documentation of agreed patient goals	FP™ Problems and Goals Assessment FP™ Cue and Response Interview FP™ Care Plan	Documented in ≥ 85% of participants
Demonstrated progress toward agreed patient goals	FP™ Partners in Health Questionnaire FP™ Cue and Response Interview  Community Care Coordination: service facilitation documented	Improvement (at least 0.5 standard deviation[SD]) in scores at intervention finish compared with start.  Documented in ≥ 85% of participants
Disease Specific Quality of Life	Chronic Respiratory Questionnaire – Self-Administered Standardized Format <sup>26</sup> (CRQ-SAS)	Clinically significant improvement at intervention finish compared with start.

**Hypothesis 3:** Care coordination plus early rehabilitation will involve collaboration with the patient's GP/practice nurse with generation of a Team Care Arrangement in at least 85% of cases.

Outcome	Outcome measure	Key Criteria
Collaboration with patients GP/practice nurse	Generation of Team Care Arrangement (TCA)  Survey of GP/Practice nurse regarding their experience of pilot intervention	TCA generated in 85% of patients  Survey completed in 80% of GP/practice nurses involved

**Hypothesis 4:** People with COPD who participate in care coordination plus early rehabilitation will have lower hospital readmission rates at 28 days and greater physical activity levels at 28 days after discharge than a control group of similar patients.

Outcome	Outcome measure	Key Criteria
Hospital readmission	Hospital readmission/ED presentation within 28 days of discharge	Significant difference (p<.05) between intervention and control group.
Physical activity level	Objective monitoring (ActivPAL <sup>#</sup> inclinometer) including changes between hospital admission and 4 weeks after discharge home in: Number of steps/day Sitting/standing/walking time/day Bouts of uninterrupted sitting >30 mins	

<sup>#</sup>The ActivPAL inclinometer was waterproofed and attached to the participant's thigh with hypoallergenic tape. The device continuously records position and movement thus downloaded data can determine time spent being sedentary (sitting/lying), standing and stepping. The ActivPAL demonstrates accurate measures of physical activity in people with COPD, who walk at slow speeds.<sup>27</sup>

Occasions of data collection carried out with participants in control and intervention groups are summarised in Table 2.

Table 2 Summary of study data collection

Measure	Conducted					In which group		Purpose
	In hospital after recruitment	At home at beginning of intervention	4 weeks after discharge	At home at end of intervention	Administratively post-intervention	control	intervention	
<b>Activity monitor data (ActivPAL)</b>	Monitors worn day 2 to day of discharge		Monitor worn 7 days			✓	✓	Hypothesis 4
<b>CCQ</b>	Day of discharge		✓			✓	✓	To compare baseline symptoms between groups
<b>D12</b>	Day of discharge		✓			✓	✓	To compare baseline symptoms between groups
<b>CRQ-SAS</b>	Day of discharge		✓				✓	Hypothesis 2
<b>2MWT</b>	Day of discharge		✓			✓	Day of discharge only	Hypothesis 1
<b>FP™ PIH scale</b>		✓		✓			✓	Hypothesis 2
<b>FP™ P&amp;G assessment</b>		✓ + weekly scoring		✓			✓	Hypothesis 2
<b>Patient/carer satisfaction (interview)<sup>#</sup></b>					✓		✓	Hypothesis 1
<b>Readmissions for respiratory/ other reasons</b>					For 28 days post-discharge	✓	✓	Hypothesis 4
<b>GPMP/TCA completion by usual GP</b>					✓		✓	Hypothesis 3
<b>GP experience of program (interview)<sup>*</sup></b>					✓		✓	Hypothesis 3

**CCQ** = Clinical COPD Questionnaire; **D12** = Dyspnea 12 Questionnaire; **CRQ-SAS** = Chronic Respiratory Questionnaire – Self-Administered Standardized Format; **2MWT** = 2 minute walk test; **FP™ PIH scale** = FP™ Partners in Health scale;

**FP™ P&G assessment** = FP™ Problems and Goals assessment

<sup>#</sup> consumer advocate and iCAHE research associate D Kay conducted these semi-structured interviews, which were audio-recorded and transcribed for analysis of themes.

<sup>\*</sup> study associate investigator J Teakle (Central Adelaide Hills Medicare Local) conducted these brief structured interviews by telephone or in person, and documented responses verbatim.

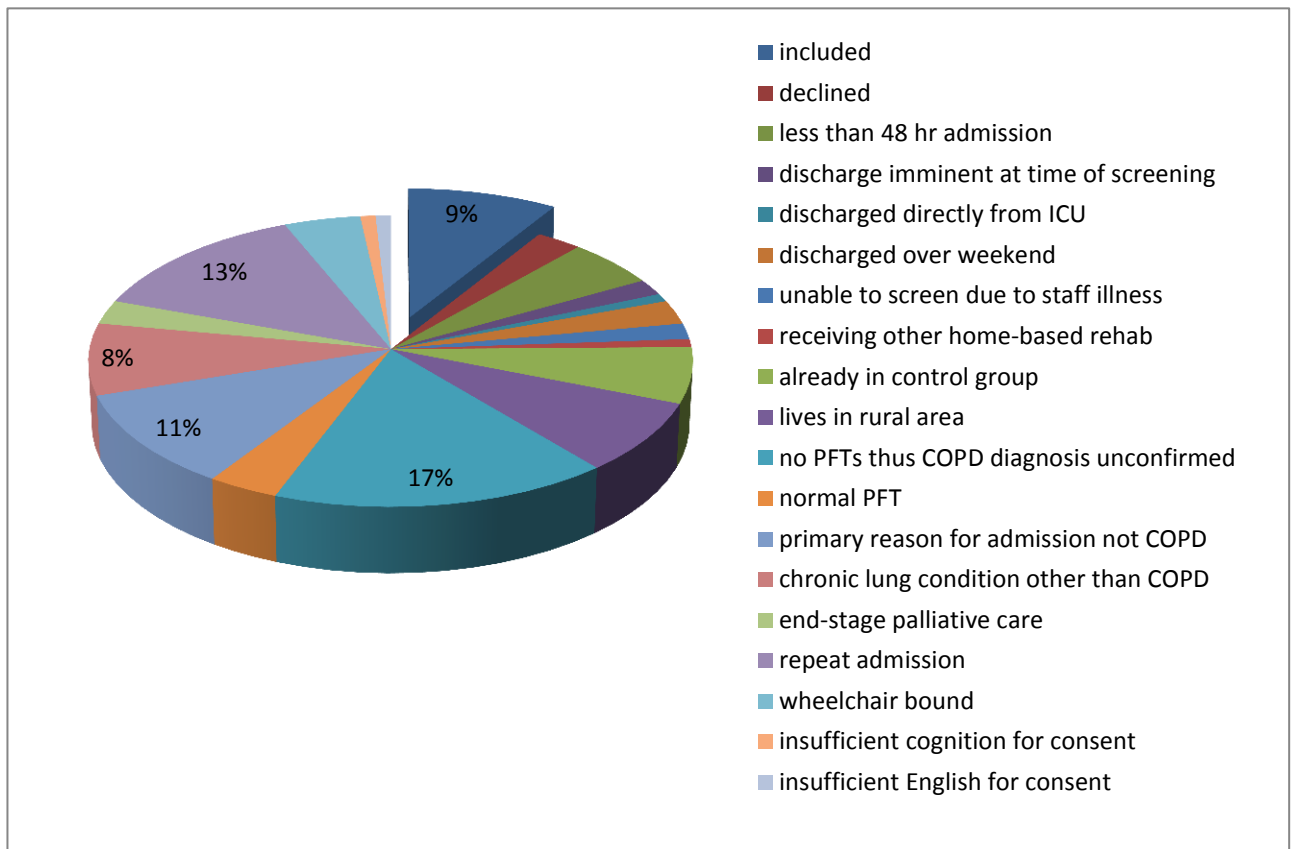
# Results

## Recruitment to the study

During the control group recruitment period of March to December 2013, 202 patients with admission coding of COPD and admission duration of at least 48 hours were screened for eligibility. Most were excluded from this study, primarily because no PFTs had been conducted to confirm COPD diagnosis (n=48, 24%) COPD was not the primary reason for their admission (n=27, 13%) or they had a lung condition other than COPD (n=21, 10%). A total of 19 participants were recruited and included in the study (9% of those screened).

A similar outcome was associated with the intervention recruitment period between January and early May 2014 (recruitment ceased on 9<sup>th</sup> May 2014) (Figure 3). 113 patients with admission coding of COPD and hospital admission duration of at least 48 hours were screened. However, the majority were excluded primarily as no PFTs had been conducted thus COPD diagnosis was unable to be confirmed (17%); repeat admission during the study period (13%) or COPD not primary reason for hospital admission (11%). A total of 10 participants were eligible and included in the study (9% of those screened).

Figure 3 Outcome of recruitment (intervention group) as proportion of patients screened (with admission coding of COPD and admission duration of at least 48 hours).



## Characteristics of study participants

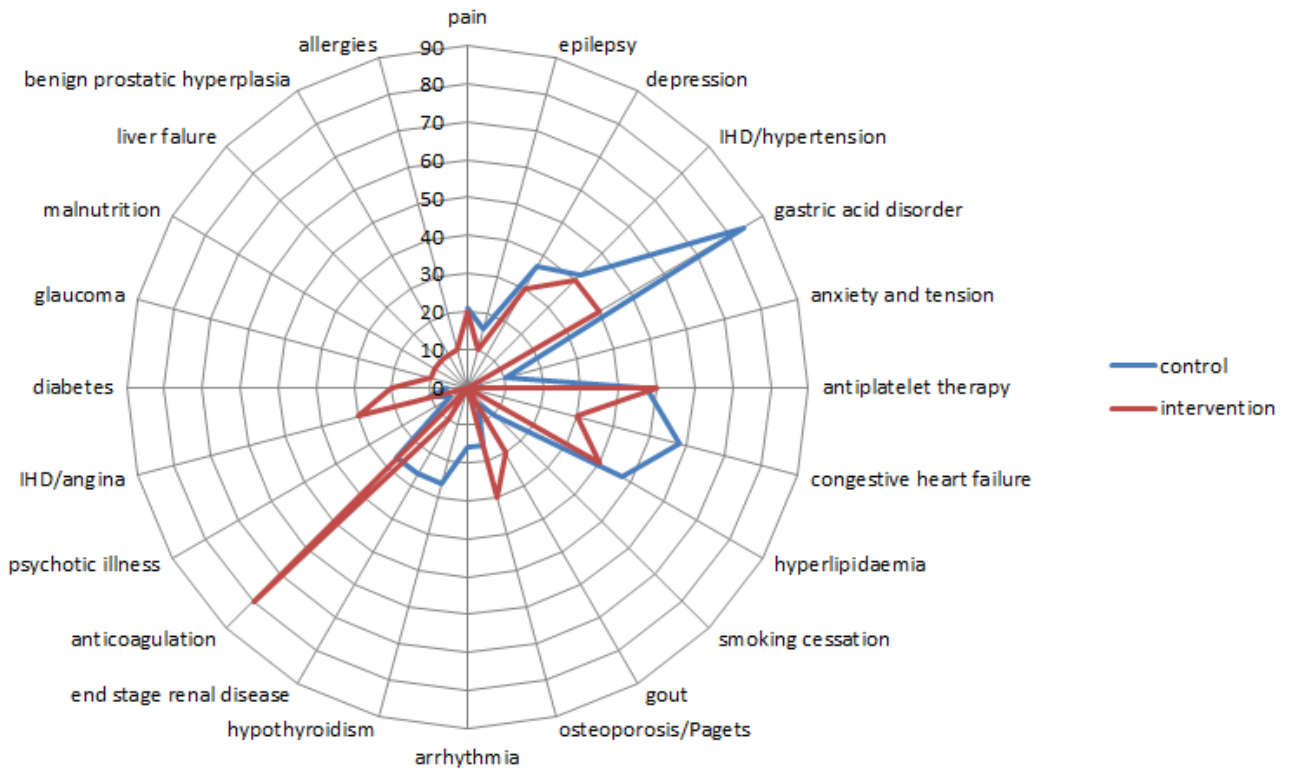
Included participants were on average elderly and had moderate-severe COPD according to the GOLD classifications (GOLD 2 or 3).<sup>28</sup> Comorbidity was high, with mean RxRisk-V score (co-morbidity score based on groups of prescribed medications)<sup>29</sup> indicating 5-6 disease categories in addition to COPD. Figure 4 illustrates the RxRisk-V categories identified in control and intervention groups. No statistically significant differences were found between groups for any variables, although a trend was noted toward older age, worse lung function and greater initial hospital length of stay in the intervention group.

Table 3 Characteristics of study participants

	control group (n=19)	intervention group (n=10)
age (years)	75(9)	79(9)
gender	12 females/7 males	4 females/6 males
length of stay	median=5 (IQR 4, 16)	median = 7 (IQR 4,8)
<b>living arrangements</b>		
Home alone	9 (47%)	3 (16%)
Home with partner	6	6
Home with other family member	3	1
Residential care	1	0
<b>most recent* previous PFTs</b>		
FEV <sub>1</sub> % pred	53(27)	44(10)
FEV <sub>1</sub> /FVC	46(15)	39(7)
GOLD 1	4 (21.1%)	0 (0%)
GOLD 2	6 (31.6%)	4 (40%)
GOLD 3	3 (15.7%)	5 (50%)
GOLD 4	6 (31.6%)	1 (10%)
home oxygen users	4	1
<b>smoking status</b>		
current smoker	5	1
ex smoker	13	9
never smoked	1	0
smoking history (pack years)	31 (18)	29(16)
Rx risk comorbidity score	5.6 (2.5)	6 (3.1)
<b>destination on discharge</b>		
returned to pre-admission destination	16	8
residential transitional care package	2	
changed to HLOC residential care	1	
transfer to secondary hospital		1
transfer to inpatient sub-acute rehabilitation		1

\*median time since most recent PFTs control group =7 months (IQR 4 mths, 2.3 years); intervention group=2.3 years (IQR 1, 3.7 years). Mean(SD) reported unless otherwise indicated.

Figure 4 Frequency of comorbidity (by RxRisk-V category, as percentage of each group) for control and intervention groups



### Results for Hypothesis 1: Intervention feasibility, fidelity and patient satisfaction

#### Feasibility

To explore study feasibility we examined rates of participant **recruitment** and **retention** and the **resource capability** of intervention staff.

**Recruitment:** At this tertiary facility we screened 315 potential patients who met our inclusion criteria in a total of 14 months, and recruited 29. This equated to screening 22 patients per month, and recruiting 2 patients per month. This was slightly under our target rate of 2.5 patients per month. However, recruitment rate was consistent between control and intervention groups in 2013/2014 respectively.

**Retention:** No participants in either control or intervention groups withdrew from the study, thus retention of people recruited to the intervention was 100%.

## Resource capability:

Both the NP (1.0 FTE) and RPT (0.5 FTE with flexibility) managed the clinical and administrative workload of 10 participants within their respective employment contracts. Time spent completing the FP™ tools alone for the NP comprised 2.6 hours per participant in administrative time. Calculations using the data from the pilot study have been made to predict the capacity of the NP role over a twelve month period. Taking into account individual professional development, research and annual leave, the NP can coordinate care for an additional sixty five eligible patients (a predicted total patient intake of 75 within a 12 month period). Considering travel, administration time and other role aspects, a maximum of 4 clinical visits with patients per day is feasible. The NP would need access to a Government vehicle for at least 3 days per week.

Table 4 Six month workload for Nurse Practitioner and Physiotherapist

Clinician workload (for 10 participants) <sup>#</sup>			
	NP	RPT	Total
Total no. visits	68	75	143
Average visits/participant	6.8	7.5	14.3
Total clinical hours	107.66	77.5	185.16
Average clinical hours/participant	10.76	7.75	18.51
Total attendance hours of ambulatory appointments with participant/carer	7.5	N/A	7.5
Average hours/participant attending ambulatory appointments	0.75	N/A	0.75
Total attendance hours of inpatient care co-ordination	8.75	N/A	8.75
Average hours/participant with inpatient care co-ordination	0.88	N/A	0.88
Total travel hours	33.75	64.75	98.50
Average travel hours/participant	3.37	6.48	9.85
Total administration time*	44.7	37.5	82.2
Average administration hours/participant	4.5	3.75	8.25

\* including phone calls (excluding calls between study clinicians), facsimile, correspondence emails (excluding between study clinicians), completion of FP™ tools, filing of documents in hospital participant case records. Administrative time does not include data management.

**#Assumptions:**

For both NP and RPT:

- Visits and clinical time do not include time for inpatient recruitment and baseline measurements

For NP:

- Clinical time does not include inpatient support visits during episodes of participant readmissions

For RPT:

- 30 mins (0.5 hours) of administration time per participant per visit (including writing up of notes, coordinating with RNP, preparing for following visit)
- Clinical and travel time totals not including visit to home to pick up activity monitors and accompanying diary following post-intervention wear period

*Fidelity of the intervention delivery***Care coordination**

All elements of care coordination were delivered as initially intended. Home visits were conducted weekly with 6.8 visits on average per participant. 100% of participants engaged in the care planning process with a copy provided to the participants' usual GP. The largest number of referrals were to pulmonary rehabilitation (n=9), for transport to assist participants to attend the pulmonary rehabilitation program (n=5), for GP/Locum intervention (n=5) and rapid respiratory assessment with INSCOPE (n=3). Other referral types included Domiciliary Care Community services (n=2), Occupational Therapy (n=2), Council (n=1), QUIT SA (n=1), Meals on Wheels (n=1), private respiratory and geriatrician physician (n=3) and hospital admission (n=1).

Screening for anxiety and depression is a part of comprehensive assessment of people with COPD. This was completed in all participants, demonstrating in 5 of the 10 participants that anxiety impacted significantly on self-management.

Incorporated into disease education and care planning were discussions about end-of-life care. This highlighted that two participants had completed Advance Directives and two participants had completed other legal documents such as Medical Power of Attorney or Enduring Power of Guardianship. On all occasions, these legal documents were not registered with the tertiary hospital participants were attending. The NP followed the hospital procedure for placing copies of these documents in the participants hospital file and logged them on the patient information system as an 'alert' to be recognised with future hospital attendance. Discussions about Advance Directives were completed in five participants who were not previously aware of the process. Three participants were assessed not to have capacity to complete an Advance Directive.

At commencement of this study, Country Health SA Local Health Network were trialling a hand held, paper wallet titled 'About My Health' (Appendix 2), which was distributed to people with a chronic disease through the 'Better Care in the Community Program'. The wallet was designed for adults with chronic and/or complex health conditions to keep a range of information about their health and assist to better manage their health, through regular self-monitoring and active communication with health providers involved in their care. Subsequent to early communication by the NP with Country Health representatives, permission was granted to offer this tool to study participants. All participants were offered the wallet to trial and eight felt it would be valuable and agreed to use it. A formal assessment of this tool during this study was not conducted, however participants found it very helpful to store health related information such as medication lists, medication prescriptions, appointment cards and documents or handouts generated from the study interventions. Participants consented to be involved in the Country Health SA evaluation of this tool.

**Early rehabilitation**

Through engagement with the mobility plan, and weekly (or more) appointments with the physiotherapist, all patients completed participation in the early rehabilitation component of the program. This exceeded the hypothesised 80% completion rate. Two participants were seen twice rather than once weekly, for a period of 2-3 weeks towards the end of the program; for one participant this was to provide additional airway clearance management, for the other it was to help



improve likelihood of long-term adherence to the activity plan. Seven of the 10 participants were seen for more than the originally estimated four week intervention period, due to acute illness creating a need for rescheduling of visits, or a perceived need for increased occasions of service to effectively deliver the program. As such, the average number of visits per participant was 7.5.

Activity diaries were utilised by 7 of the 10 participants (70%), with the nature of their use tailored to the individual. For some this was recording completion of their prescribed activity plan, for others it was making note of any/all forms of physical activity undertaken on a day. The diary was used in conjunction with pedometers for 4/10 participants, recording their daily step count and aiming to increase this incrementally over their time in the program. For one participant, who found the diary a particularly useful way of maintaining motivation and adherence to the prescribed plan, a long-term diary was provided, allowing her to continue to record her daily activity and exercises for a further six months. Appendices 3 and 4 provide examples of the mobility plans and activity diaries utilised by patients in the study.

In addition to the mobility plan, the RPT also provided symptom management as participants required it. This included airway clearance techniques (both hands-on and teaching self-management), education and practice of techniques around pacing of activities, and training around techniques to manage shortness of breath (such as breathing exercises and positioning). These elements were not initially considered as part of the physiotherapist role within the context of this study, but were revealed to be intrinsically important in optimising the delivery of the program.

Figures 5 and 6 illustrate the scope of the NP and RPT roles in delivering the program. Some aspects of the service delivered had not been initially considered, but were found to be inherently important in the population in whom the program was being piloted.

### **Handover and communication**

The communication of participant and carer information was paramount in the handover process. Transition from hospital to primary care is just one aspect of handover when providing care co-ordination; handover was much broader and occurred at multiple points in the participant and carer journey. It included ongoing communication between the NP and RPT, between the study clinicians and participants and carers, between the NP and private specialists and at completion of the intervention with the GP and tertiary hospital.

Following completion of the FP™ Problems and Goals tool and initial RPT assessment, early communication between the NP and RPT about participant's goal was important to confirm that they were realistic, time based, measurable with the 0 – 8 scale and action based involving a degree of challenge. The FP™ tools served as a handover platform for both clinicians to interact with the documentation, and preface the participant's needs and goals. The first draft of a care plan generated by the NP was forwarded to RPT for addition of physiotherapy interventions and both clinicians provided input into services to be coordinated and referrals to be made. Handover between the NP and RPT continued with verbal communication with all occasions of exacerbation and at the end of each working week via email to inform of scheduled home visits and logistical issues.

The care plan was a living document for the duration of participants' involvement in the program. At completion of their home-based program, participants were provided a copy of their care plan with

discussion about various components including those completed, their role in continuing actions yet to be completed, referrals currently in place and who all members of health care team will be. The participant signed the care plan, reflecting accuracy of the content and handover to the participant.

Where participants felt more confident with the NP being present for practice care planning, the NP organised with the practice a double appointment slot and notified the practice that they were attending for development of a GPMP/TCA and to complete the handover process. The NP being present with practice care planning occurred in three participants. In all participants a summary letter and copy of care plan was mailed to the GP and in 90% of participants provided with referral for PR.

Informing the tertiary hospital of process and participant outcomes closed the handover loop. Registering existing or new legal documents occurred by placing copies of these documents in the participants hospital file and logging them on the patient information system, Australian Patient Management System, as an 'alert' to be recognised with future hospital attendance. Copies of private correspondence, pathology and investigations i.e. echocardiogram or lung function were filed in participant case files to prevent future duplication with investigation and where participants were readmitted, documentation in case-notes of involvement in program, social circumstances, functional status, self-management capability, community services and current referrals. A copy of the study summary letter placed in the case record represented final handover of information back to the hospital.

Figure 5 Scope of practice of Nurse Practitioner

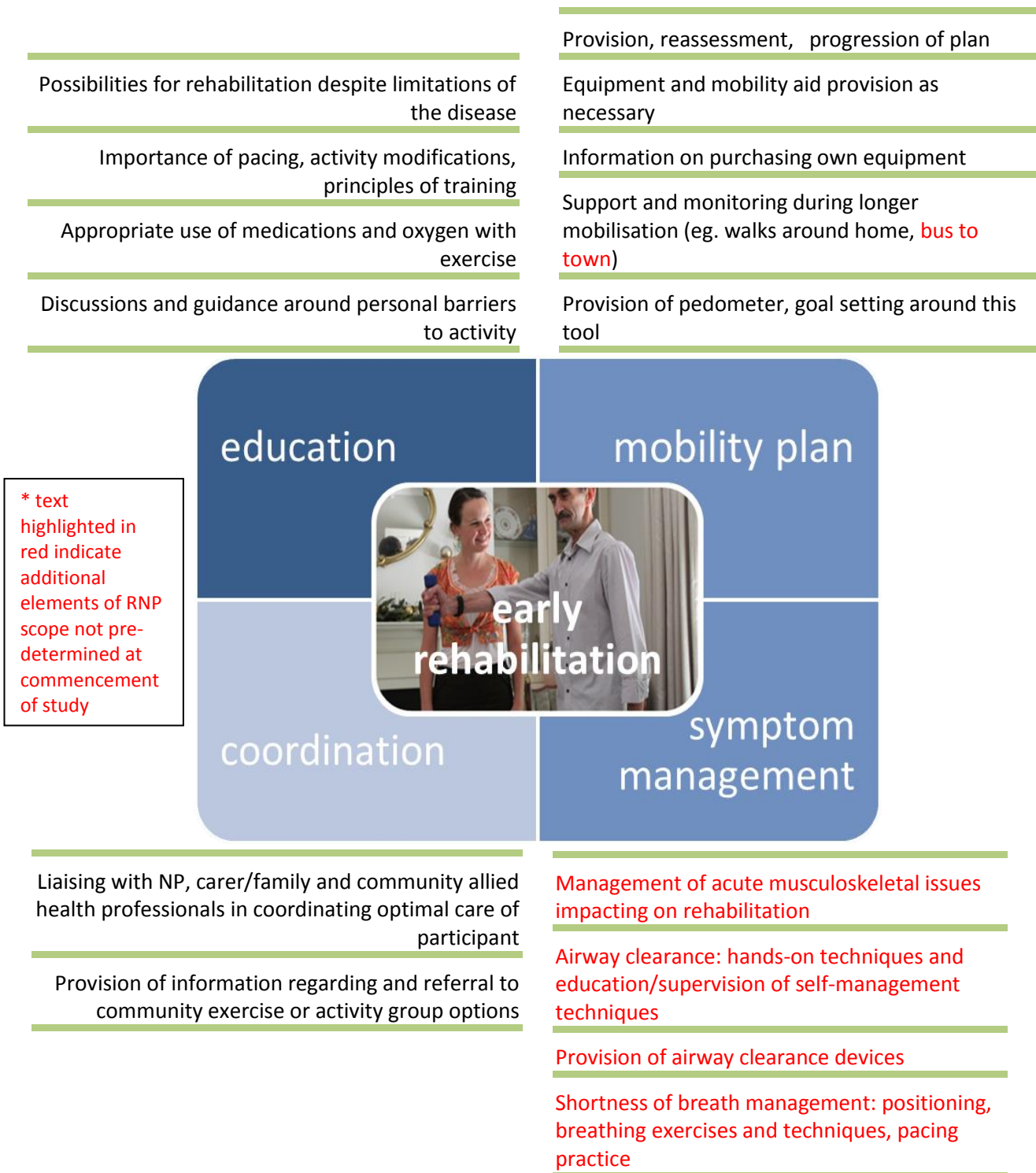
Problems and Goals assessment	
<b>Screen impact of COPD, and anxiety and depression *</b>	Ensure important aspects of COPD management have been addressed in care planning including, but not limited to; understanding of pathophysiology, risk factors for progression of disease, medication and exacerbation management, nutrition, symptom management, physical and surgical approaches to care
Completion of individualised care plan identifying a team approach outlining the responsibilities of the team members including the participant	
Ongoing problem solving and review of goals	Reinforce information over time
<b>Advance care planning including discussions about support networks *</b>	<b>Provision of self-management tool 'About my Health Wallet' *</b>
Empower participant/carer re: communication strategies with the health care team	

\* text highlighted in red indicate additional elements of RNP scope not pre-determined at commencement of study



<b>Lodgement of advance directives and other relevant legal documents with hospital systems *</b>	Ongoing verbal communication between all members of the health care team: RPT, GP, INSCOPE team, private specialists, community services and hospital
Provision of written summary +/- copy of care plan (where relevant) +/- <b>external test results/discharge summaries to prevent duplication*</b> to the following: GP, private specialists, hospital, pulmonary rehabilitation team	Advocate and negotiate for the participant/carer
Attendance for primary care handover with GP as required	<b>Consultation with health professionals when participant readmitted or attending ambulatory appointments *</b>
	<b>Continuity of care by attending ambulatory appointments or inpatient readmission with participants *</b>
	Referral to appropriate services, multidisciplinary teams and access to INSCOPE
	<b>Prioritise appointments and cancel where duplication exists *</b>

Figure 6 Scope of practice of Research Assistant Physiotherapist



### *Participant and carer satisfaction*

In order to determine patient and carer experience of the intervention, semi-structured interviews were conducted by an independent, experienced consumer advocate at program completion. Carers were included in the interview when this was the preference of the patient. The interviewer had not been involved in any other aspects of the study intervention or data collection. The interview guide (Appendix 5) was designed to determine aspects of the program that were most helpful, and aspects that could be improved. Additional questions were designed to determine the benefit or otherwise of key aspects of the intervention, specifically:

1. articulation of and progress towards personal goals;
2. the process of care coordination, getting the care needed in the transition from hospital to home; the Nurse Practitioner's role in this
3. a better coordinated team care arrangement; this is a plan made with the patient's GP about ongoing care;
4. early rehabilitation/exercise by weekly home visit by physiotherapist.

Interviews were conducted in the participants' home, audiotaped and transcribed. Transcripts were analysed (content analysis<sup>30</sup>) to determine key themes from participant responses in relation to the interview questions.

The major themes and sub-themes arising from the interviews are displayed in Figure 7. Appendix 6 provides examples from transcript data that illustrate and support all themes and subthemes. Examples of data contradictory to the predominant themes or sub-themes are also included where present. Box 1 highlights a few examples of the data.

#### Box 1 Examples of participant interview responses

##### **POSITIVE PROCESS**

"I feel really, really at ease with what's happened and it's really helped me along step by step, it's really helped me along. It's really great." (id01)

"So much easier and it's sort of one on one, whereas in the hospital there's always distractions...simply because there's no interruptions and you can really sort it out with one another and work on it." (carer id02)

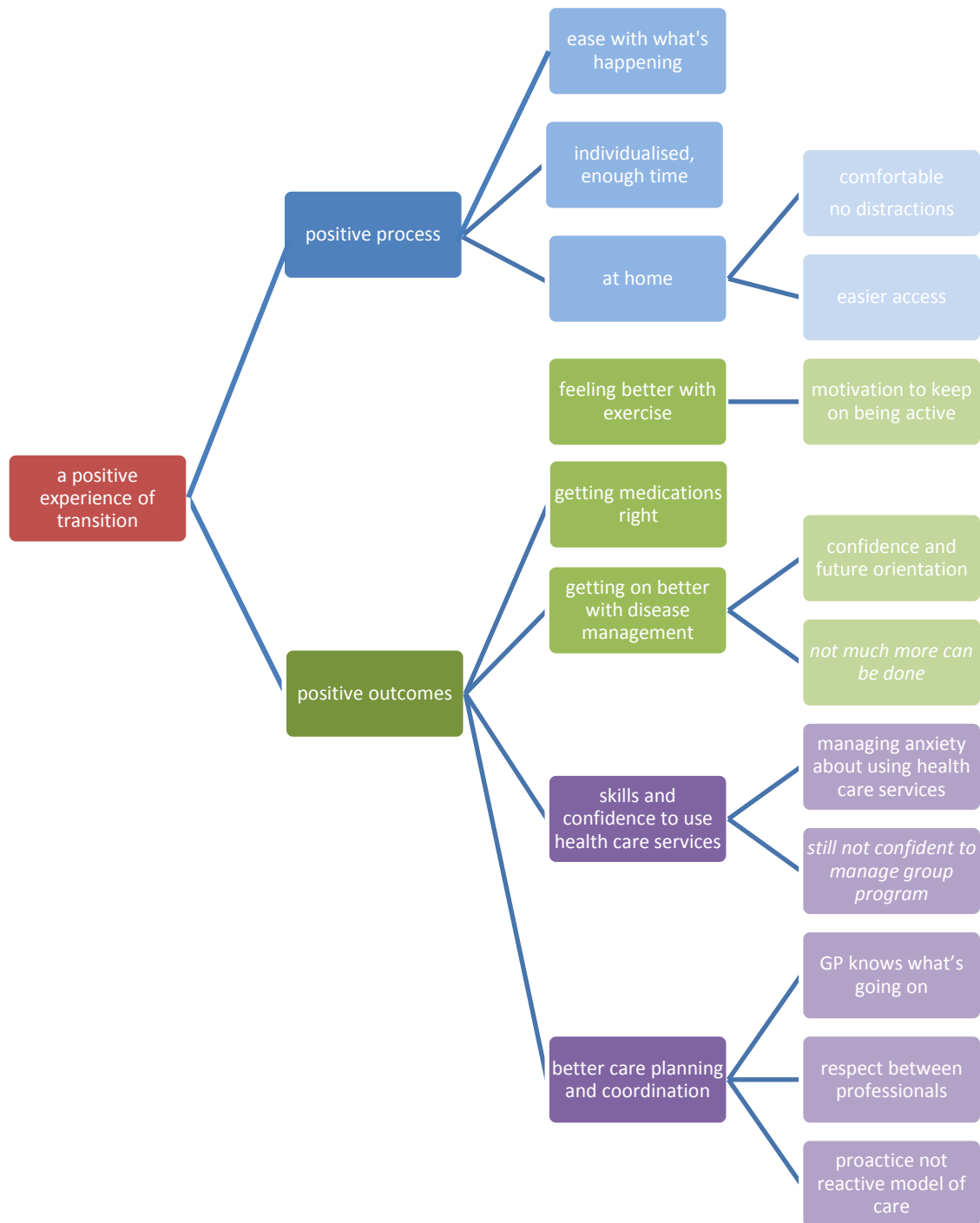
##### **POSITIVE OUTCOMES**

"Because when I first came out of hospital I couldn't sort of go very far or do anything and it just gets you down when you can't do everything. Because we're used to going out to walk but we haven't been out for quite a while but we're back now doing what we used to do." (id07)

"She went through it with me and what each medication did and what order you should take it in, which I thought I had but it was obviously wrong, but what she's told me has worked out to be beneficial to me." (id05)

"In all, we've got a lot more confidence knowing what to do, but the other is to actually asking, which we needed to have. We needed to have confidence that we could do it and it was through Mary that we did that." (carer id05)

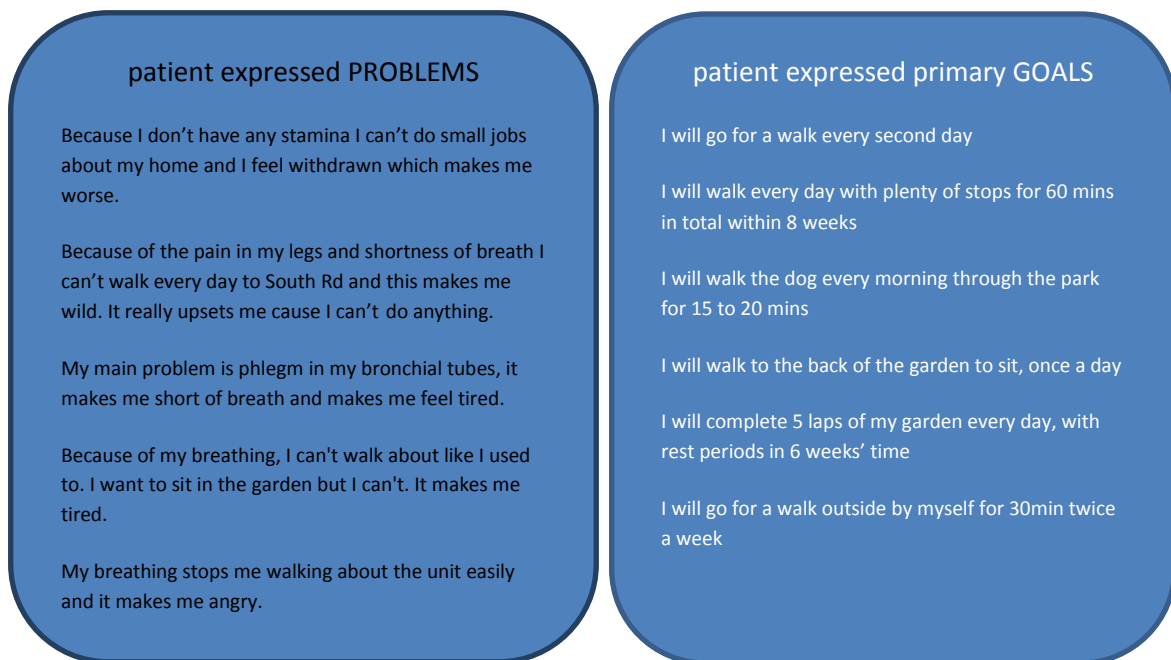
Figure 7 Major themes and sub-themes arising from participant/carer interviews



## Results for Hypothesis 2: Effects of intervention on documentation and progress toward patient goals

**Documentation of patient goals:** in all intervention cases the FP™ Care Planning process was completed. A strength of the patient-centred FP™ approach was facilitating the expression of each participant’s main problem and the setting of a goal (or goals) **in their own words** (Figure 8).

Figure 8 Examples of expressed problems and goals of the participants



*Phrases that people used to express their problems included:* no stamina, can’t walk, tired, short of breath, pain in legs, phlegm, stay home alone, stops my physical exercise.

*Phrases that people used to describe how the problem made them feel included:* withdrawn, angry, wild, upset, awful, flat, bored, lonely, can’t do anything, don’t feel like doing anything.

**Progress toward patient goals:** Before and after the intervention, participants rated the severity of their self-expressed problem, and their progress toward achieving their self-expressed goal on a scale of 0-8 using the FP Problem and Goals monitoring record (Figure 9).

Figure 9 FP™ Problem and Goals monitoring record scales

<p><b>How much of a problem this is for me:</b></p> <p><b>0 1 2 3 4 5 6 7 8</b>                  Not at all    Very little    somewhat    a fair bit    a lot</p>	<p><b>My progress towards achieving this goal:</b></p> <p><b>0 1 2 3 4 5 6 7 8</b>                  complete success    75%    50%    25%    no success</p>
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Participants in the intervention group reported significant reductions in the severity of their self-expressed problem, and significant progress toward achieving their self-expressed goal over the 4

week duration of the intervention (Table 5, n=10). Based on the scales, participants' progress toward achieving their goal was around 80% on average after the intervention (compared with around 24% success pre-intervention).

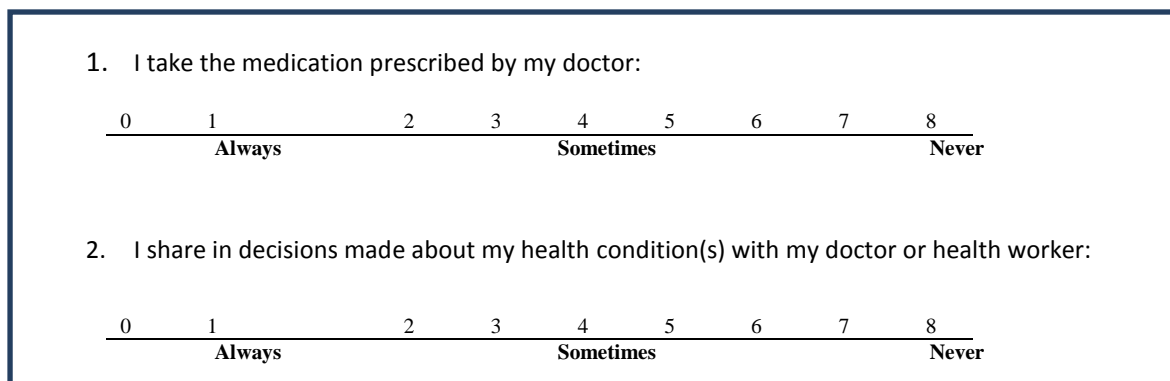
Table 5 Changes in problem severity and progress toward goals

Problems and Goals monitoring progress	pre-intervention	post-intervention	difference
How much of a problem is this for me?	6.4 (1.0)	3.5 (2.3)	2.9 (95% CI .9, 4.9) p=.002
My progress toward achieving this goal	6.6 (1.2)	1.8(1.9)	4.8 (95% CI 3.2, 6.4) p<.001

**FP™ Partners in Health Scale**

The FP™ Partners in Health Scale is a measure of patient-perceived chronic disease self-management (CDSM), and was completed by participants in the intervention group pre and post intervention. In this scale a lower score reflects a greater degree of patient-perceived CDSM.

Figure 10 Example questions from the Partners in Health Scale



As Question 7 in the PIH scale was not a central aspect of CDSM in COPD (referred to daily recording of symptoms) it was excluded from the scoring, resulting in a maximum possible score of 104, minimum score = 0.

After the intervention participants (n=10) reflected a greater degree of chronic disease self-management (13.3(8.3) vs 30.3(11.9), mean difference =17, 95% CI 8, 26, p=.002).

*Effects of intervention on symptoms and quality of life*

**Symptom questionnaires:** Two questionnaires were used at discharge from hospital, and repeated at 4 weeks after discharge, in order to compare the symptoms reported at these times by the control and intervention groups. No significant between group differences were detected, although a trend for severity of affective dyspnoea to worsen after discharge in the control group, and improve at 4 weeks in the intervention group was noted (as indicated by the Dyspnoea 12<sup>31</sup> score, Table 6).



Table 6 Symptom questionnaire scores intervention and control groups

questionnaire	At hospital discharge		4 weeks after discharge	
	control (n=13)	intervention (n=10)	control (n=13)	intervention (n=10)
Clinical COPD Questionnaire (CCQ)	2.4 (0.7)	2.3(1.1)	median* 2.4(IQR 1.4)	median* 2.0(IQR 2)
Dyspnoea 12 (D12)	12.9(7.1)	14.1(8.0)	16.5(10.2)	12.5(7.6)

\*Median reported for 4 week CCQ due to outliers in data: 1-2 participants extremely symptomatic.

### Health Related Quality of Life: Chronic Respiratory Questionnaire (CRQ-SAS)

This questionnaire was collected in the intervention group only (n=10), at the beginning and end of the intervention. The CRQ has four subscales, and questionnaire authors recommend that these should be reported separately, reflecting the domains of dyspnoea, fatigue, emotional function and mastery.

No significant differences were detected (Table 7). However, improvements in fatigue, emotional function and mastery subscales were greater on average than the minimally important clinical difference in CRQ subscales (reported as .5 points).

Table 7 Chronic Respiratory Questionnaire scores pre and post intervention

CRQ-SAS subscale	pre-intervention	post-intervention	mean difference
CRQ- dyspnoea	4.4(1.5)	4.7(1.1)	.4 (1.7)
CRQ-fatigue	3.8(1.3)	4.0(1.1)	.6 (2.2)
CRQ-emotional function	4.1(1.2)	4.6(1.2)	.5(1.7)
CRQ-mastery	4.0(1.6)	4.7(1.4)	.8(2.5)

Box 2 illustrates a participant's experience of identification and progress toward patient goals.

### Box 2 Participant story: Mr W

Mr W is 85 years of age, lives on his own, and receives cleaning support from domiciliary care. He has severe COPD, which limits his physical activity and social interaction. He also has six other significant health conditions, three of which require ongoing active management (type 2 diabetes, peripheral vascular disease and ischemic heart disease). A keen bowler, Mr W had stopped attending his local club due to his shortness of breath and leg fatigue. He wished to return to a daily routine of walking the block around his house, and return to playing bowls 1-2 times per week.

On initial assessment at home, Mr W could only walk 200m on his street, with frequent rests.

Main problem: ***"Because of the pain in my legs and shortness of breath I can't walk every day to [the main] road and this makes me wild. It really upsets me because I can't do anything."***

Initial scoring of main problem: 8/8 (indicating maximum impact of problem)

Goal statement: ***"I will walk every day, with plenty of stops, for 60mins in total, within 8 weeks."***

Initial scoring of goal: 6/8 (indicating 25% progress towards achieving goal)

An individualised, home-based activity plan to address this goal was established for Mr W to complete each day at home. Over 6 weeks the intensity of this program was increased in line with Mr W's improving endurance. ***"I keep on doing it as long as I can...I'm not going to give it away because I feel that good."***

Mr W had trouble with removing secretions, which was identified by the physiotherapist. Following education and practice of exercises to help clear secretions with a PEP device, Mr W was able to manage this independently.

With the NP, Mr W focused on getting the most benefit from his inhaled medications and learnt, with the ongoing support of the NP, how to identify symptoms related to an exacerbation of his COPD, and the steps to manage this situation in conjunction with his GP. ***"And plus when Mary comes, I mean to do my puffers and like that, but I was doing it, but I wasn't doing it the right way. But now I do them the right way..."***

Within 3 weeks, Mr W's problem score reduced from 8 to 0 and he was at 75% with progress to achieving his goal with a score of 2. By week 6, Mr W could walk 800m and had the confidence to try a game of bowls. ***"But this year I'm going to play, the way I feel now I'll be an even better bowler."*** Mr W planned to continue his home program and attend pulmonary rehabilitation to maximise his physical function.

### Results for Hypothesis 3: Effects of intervention on collaboration with primary care

#### *GP Management Plan/Team Care Arrangement*

In the general practice setting, Medicare Benefits Schedule (MBS) items that may reflect care planning carried out by the GP or practice nurse include generation and review of a GPMP and/or TCA. One of the aims of our intervention was to collaborate with the patients' GP, and to create an opportunity for the patient-centred care plan generated at the time of transition (using the FP™ Care Planning Tool) to be integrated with the GP's ongoing care planning in a new or revised GPMP/TCA. Within the Australian health care system this would reflect documentation of continuity of care coordination.

At the time of enrolment into the study, 10% of participants (1/10) had a current and up-to-date GPMP and/or TCA in place.

At end intervention, **a GPMP/TCA had been generated or reviewed in all other participants** as a result of the NP collaboration with general practice as part of this study intervention (data available in 7 post-intervention GP interviews to date).

#### *GP experience of intervention*

Information on GP or practice nurse experience of the program was obtained using a brief structured interview (telephone or face-to-face) conducted by an associate investigator (JT). This investigator was also a Medicare Local senior project officer, but had not been involved with other aspects of study delivery or data collection. Interview questions (Appendix 7) examined GP awareness of their patients' involvement in the program; their thoughts about the program and specifically about the value of care coordination in transition; whether the program had resulted in generation or review of care planning items, namely GPMP and/or TCA; any other recommendations to the DOH about this program. Responses of the GPs (n=6) and practice nurses (n=1) are summarised in Table 8. One additional GP had retired from practice prior to completion of his patient in the study and was unable to be contacted for interview.

Table 8 Responses to interviews with general practice professionals regarding the intervention

<p><b>1. Were you aware that (patient name) had been involved with this study?</b>                  Yes in all cases; GP recalled receiving letter (n=6) and phone call (n=3) about the study prior to hospital discharge of the patient.</p>
<p><b>2. What are your thoughts about the program?</b>                  I think this is an excellent initiative. (Patient) has commented to the GP that "this is the best she has felt in ages"                  I feel it was a very valuable service, particularly as (patient) lived alone                  I think it is an excellent program                  (Patient) spoke very highly of his experience. He loved being visited at home. I think it is an excellent initiative                  It was a very comprehensive program. Although (patient) is still breathless the patient "is much improved"</p>

**3. Was it helpful having a health professional who knew the patient in hospital, and had spent time planning care with the patient in transition to provide information to your practice in order to help review or generate your care plan for that patient?**

Yes very helpful (in all cases n=7)  
 (Patient) loved it (reported specifically in 2 cases)  
 Yes very helpful. It was fantastic that the patient was followed up at home  
 Yes – It was very helpful that Mary met (patient) during his hospital admission and then followed him up at home  
 Yes it was excellent

**4. Was a GPMP/TCA generated or reviewed for this patient as a result of this intervention?**

Yes (n=6)  
 Scheduled for practice plan however not completed at time of interview (n=1)  
 There was a care plan generated as a result of the intervention  
 I received a copy of the care plan which was very comprehensive.  
 I thought the care plan generated from Mary was excellent  
 I received a copy of the care plan which was very thorough  
 I plan to review the care plan with (patient) as part of a GPMP review  
 It was very helpful to be aware of (patient's) follow up appointments – outpatient appointments (specialist, dietician, physio, nurse)  
 The care plan that was generated was very comprehensive; including care plan goals  
 Good for (patient's carer) to be involved in the care planning/goal setting process, and aware of the goals that were set  
 Follow up appointments arranged for PR (pulmonary rehabilitation) at AHCHS (Adelaide Hills Community Health Service).  
 There was a care plan generated as a result of the intervention, however unfortunately (patient) passed away between the time of finishing the study and follow-up with the GP (GP was on leave)  
 It would be helpful to include a place or comment in the care plan where the GP could include/identify/add their own specific goals or priority areas for the patient  
 The Practice Nurse has reviewed the care plan as a result of the intervention.  
 The GP thought the care plan generated from the study was very helpful.

**5. This trial was funded by the DoH and if we were to recommend this continue, would you recommend any changes to assist transition of patients back to primary care?**

No – it was a very thorough process (n=3)  
 No – it was a very good process  
 No – think it is a valuable service, and fantastic initiative and would definitely recommend for other patients

**6. Any other comments?**

Overall excellent program  
 It was a very positive experience for (patient) and (GP)  
 Overall very good (n=3)  
 (Patient) had a very positive experience  
 (Patient) is well known at the practice, and frequently visits for weekly INRs, etc. GP was away on leave recovering from recent surgery. (Practice Nurse) met with Mary in (patient's) home to discuss care plan  
 It was a very positive experience for (patient)

*Intervention Nurse Practitioner experience of collaboration with primary care*

Some General Practices did not involve their practice nurses in development of a GPMP/TCA (n=3), which meant that discussions regarding practice based care planning following recruitment of the participants to the study were directed to the General Practitioner (GP) and often delayed whilst awaiting GP response. These GPs on all 3 occasions developed a care plan for their patients.

Practice nurses not involved in care planning did not have access to participant clinical information which limited their interaction with the NP. On all other occasions, there were no limitations with accessing a practice nurse by phone to discuss logistics of care planning for their practice.

Half of the GP's providing care for participants in this study worked part-time. This had an impact on the NP, delaying initial contact with the GP regarding care planning for their patient. In three cases this also impacted the patient, with delayed exacerbation management knowing their GP was not available. In another example, one GP practiced at a 'walk in centre'. For the participant this meant they could not pre-book an appointment resulting in waiting times of a minimum of 3 hours.

**Results for Hypothesis 4: Effects of intervention on hospital readmission and physical activity***Readmissions for respiratory reasons in 28 days*

In the control group, 6/19 participants (**32%**) were readmitted to hospital within 28 days of their index discharge due to a respiratory problem.

In the intervention group, 1/10 (**10%**) were readmitted within 28 days due to a respiratory problem.

Our pilot study had insufficient numbers to be confident that this did not occur by chance (chi square test,  $p=0.2$ ) but this data does provide important information in order to adequately power a definitive trial based on a likely difference of 22% in the 28 day re-admission rate for respiratory problems.

*Readmissions for other reasons in 28 days*

In the control group, one participant was hospitalised for a non-respiratory reason within 28 days (cataract surgery). In the intervention group, two participants were hospitalised within 28 days of discharge due to non-respiratory reasons (rapid atrial fibrillation, and hyponatraemia/hypertension causing collapse). This resulted in *all cause* admission rate within 28 days being similar between groups (37% in control group, 30% in intervention group).

*Avoidance of adverse events*

In three participants, seven emergency department presentations due to exacerbation of symptoms were avoided. Of these three participants, all had been provided with COPD action plans from the GP (n=1), their private respiratory physician (n=1) and following admission to hospital (n=1). In all cases, participants were not confident with self-managing the situation independently. Weekly visits from the NP supported participants by facilitating use of existing action plans with up-titration of

bronchodilators, +/- commencement of prednisolone or antibiotics. The NP supported the patient and carer to access their GP for review and where a GP was not available, the Locum service. On two occasions where a participant was not responding to initial treatment, review with their private respiratory physician or the INSCOPE respiratory physician was coordinated.

A total of six participants had a COPD action plan and emergency pack at time of home intervention. Only one participant could articulate how to follow a plan and commence use of their emergency medications appropriately. All participants underutilised bronchodilator therapy when managing shortness of breath, particularly related to exacerbation and exercise. COPD action plans were not recommended in two participants due to cognitive impairment and three participants obtained a COPD action plan from their GP during the study.

Initial assessment by the NP during the first home visit in one participant, prevented a hospital admission due to ongoing hypoxia. Oxygen therapy was coordinated within 24 hours via access to INSCOPE respiratory physician.

*Physical activity measures*

In the control group, there were **no significant improvements in activity measures between data collected at the time of hospital admission and 4 weeks later**. However in the intervention group, significant improvements were observed between admission and 4 weeks after discharge. These improvements were:

Percentage of awake time spent sitting (in total) reduced by 15%, from 93% during hospital admission to 78% 4 weeks later (95% CI of difference 27 to 3%;  $p=.02$ )

Percentage of awake time spent in prolonged sitting (sitting 30 mins or more without interruption) reduced by 31%, from 81% during hospital admission to 50% 4 weeks later (95% CI of difference 54 to 7%;  $p=.017$ )

Percentages of awake time spent standing increased by 12%, from 6% during hospital admission to 18% at 4 weeks after discharge (95% CI of difference 2 to 22%,  $p=.027$ ). *This represents an average improvement for the patient of 200% on their standing time.*

Percentages of awake time spent stepping increased by 3%, from 1% during hospital admission to 4% at 4 weeks after discharge (95% CI of difference 1 to 5%,  $p=.009$ ) (Figure 11).

Number of steps per day on average increased from 242 in hospital to 1202 four weeks after discharge, mean difference = 961 steps (95% CI of difference 187 to 1734,  $p=.02$ , Figure 12)

Number of transitions from sit to stand (ie breaks in sitting) per hour of sitting time increased from 2 in hospital to 4 at four weeks after discharge, mean difference =2 (95% CI of difference .3 to 3,  $p=.03$ , Figure 13)

Figure 11 Percentage time use during hospital admission and 4 weeks after discharge intervention group

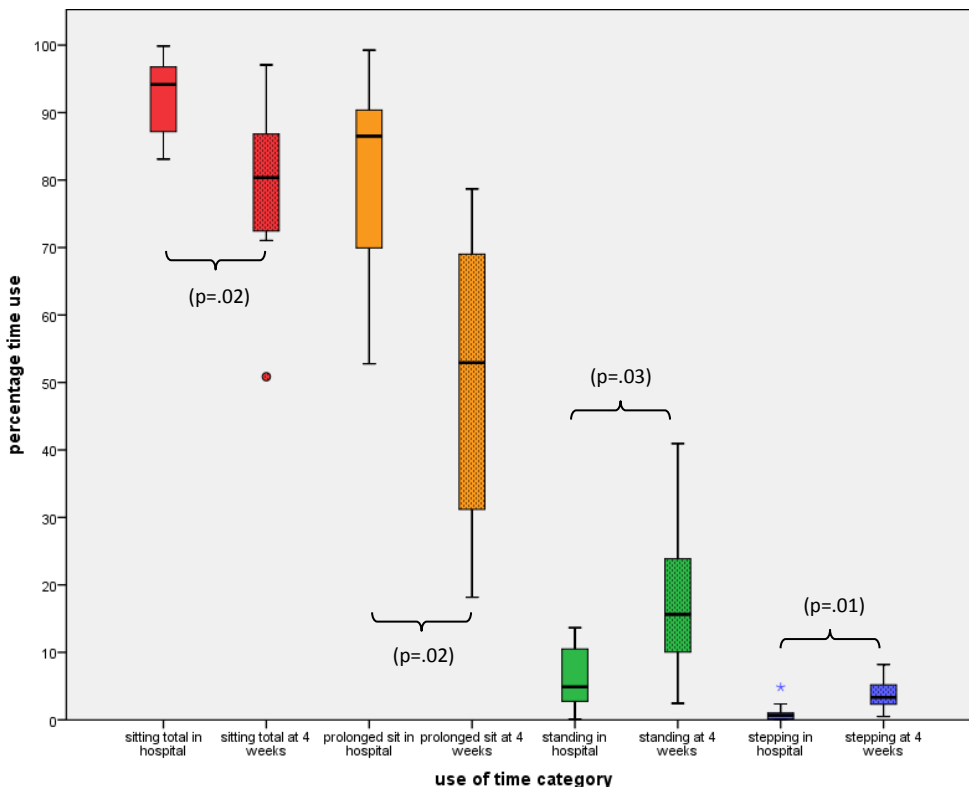


Figure 12 Steps per day intervention and control groups

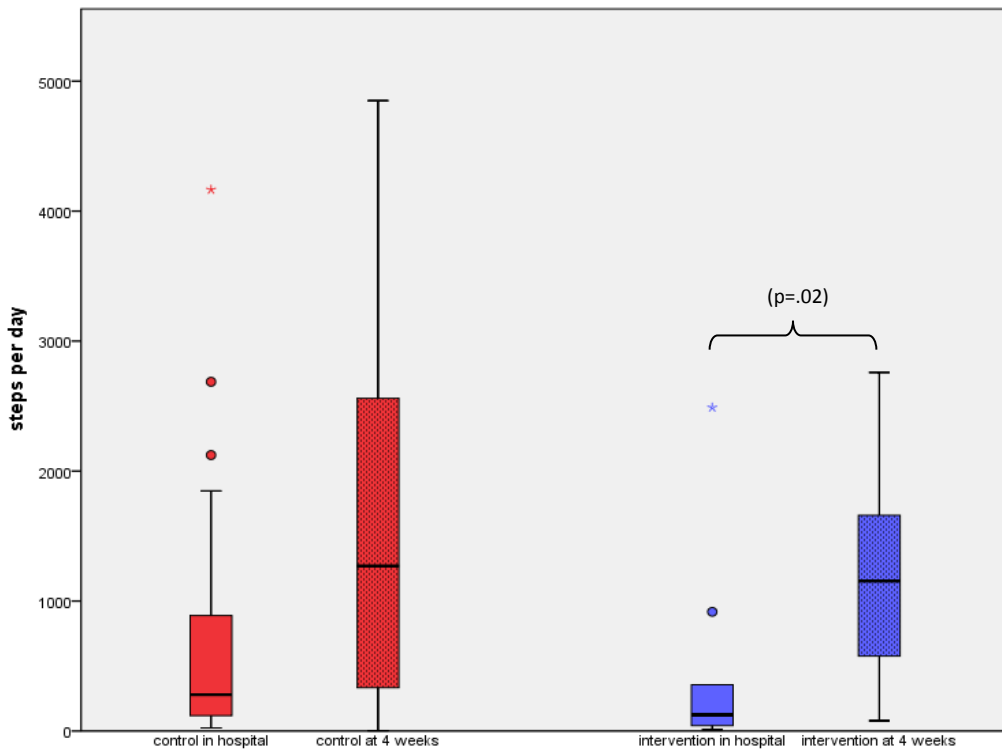
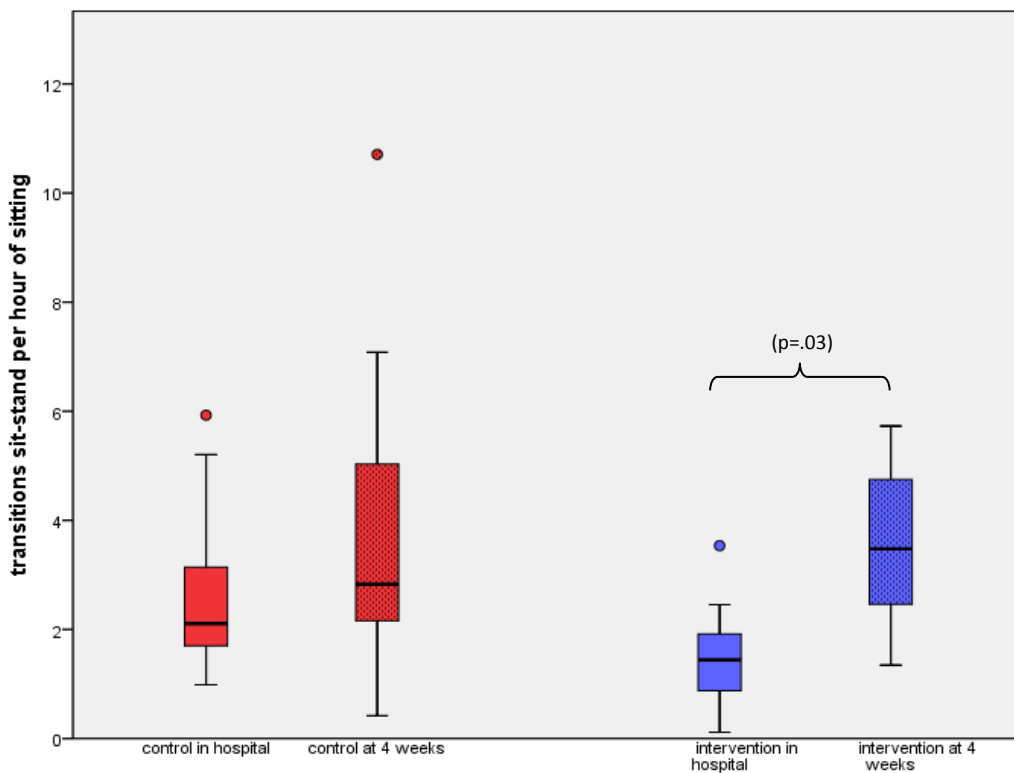


Figure 13 Transitions sit-stand per hour of sitting intervention and control groups





## Discussion

This study successfully piloted the implementation of care coordination plus early rehabilitation (by a team of NP and physiotherapist respectively) in people with COPD in transition from a hospital admission to home. Results have been reported for the four *a priori* hypotheses, but as the study progressed much further valuable information unfolded regarding strengths of this model of care and challenges still remaining.

### Key findings in regard to *a priori* study hypotheses

1. The intervention was feasible, delivered with fidelity and perceived as highly valuable to participants and their carers, delivering a positive experience of both the process and outcomes of their transition from acute to community-based care.
2. The intervention created opportunity for patients to articulate goals. In the intervention group overall, a significant reduction in perceived severity of patient problems, and significant progress toward their self-selected goals was achieved between 4 – 6 weeks at home after discharge from hospital.
3. The intervention enabled collaboration with the patient's general practitioner or practice nurse, resulting in the review or generation of a GPMP and/or TCA in all cases. General practitioners reported a positive experience of the program for both themselves and their patients.
4. Patients who participated in the intervention demonstrated significant changes in their patterns of physical activity at 4 weeks after discharge from hospital compared with during their admission. These included a lesser percentage of awake time spent sitting or in prolonged bouts of sitting; a doubling in the percentage of time spent standing; increases in the time spent stepping, number of steps per day and number to sit-stand transitions per hour of sitting. No such significant changes occurred in activity patterns between hospital admission and 4 weeks later in the control group. Although this study was not powered to detect a significant difference in 28-day readmission rates for respiratory conditions, this occurred in 32% of the control group and only 10% of the intervention group.

### Strengths of this model: patient centred, flexible, care coordination, mobility focused

Our finding of a trend toward reduction in readmission for respiratory reasons during the first month after hospital discharge with care coordination and early rehabilitation is consistent with reports of transitional care initiatives in medically complex older populations after hospital admission.<sup>32</sup> Our pilot intervention directly addressed commonly identified problems with transition through a high degree of fidelity to the principles and practices of patient-centred, flexible care coordination and early rehabilitation.

#### *Patient centred approach*

Participants in this study were central in their care delivery, with their needs reflected in the development of a care plan following completion of all components of the FP™. The FP™ offers a structured framework to measure self-management capacity, explore the principles of self-

management, identify the person's problems and goals and develop a plan for a defined period which outlines the aims and interventions tailored to meet the identified needs and priorities for the person. Patient-centred care, according to the Australian Commission on Quality and Safety in Health Care, is "health care that is respectful of, and responsive to, the preferences, needs and values of patients and consumers".<sup>33(p1)</sup>

The FP™ is comprehensive and took on average 2.6 hours per patient to complete and drove the care delivered by the NP and RPT. The Problems and Goals assessment and monitoring record provided the opportunity for weekly review of participant's progress towards achieving their goals.

Most patient-identified problems were associated with breathing or physical function and corresponding goals were generally around improving individual activity levels to improve social interaction. This is consistent with qualitative studies that indicate retaining the physical ability to maintain social interactions is a key motivator for exercise in people with COPD.<sup>9</sup> Sub-goals were also set with participants which were quite general and incorporated diverse aspects of managing COPD (managing exacerbations in the middle of the night, learning how to better use inhalers) whilst others were more specific relating to other co-morbidities or social needs, for example having short term memory difficulties assessed or feeling confident to leave the unit to have their nails done. Study clinicians did focus on goals related to the study interventions given the short time frame to demonstrate change, however sub-goals will continue to be monitored by the participants usual GP with review of their GPMP or TCA.

The process of care planning provided flexibility to meet the changing and widely varied needs and values of the participants and their carers. For example, one participant was very clear that they did not wish to self-manage medications. This was the role of the carer, so the care plan reflected this and education and support in this area was then directed toward the carer and communicated with other members of the health care team. Another participant acknowledged the pivotal role their carer played in providing support with daily domestic duties; that their involvement was key to the participant remaining independent within the family home. As a result, support for the carer was incorporated in service coordination.

With increased knowledge and skills to manage the symptoms associated with COPD, participants demonstrated changes in their behaviour over time. Repetitive daily practice of breathing techniques, muscle strengthening exercises and optimal use of medications helped one participant realise they could safely push past their perceived physical limitations and understand their potential for improvement and control over their condition. This provided the motivation to maintain their new home regimen. Another participant had clear goals from the outset around social activity that was meaningful to the relationship with their spouse. Improvements during the program in physical strength and symptom management, a new experience, drove adherence to the program and goal attainment. This approach is likely to have built self-efficacy for lifestyle change in participants which is associated with long term sustainability of such changes.<sup>34</sup>

### *Flexibility of the service*

Flexibility in this program was created by applying the principles of a patient-centred approach to care. The home-based nature of care delivery encouraged autonomy within the person's own environment. Clinicians provided interventions in participant's own environment which helped both

learn where barriers and facilitators were and how interventions could be meaningful and tailored to fit with lifestyle and routine. On one occasion, the RPT got on the bus with the participant and attending a typical trip to town to assess and address barriers to function. Both NP and RPT worked together to source a local shopping centre for shopping deliveries to minimise amount of shopping to be carried up 3 flights of stairs where the participant lived. Another participant would have refused outpatient-based services following discharge due to high levels of anxiety, low confidence levels, overwhelming fatigue, and resistance to structured rehabilitation where they felt they did not have control. However this participant welcomed a home-based exercise intervention.

Our flexible patient-centred approach to care planning recognised if the participant did not want to, or could not self-manage their chronic condition. One participant was unable to self-manage because of memory issues, resulting in referral for formal memory assessment and clear documentation that they do not have capacity to self-manage or complete documents such as advance directives. The NP role in the care of this participant was focused on advocacy and care coordination. The participant continued successfully with the physical rehabilitation intervention.

Program flexibility allowed clinicians to respond immediately and effectively to acute changes in people's condition. For example, the RPT increased physiotherapy visits to alternate days for provision of manual airway clearance during one participant's pseudomonas exacerbation. This flexibility supported the participant and specialist with implementing intensive treatment strategies at home (ie. different choices of antibiotics, nebulised mucolytics, airway clearance techniques, sputum collection for cytology) to avoid hospital admission that would have otherwise been likely due to inability to effectively clear excess secretions.

### *Care Co-ordination*

Care co-ordination is a “deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care”.<sup>35(pv)</sup>

Co-ordination of care in this study was included in the scope of practice for the NP (accounted for 32% of NP workload, Table 4) and occurred across the acute, primary and community sectors. Care coordination in this study encompassed communication between all members of the health care team, co-ordinating and prioritising appointments and referrals, rapid movement of the participant between clinicians to manage exacerbations and facilitating advance care planning.

Consultation of the NP with health professionals when the participant was readmitted or attended ambulatory appointments provided support to the participant and continuity of care. One carer expressed that the program offered substantial support for her with navigation of medical communication (ie. improved knowledge about the frameworks to be able to access and communicate with their specialist) and interventions (ie. medication regimes including choice of antibiotic given they were challenged with a resistant pseudomonas infection).

Early communication between the NP and GP involved description of the study interventions, expectations regarding future exacerbation management for patients (ie. with GP or INSCOPE),

clarification that they were happy if relevant referrals were generated by the study clinicians for the participant and that the GP was happy to complete a practice based plan. GPs were kept informed about issues relating to changes in oxygen prescriptions, clinical deterioration and exacerbation management, emergency or elective admission to hospital and in some cases, provided copies of separation summaries not provided by the hospital in a timely manner.

Communication about the participant's needs and goals was central to the process of care co-ordination and is reflected in the NP role, with 4.5 hours/patient spent on administrative activities and 1.6 hours/patient in direct consultation with their treating health professionals. While the time spent on communication was substantial, an absence or lack of communication between health professionals and patients, or between different health practitioners regarding the care of a given patient, is consistently highlighted as a dangerous gap in the safety and quality of health care.<sup>4,14</sup> To reduce the rate of adverse events including hospital readmissions that result from inadequate handover, significant time must be invested in communication.<sup>4</sup>

### *A focus on mobility and becoming more active*

The individualised provision of active early rehabilitation at home resulted in very meaningful improvements in physical activity in the post-discharge period that were not observed in the control group. This early improvement in time spent standing and walking may be associated with lower hospital readmission. Greater physical activity levels at one month after hospital discharge (4% of awake time spent walking) were reported by Pitta and colleagues<sup>6</sup> in COPD patients who avoided hospital readmission at 12 months, compared with those who required hospital admission within 12 months (2% of awake time spent walking). A longitudinal cohort study demonstrated the association of greater physical activity with reduced morbidity and lower hospitalisation rates over 12 years in people with COPD.<sup>36</sup> Early rehabilitation in the context of transition care coordination was effective to improve physical activity patterns in a short space of time.

Many self-selected patient goals focussed on mobility, reflecting a patient concern to improve physical activity and function. The flexible, home-based nature of the study intervention overcame many of the documented barriers to participation in pulmonary rehabilitation or exercise reported by people with COPD such as difficulty with transport, and feeling too unwell to attend exercise sessions.<sup>9</sup>

### **Translation into practice: Role of the Nurse Practitioner in the community setting**

Community based care-coordination is essential for hospital avoidance.<sup>37,38</sup> Specialist teams positioned within community settings is one of the models being developed to support the long-term management of the patient with COPD.<sup>39</sup> An example of this model is INSCOPE, developed by the Department of Thoracic Medicine, RAH. The aim of INSCOPE is to address factors currently associated with admission while the patient remains at home using rapid response processes to achieve complete hospital avoidance, or facilitate direct admission if required (avoiding emergency department attendances). Case management, care coordination and pulmonary rehabilitation will focus on self-management and promote independent function at home. Care will be reorganised with tasks currently completed in hospital being addressed in an ambulatory setting. The primary focus is on optimising patient care and the support needed for the home carers. It is planned that

the respiratory NP will enhance shared care between GPs and the INSCOPE team, implementing care coordination as defined and trialled for the first time in this study.

Implementation of the specialist respiratory NP role, with ability to work across acute and community care is essential to coordinate care in transition, facilitate access to specialist services and to hand care over to general practice/community care. The NP has advanced clinical skills and knowledge in COPD and chronic disease management, ability to communicate effectively, experience working within multidisciplinary teams and ability to work autonomously. Assisting with integration of the new role was the NP's established rapport with respiratory physicians and hospital clinicians as a leader in respiratory care delivery and their understanding of existing acute and primary care systems. Rapport with acute teams assisted with rapid access to services when required.

The NP role has flexibility to provide services for patients being cared for by other sub-acute teams such as 'Rehabilitation in the Home'. Implementation of early rehabilitation could take place utilising physiotherapy workforce in 'Rehabilitation in the Home' services that currently exist to facilitate discharge from acute care.

### **Challenges and limitations of this study**

**Low confirmation of COPD diagnosis amongst admitted patients:** Our screening data indicated that 24% of patients with admission coding of "COPD" did not have confirmation of that diagnosis with pulmonary function testing (and thus were ineligible for inclusion in this study). Lack of clarity regarding COPD diagnosis may generate uncertainty in the application of disease specific clinical pathways and guidelines, or appropriateness of disease-specific transition and primary care services. This finding is consistent with a retrospective chart review of patients admitted with COPD as a primary or secondary diagnosis<sup>40</sup> that found only 31% (173/553) of those with a clinical diagnosis of COPD had this confirmed with pulmonary function testing. While the ideal scenario would be to increase uptake of pulmonary function testing in people with suspected COPD in primary care, conducting or planning of pulmonary function testing at the time of hospital discharge could also be encouraged.

**Non-randomised allocation to control and intervention groups:** In this pilot study group allocation was determined by time of hospital admission, with all participants recruited during 2013 allocated to the control group. Participants recruited in 2014 were allocated to the intervention. Future studies should seek to incorporate random allocation of intervention and control groups, although this is challenging to implement in the context of an integrated system of health care delivery.

**Lack of prescribing rights in NP:** The NP in this study was not endorsed to prescribe medications relevant to COPD management. A respiratory NP with prescribing rights could have prescribed and commenced emergency packs in patients who didn't have them, and prevented delays associated with accessing GPs in instances where they are not available.

### **Implications for future research and practice**

Based on the positive results of this pilot project, care coordination plus early rehabilitation in people with COPD at the time of transition from hospital to home should be implemented in a larger

controlled study that is adequately powered to determine a difference in readmission rates between the intervention and usual care. This would provide stronger evidence for this approach and support translation into policy and practice.

The framework detailed in this study integrates a patient-centred approach to care with best practice COPD management,<sup>41</sup> with multi-disciplinary involvement, coordinated across acute and primary care sectors. The framework for transition of care for people with COPD demonstrates progress toward meeting the needs of people with COPD and has begun to apply a palliative approach to chronic disease management.<sup>42</sup> All components of this intervention are transferable for care of people with COPD at end of life, however the areas of bereavement risk assessment and spiritual support<sup>43</sup> would need to be incorporated, with staff trained in this area accordingly.

The study intervention team of specialist respiratory NP and physiotherapist demonstrated ability to implement all planned components of care coordination and early rehabilitation in this population and also to expand scope to meet further identified and previously un-addressed needs. This workforce combination is indicated to implement the intervention.

Implementation of early rehabilitation could take place utilising physiotherapy workforce in existing 'Rehabilitation in the Home' services that currently facilitate discharge from acute care.

Implementation of the specialist respiratory NP role, with ability to work across acute and community care is essential to coordinate care in transition, facilitate access to specialist services and to hand care over to general practice/community care. Positioning of this NP role within a community-based specialist team would be consistent with effective integrated care models to support the long-term management patient with COPD.

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# Appendices

## Appendix 1: Early rehabilitation component of the intervention

<b>WALKING PROGRAM</b>		frequency/duration
<i>Check walking aid prescription and use 4WW if indicated</i>		
Walking practice start at approx. 40% of peak speed in 2MWT/using 3-4 (slight-moderate) on Borg scale as guide to exercise intensity		10 mins x 2 daily*
Less intense options if necessary: <ul style="list-style-type: none"> <li>• marching on spot with upper limb fixation</li> <li>• sit-stand with upper limb support/fixation</li> <li>• squats with upper limb fixation</li> </ul>		2-3 mins continuously <u>OR</u>  10-15 reps x 3 sets x 2 daily
<b>LOWER LIMB STRENGTHENING</b>		
<i>Weaker muscle groups identified and targeted when prescribing strengthening exercises</i> <i>2-3 exercises prescribed</i>		
exercise example	intensity and duration	frequency
seated knee extensions	Free exercise/0.5kg/1kg/2kg weights	4-5 x weekly
sit-stands	Determine 10 rep max	
marching on spot	1-3 sets of 10 reps	
<b>UPPER LIMB STRENGTHENING</b>		
<i>Weaker muscle groups identified and targeted when prescribing strengthening exercises</i> <i>2-3 exercises prescribed</i>		
exercise example	intensity and duration	frequency
biceps curls	Free exercise/0.5kg/1kg/2kg weights	3-4 x weekly
forward punches	Determine 10 rep max	
upward punches	1-3 sets of 10 reps	
<b>BREAKING UP SEDENTARY TIME</b>		
Consult pattern of physical activity from objective activity monitoring to generate realistic goals <ul style="list-style-type: none"> <li>• determine periods of sedentary time to target (eg &gt; 30 mins; &gt;1 hour)</li> <li>• identify sedentary “hotspots” in the day</li> </ul> With patient/carer, plan appropriate strategies to break up sedentary time Use of pedometer to incentivise increased periods of stepping/mobilising around home		

# The highest appropriate level of exercise prescription was implemented

\*Duration may progress to 15 mins twice daily

## Appendix 2: 'About My Health' wallet



**Appendix 3: Examples of activity plans provided to patients**

id102: finalised home exercise program

The image displays three hand-drawn activity plans for a patient with COPD, each featuring photos of exercises, a yellow sticky note with instructions, and a weekly checklist.

**Plan 1: Walking**

- ① House → big shed → edge of house (side) → House RESTS 2 times / day
- ② Kitchen ↔ lounge walks Hourly

Oxygen ↑ + ↓ 10-15 min after

M	T	W	Th	F	S	S
✓	✓	✓	✓	✓	✓	✓

**Plan 2: Knee straightening and Marching at bench**

- ① Knee straightening 1.5 kg weights x 10 3 sets, 2 x / day REST BETWEEN
- ② Marching at bench 1.5 kg weights x 10 3 sets, 2 x / day REST BETWEEN

M	T	W	Th	F	S	S
✓	✓	✓	-	✓	✓	✓

**Plan 3: Hands on shoulders and Forward punches**

- ① Hands on shoulders Reach up to sky x 10 2 sets, 2 x / day
- ② Forward punches x 10 each arm 2 sets, 2 x / day

NOT LEFT ARM \*

M	T	W	Th	F	S	S
✓	✓	✓	✓	✓	✓	✓

id104: home exercise program, including airway clearance exercises

BREATHING EXERCISES							WALKING						
Every morning - Medium blows - 3 seconds - 5 blows (with rests between) - Then rest 1-2 minutes - DO 4 rounds - Then try 1-2 <u>HUFFS</u> (like fogging-up mirror)							Aim every morning <b>AND NIGHT</b> To South Rd and back Rest often Take puffer with you Short walks each hour inside during day						
M	T	W	Th	F	S	S	M	T	W	Th	F	S	S
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
M	T	W	Th	F	S	S							
<u>PHONEBOOK TAPS</u> x10 each arm with 3kg leg weights (SWAP WEIGHT)			<u>WALL PUSH UPS</u> x20		<u>SIT TO STANDS</u> x15 hands on knees		<u>BOOM BOOMS</u> x10 each arm with 2kg hand weights UP + FORWARD						
2 sets morning + night 5 days/week													
M	T	W	Th	F	S	S	M	T	W	Th	F	S	S
✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

**Appendix 4: Examples of activity diaries utilised by patients**

id106: activity diary

<b>My weekly activity</b>			
<b>Monday 14/4/2014</b>	LEGS 5 LEG STRETCHES 5 " " 5 STAND UP 5 STAND UP	ARMS 5 EACH ARM ✓ a.m. 5 EACH ARM ✓ P.M.	WALK 1 WALK. 1 WALK 1 WALK.
<b>Tuesday 15/4/2014</b>	5 LEG STRETCHES 5 " ✓ 5 STAND UP ✓ 5 STAND UP.	5 EACH ARM ✓ A.M. 5 EACH ARM ✓ P.M.	1 WALK. WALK DOWN GARDEN & BACK
<b>Wednesday 16/4/2014</b>	5 LEG STRETCHES ✓ 5 LEG STRETCHES ✓ 5 STAND UP ✓ 5 STAND UP ✓	5 EACH ARM ✓ A.M. 5 EACH ARM ✓ P.M.	1 WALK. 1 WALK 1 WALK.
<b>Thursday 17/4/2014</b>	5 LEG STRETCHES ✓ 5 LEG STRETCHES ✓ 5 STAND UP ✓ 5 STAND UP ✓	5 EACH ARM ✓ A.M. 5 EACH ARM P.M.	1 WALK. 1 WALK IN GARDEN.
<b>Friday 18/4/2014</b>	10 LEG STRETCHES ✓ 10 LEG STRETCHES ✓ 5 STAND UP ✓ 5 STAND UP ✓	10 EACH ARM ✓ A.M. 10 EACH ARM ✓ P.M.	1 WALK. 1 WALK 1 WALK
<b>Saturday 19/4/2014</b>	10 LEG STRETCHES ✓ 10 LEG STRETCHES ✓ 5 STAND UPS AM 5 STAND UPS PM	10 ARM EACH A.M. 10 ARM	1 WALK WALK TO CLOTHES LINE TWICE.
<b>Sunday 20/4/2014</b>	10 LEG STRETCHES ✓ 10 LEG STRETCHES ✓ 5 STAND UPS ✓ 5 STAND UPS ✓	10 ARM EACH A.M. AND ARM EACH P.M.	1 WALK 1 WALK 1 WALK

id105: activity diary

### My weekly activity

<p><b>Monday 17/3/2014</b></p> <p>TRICEP 15x2                      BI CURL 30x1                      LATERAL 15x2                      KNEE 30x1                      SIT &amp; STAND 20x1</p>	<p>walked Dog x 2                      March 30x1 x 2kg</p>
<p><b>Tuesday 18/3/2014</b></p> <p>TRICEP 20x1  <del>LATERAL 20x1</del>                      LATERAL 20x1                      SIT &amp; STAND 20x1</p>	<p>walked Dog 525 METRES approx                      March 30x1 x 2kg                      KNEE EXT 30x1 x 2kg                      Pull Down Black 40x1</p>
<p><b>Wednesday 19/3/2014</b></p> <p>TRICEP 20x1                      KNEE 20x1                      SIT &amp; STAND 20x1                      March 40x1 x 2kg                      KNEE 30x1 x 2kg</p>	<p>walk Dog 525 METRES                      Feel exhausted / Breathing Harsh                      Before Starting                      7642 Steps</p>
<p><b>Thursday 20/3/2014</b></p>	
<p><b>Friday 21/3/2014</b></p>	<p>Ten Yin Bowls 2 Hrs                      walked Dog</p>
<p><b>Saturday 22/3/2014</b></p> <p>SIT &amp; STAND 20x1                      KNEE EXT 15x2                      LATERAL 20x1                      TRICEP 20x1                      TRICEP 20x1</p>	<p>walked Dog Along S to Park x 1                      March 15x1</p>
<p><b>Sunday 23/3/2014</b></p>	<p>walked Dog                      R.D.O DID NOT FEEL FLARE</p>

## Appendix 5: Semi-structured interview guide (patients and carers)

### Preliminary notes

Participants in this context are people with COPD, who have been part of the study “Helping you get back on your feet after being admitted to hospital with your chronic respiratory condition”, with their carers (where the person wants them involved).

Participants can be considered partners in research and invited to assist us to make recommendations for future service delivery. Explain we will be making a report to the funders of this pilot program about how useful the service is and what recommendations for the future could improve such a service.

Participants will be able to refer to their experience by way of example and also to speak about how people in a similar situation to their own might be best supported (ie in the transition from hospital to home, with health service links transitioning from hospital care to primary/community care).

Specific aspects of the care coordination plus early rehabilitation intervention that we are seeking to gain the participants’ thoughts on the benefit or otherwise of are

- (1) articulation of and progress towards personal goals
- (2) the process of care coordination, getting the care you need in the transition from hospital to home; the nurse practitioner’s role in this (Mary)
- (3) a (better coordinated) team care arrangement; this is a plan made with the patient’s GP about ongoing care
- (4) early rehab by weekly home visit (Claire)

Interviews will occur at about 5-6 weeks post discharge from hospital, after interaction with the study nurse and physiotherapist has ended.

### Question guide

1. What were the most helpful things about the service you have received (from Mary and Claire) during the last month or so since leaving the hospital?  
Why have these parts of the service been helpful?
2. Part of the focus of this service has been to help people
  - identify problems they are having
  - set goals to overcome those problems
  - make progress toward achieving those goals.

How helpful did you find these parts of the service?

3. Part of the focus of this service has been improving communication with your GP about your ongoing care and your goals.
  - Is this important?
  - Did the service help make this connection with your GP in your case?
  - What would you recommend about this part of the service for the future?



4. Part of the focus of this service has been helping you get back on your feet, or become as active as possible after your hospital admission.
  - How was this part of the program for you?
  - What would you recommend about this part of the program for the future?
  - How well did/does home-based rehab work for you?
  - Should it be the usual way of doing things or would you prefer/be happy to attend a group at a local centre to assist with exercise and walking in the first month after leaving hospital? *(also interested in the timings of this eg needed help at home at first after leaving hospital, but now would be able to go to a group? Or NOW still feels could use more rehab at home?)*
  - How do you feel **now** about being active/mobile in the local community (confidence/ability to join in a community group or publicly available exercise/walking program for example?)
  
5. Has the program made you aware of other services available to help you at home or in the local area? Have you used any such services? (for example, \_\_\_\_\_)
  
6. Are there any other things you would recommend need to be in place for other people in a similar situation to what you were, that is going home after a hospital admission because of a lung condition.

**Appendix 6: Interview themes, data examples and contra-examples**

THEMES	DATA EXAMPLES/CONTRA-EXAMPLES
<b>A positive experience of transition</b>	
<b>Positive process</b>	
Ease with what's happening	I feel really, really at ease with what's happened and it's really helped me along step by step, it's really helped me along. It's really great. (id01)
Individualised, enough time	<p>I think it's a good idea because sometimes the local GP doesn't have time to sit with patients, whereas Mary sat and explained the things and can get around it better. (carer id02)</p> <p>Patient: Oh yeah talking one to one is always easier than in a group.                      Carer: So one on one to have Mary here to answer our questions.                      Patient: It was more a personal thing put it that way.                      Carer: So that was really, really good wasn't it?                      Patient: Yeah. (id05)</p> <p>You're not in a hospital and thinking you're using up people's precious time. There was no... Mary stayed here quite often a lot longer than I thought (carer id05)</p> <p>I think if I've got somebody there pushing me... Yeah it's easier at home. (id07)</p> <p>She had a video that told you about your lungs... I've never sort of seen the lungs before apart from when I had an x-ray and you see them like that but they don't sort of go into all the bits that are on them. So that was good, seeing that. Yeah it was very good. (id07)</p>
<p>At home: comfortable, no distractions</p> <p>At home: easier access</p>	<p>So much easier and it's sort of one on one, whereas in the hospital there's always distractions..Simply because there's no interruptions and you can really sort it out with one another and work on it. (carer id02)</p> <p>I reckon better here... people walking around it's not too good, you're sitting there and you don't feel... that comfortable, people sick all around you and that sort of thing. (id04)</p> <p>Because we didn't... our car's not the best so it was a lot easier for us... for them to come here and do it. (id07)</p> <p>Oh yes, well if I'd had to go to them every time you might think I can't be bothered to go there, I think I'll miss today and not bother going- so it's good when they come home. (id07)</p>
Practitioners' personal traits	They were very nice people, you felt comfortable with them... You know if it was somebody that came and you didn't like them very much and you think 'God I don't want her to come again!'... Both of them were very nice. (id07)

<b>Positive outcomes</b>	
Feeling better with exercise	<p>Since I've been doing exercise and that... and exercise has made me feel 100% too, it's made my legs feel better.</p> <p>So I had to give away bowls this year because the cramps were playing up too much, but I went across the other day and did four rounds just to see how... not much pain at all so I'm playing bowls since that day. (id04)</p> <p>Because when I first came out of hospital I couldn't sort of go very far or do anything and it just gets you down when you can't do everything. Because we're used to going out to walk but we haven't been out for quite a while but we're back now doing what we used to do. (id07)</p> <p>It did work, yes. Yes it worked because I didn't know really where I was and when I came out of hospital I was a bit down so she sort of built that up (id07)</p>
<i>Motivation to keep on being active</i>	<p>Weights and ankle weights and I'm still doing what Claire taught me, I'm still doing it, I keep on doing it. I keep on doing it as long as I can. I'm not going to give it away because I feel that good. (id04)</p> <p>Yeah keep them up, even when I'm watching television I'm doing this one. (id07)</p>
Getting medications right	<p>She went through it with me and what each medication did and what order you should take it in, which I thought I had but it was obviously wrong, but what she's told me has worked out to be beneficial to me. (id05)</p> <p>Yeah and telling me about what my puffers really did. I didn't really know what they all did. I know they all did different things but I wasn't into what they all did. (id07)</p>
Getting on better with disease management	<p>Before I didn't have a care plan and this has really helped me the way she's set it all out...She's given me the steps of what I look out for if I get low before I ring an ambulance or whatever. It's working out fine (id01)</p> <p>I know what to do and it's really helped me a lot. (id01)</p> <p>And I think she made him feel like he wasn't a hypochondriac, that he knew his condition...Better than me, better than the doctors, better than anyone. (carer id05)</p>
Confidence and future orientation	<p>And if they hadn't done it, I wouldn't have known the steps that I had to take to keep myself in control. I've just gone leaps and bounds, it's really good. (id01)</p> <p>All you've basically got in hospital was from the doctors- "you can only get worse" (id05)</p> <p>She's got everything together in a lovely folder which we've got all the plans for. In all, we've got a lot more confidence knowing what to do, but the other is to actually asking, which we needed to have. We needed to have confidence that we could do it and it was through Mary that we did that.(carer id05)</p> <p>... it's a program that I hope they keep going for other people because it's a terrible disease an absolutely terrible disease but it does help you cope a bit better. (carer id05)</p>

<i>Contra-data: not much more can be done</i>	I don't think there's anything else I could have, you know according to the doctor I've got everything for my lungs that there is so I can't do much else. (id07)
Skills and confidence to use health care services	<p>As far as having the confidence to get on the phone and ring the specialist, I didn't have that before. I kept on thinking he was a man up here and I was down here, I would have felt happy about ringing the GP but he quite frankly couldn't do any more for (patient). (carer id05)</p> <p>But we didn't have that confidence until Mary gave us it. I'd sit there and we'd wait days and even when (patient's) saying will you ring him I'd think 'ohh do I need to ring him yet?' (carer id05)</p>
<i>Managing anxiety about using health care services</i>	I know what's going to happen when I go to these clinics and rehab and I know what to expect. (id01)
<i>Contra-data: still not confident to manage group program</i>	<p>Carer: They've put him onto... there's like a rehab coming at Mt Barker sometime apparently at the end of the month, which is supposed to help him breathe and walk and exercise and whatever so...</p> <p>We've got to go there to Mt Barker because apparently it's a group.</p> <p>Patient: I don't think I'll make it.</p> <p>Carer: I'm a bit doubtful he'll make it though. I mean it was the offer's there and it's there if you want it. But I think it's a bit too much walking for him. By the time he gets into the car he's puffing now basically walking into rooms from here. Really puffs to get out to the car and I just pull it right out the front just out there so. (id02)</p>
Better care planning and coordination	<p>Patient: But we're on a healthcare plan now which is Mary got... I've had one before but she...</p> <p>Carer: Put everything together.</p> <p>Patient: And I instigated the whole lot through specialists and my GP and it's got that interaction put it that way- which wouldn't have happened before. (id05)</p>
<i>GP knows what's going on</i>	<p>She organised it with the nurse that's in the clinic so they've got all the data and details down there so they can always go from there as well. (id02)</p> <p>Yeah it's all done through them as well, coordinating with them so I think that's one of the bigger things too because they know what's happening as well. (carer id02)</p> <p>Yeah she saw him and I think she was telling him what she was doing and how I was going, yeah and then he was asking me how it was going yeah so it was good. (id07)</p>
<i>Respect between professionals in health care team builds consumer confidence</i>	And from both the doctors and the specialist, we got a really good report about Mary, about her ability and about her know how about the disease and everything. So when you hear that from professionals as well, you've certainly got the right person. (carer id05)
<i>This model of care proactive not reactive</i>	I said there's got to be something, he said 'oh I can recommend you go to a respiratory physio' because this was two years down the track and we could have been doing that beforehand. I find with the medical system that they don't tell you things, you've got to ask whereas Claire and Mary told us things, they told us. But we had to think before what to ask and you feel like you sound a bit silly if you say there's got to be something more. (carer id05)

## Appendix 7: GP interview questions

### **Implementing care coordination plus early rehabilitation in high-risk COPD patients in transition from hospital to primary care**

Basically we want to know, is this service what GPs want to improve transition of patient care and care planning from hospital to general practice?

#### **Interview with general practice: GP/practice manager/practice nurse**

**Name:**

**Date:**

**Patient:**

**Interviewer:** *Jo Teakle (CAHML – COPD Senior Project Officer)*

#### **Interview Questions:**

- 1. Were you aware that (name) had been involved with this study?** (The GP would have received an information sheet from us and Mary would have contacted them)  
❖  
❖
- 2. What do you think about the program?** (home-based: physical rehabilitation / self-management training / coordination of required services and referrals / goal setting and care planning with the patient and carer / information provided to the practice to inform development GPMP, TCA or review of existing plans)  
❖  
❖
- 3. Was it helpful having a health professional (Mary) who**
  - knew the patient in hospital, and
  - had spent time planning care with the patient in transition to provide information to your practice in order to help review or generate your care plan for that patient?❖  
❖
- 4. Was a care plan generated or reviewed for this patient (name) as a result of this intervention?**  
❖  
❖
- 5. This trial was funded by the DoH and if we were to recommend this continue, would you recommend any changes to assist transition of patients back to primary care?**  
❖  
❖
- 6. Any other comments:**  
❖