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A pilot of the Patient Concerns Inventory – Ward Discharge in patients following major reconstructive surgery for head and neck cancer

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#### **Abstract**

Planning discharge from hospital following microvascular free-tissue surgery can be complex and challenging. Planning involves the patient, carers and multiple health professionals. Poor communication and expectations can delay discharge or give a suboptimal discharge process. It was hypothesised that prompt-list modelled along the principals of the Patient Concerns Inventory (PCI) could be help in discharge planning. The aim of this study was to define the items and format of a PCI-Ward Discharge (PCI-WD) and undertake a small pilot. Items appropriate for the PCI-WD were formulated through discussion with patients, carers, ward staff, Head and Neck Clinical Nurse Specialists, and clinicians. The pilot took place over 3 months from December 2019 through February 2020. Audit approval was given by the hospital Audit Department. The PCI-WD comprises 43 items. Items from existing PCIs for use at diagnosis and follow-up consultations were reduced in number and 38 new or modified items added; 6 treatment related, 5 social care and social well-being, 4 psychological, emotional and spiritual well-being, 7 physical and functional well-being and 16 discharge related. The pilot involved 14 free-tissue transfer patients, 7 male, 7 female, with age range 57 to 87 and average age 72. Eight PCI-WD were returned. PCI-WD items identified most frequently were 'surgery site other than head/neck', 'when do I come back to hospital', 'dental check-up/oral health care' and 'diet/eating'. Early findings suggest that PCI-WD could be a useful tool in aiding the discharge process. Further evaluation is required. **Keywords:** Patient Concerns Inventory; prompt list; head and neck cancer; ward discharge planning

#### Introduction

Ward discharge planning following microvascular free-tissue surgery can be complicated and requires multi-agency involvement. There is a lack of studies in this area. Transition from hospital to home and continuity of care after hospital discharge are key components. <sup>1</sup> Discussing concerns early can get patients home sooner and settling into a more independent daily routine. <sup>2</sup> Patients and their carers can be frustrated when delays occur yet there is a necessity to ensure 'safe' discharge with appropriate support. Delayed discharge results in additional financial burden to the NHS and reduces bed capacity for other patients needing in-patient admission. Discharge-related problems are often a source of complaints as reported by the Parliamentary and Health Service Ombudsman for the NHS in England in 2016 who drew attention to the fact that complaints relating to discharge arrangements were increasing. <sup>3</sup> Living alone, availability of care after discharge, caregiver depression, stress or other difficulties are all risk factors for patients producing adverse health outcomes after discharge and the reasons patients are often advised to stay in hospital until suitable provisions facilitate a safe discharge. <sup>4</sup> For head and neck oncology patients, following major free flap surgery, issues related to 'safe discharge' can be complex. It can involve several agencies with multidisciplinary assessments which can include speech and language therapy, dietetics, physiotherapy, occupational therapy, social services and the district nursing services. Patients may have feeding tubes, wounds requiring ongoing care, relatively limited family support and additional socio-economic factors in the context of a regional service. <sup>5</sup> Careful planning is required to ensure patients access healthcare required in their community setting. Ward visiting for carers can be limited to several hours a day and can be stopped altogether during periods of infection such as MRSA outbreak or Covid-19. This makes effective communication with patients' carers even more challenging.

The Patient Concerns Inventory (PCI) first published in 2009 <sup>6</sup> was developed as a promptlist to aid discussion of issues important to patients during follow-up consultations following head and neck cancer (HNC). <sup>7</sup> Subsequently, other PCIs have been developed and examples include at diagnosis of HNC, <sup>8</sup> rheumatology, <sup>9</sup> and burns. <sup>10</sup> A systematic review and content comparison of unmet needs self-report measures used in patients with HNC favoured the PCI HNC compared to 13 other tools. <sup>11</sup> There is a body of work emerging demonstrating the benefit of the PCI HNC in routine practice <sup>12</sup> with the strength of the prompt-list approach being a patient-clinician communication aid. <sup>13</sup> The aim of this study was to devise and pilot a Patient Concerns Inventory module specific for ward discharge (PCI-WD).

#### **Patients and Methods**

There were two aspects to this pilot study. Phase 1: Agreement of items and formatting of the prompt-list. and Phase 2: Pilot study.

#### Phase 1: Agreement of items

The PCI-WD was developed using an adapted version of the PCI after Diagnosis and the PCI Post-Treatment used at Aintree University Hospitals. Adaptations were made following multi-professional feedback from clinicians, clinical nurse specialists, dietitians, speech and language therapists, allied health professionals, nursing staff, Patient Advice and Complaints Team (PACT), healthcare assistants and crucially once a draft was formulated, using feedback from patients and carers. This information was gathered from 19 individuals through face-to-face discussion with the lead author. The four main PCI headings of 'Treatment related', 'Physical and functional well-being', 'Psychological, emotional and spiritual well-being', and 'Social care and social well-being' were retained. Under each

heading from previous versions of the PCI, items were added, removed or modified to be more appropriate to in-patient stay. A supplementary section 'Discharge related' concerns was added.

Phase 2: Pilot study

A 2-page section for individual comments at the end of the resource was used to allow patients and their careers to make comments on any areas not covered by the prompt-list, to expand on prompt-list points and to register concerns in their discharge planning. The intention was to include consecutive admissions up to 10 completed PCIs over the 3-month period from December 2019 through February 2020. Head and neck oncology patients undergoing free flap surgery were invited to participate. When clerked into hospital prior to surgery, patients were offered the opportunity to complete the PCI-WD throughout their stay. MFU Dental Core Trainees (DCTs) collected and collated information from the prompt-lists. Approval was given by the hospital Audit Department.

#### **Results**

Phase 1: Agreement of items

The PCI-WD prompt-list comprises 43 items. 'Treatment related' concerns were adapted to treatment more likely to be of immediate concern for in-patients or a patient soon after discharge. Prompt items relating to investigations were removed as patients had had most investigations completed on arrival at hospital. The 'Discharge related' section was constructed as detailed in Table 1, with 'Cause of cancer' section removed. 'What will I be like' and 'Follow-up' sections had their contents modified and added to 'Discharge related' concerns.



#### Phase 1: Formatting of the PCI-WD

The PCI-WD (Figure 1) pilot consisted of a 4-page form with a prompt-list component of 2 pages and a further 2 pages for additional open-ended personal comments. The prompt-list portion consisted of 43 items with 4 prompt-boxes relating to one concern. Each of the 4 prompt-boxes related to a different stage of the patient's stay i.e Admission to Day 2, Day 3 to 5, Day 6 to 8, Day 9+. The rationale for such a design was to have a single document to remain with the patient throughout their stay in hospital to monitor progression of their concerns and register if their concerns were addressed or persisted.

#### Phase 2: Pilot study

14 patients agreed to participate and were given the PCI-WD, 8 were returned, with 3 of those blank. 1 completed PCI-WD was retrieved from computer-scanned notes. Of all patients that participated, 7 were male, 7 were female, the average age was 72, with length of stay ranging 5-30 days post-operatively. The majority underwent surgery for squamous cell carcinoma with one adenoid cystic carcinoma. TNM stage was from T<sub>1</sub>N<sub>0</sub>M<sub>0</sub> to T<sub>4</sub>N<sub>2</sub>M<sub>0</sub>. Microvascular free tissue transfer comprised of radial forearm free flap (9), anterolateral thigh (2), scapula (1), fibula (1) and DCIA (1). From the 6 completed PCIs, 4 items from 2 headings predominated for 5 out of 6 patients (Fig 2); 'Surgery site other than head/neck', 'When do I come back to hospital', 'Dental check up/Oral health care' and 'Diet/eating'. In the personal comments section, visitors were concerned about a patient's ability to communicate with a tracheostomy. Others expressed concerns included worry about their relative/friend undergoing a general anaesthetic, length of the operation, distance they lived from hospital, and awareness of needing to plan for how their friend/relative would manage when leaving hospital.

#### **Discussion**

Optimal ward discharge planning relies on good communication between patient, carers and healthcare professionals. Although the PCI has been used with HNC patients in clinic with evidence of improved patient satisfaction <sup>14</sup> it has never been designed for use for in-patients. Each extra day in hospital exceeds £500 per patient and for the patient is another night in unfamiliar surroundings. Patients and carers will have individual concerns and a prompt list might be a suitable tool to help these to be addressed.

Although the PCI-WD is novel this project has several limitations. A strength is that it has been developed through multi-professional involvement and participation from patients and carers, however, the process lacked the rigour of formal focus groups and qualitative methodology. The pilot work was undertaken in the context of service evaluation and a more formal evaluation is required. Another weakness is the small number of patients returning the PCI-WD sheets. The main reason for this was the busy ward environment and the various sheets of paper involved during the admission resulting in the PCI sheets going missing. Rather than a paper version, it might be better when used in clinical practice, to have a vibrant clipboard that can be wiped clean and kept by the patient's bed, or to have an electronic tablet version. In this pilot there was no attempt to assess the impact of the PCI-WD in respect to patient and carer satisfaction and if it facilitated an improved discharge and allowed for more appropriate support at home.

The pilot has revealed that patients have multiple concerns relating to hospital discharge.

Effective communication is an integral aspect of holistic cancer care. The most valuable time to discuss a PCI-WD was with visitors present. This not only allowed explanation of its purpose but also a focal point for nurse-doctor-patient-carer discussion around post-operative

progress, concerns and expectations. Some issues did not relate to the discharge planning process yet were very important to patients. An example of this was the presence of the temporary tracheostomy tube which caused difficulties in communication <sup>15</sup> and this was compounded by the presence of a cannula in the dominant hand which made writing problematic. Patients wrote about powerful effects of medication in ICU on thinking and concentration. Concerns expressed by others included 'muzzy head', 'sore throat' and 'dry tongue affecting swallowing'. Lack of sleep, strength outcome for an operated limb, cosmetic appearance and the duration of the NG tube were highlighted in the additional open-ended personal comments section.

Further feedback regarding the design of the PCI-WD and its use is required from the nursing staff and other professionals, however informal comments have been supportive of the pilot and modifications have already been suggested. Table 2 shows potential modifications to the PCI-WD along with future considerations. A potential second iteration of the PCI-WD is shown in Figure 3.

In conclusion, although further validation is required, the PCI-WD would seem to have potential as a resource to be used prior to discharge in consciously focusing patient, carer and ward staff attention on the unacknowledged and potentially complex factors of discharge. By identifying possible challenges early, it may facilitate discharge and allow patients to reflect on their vulnerability thereby encouraging them to have measures put in place to give them as much independence as possible.

#### **Ethics Statement / Confirmation of Patient's Permission**

The data, which had been collected as part of a service evaluation rather than for research, met the criteria of the local Audit Department. Patient permission not applicable

### **Conflict of Interest**

We have no conflicts of interest.

### Acknowledgements

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 $Figure \ 1-Patient \ Concerns \ Inventory-Ward \ Discharge$ 

[PCI] Aint	ree Un	iversity NHS Fo	undation	Trust	HS	Treatment related: Tracheostomy stoma Tubes and drains Feeding tubes Discomfort/pain	Day	Adm-2	3-5	6-8	9+
Head and Ne	ck - \	Nard	Disc	char	ge	Future treatment Side-effects of treatment	lla ataza				
Patient Conc	erns	Inver	ntor	y P	[IDY	Physical and functional we Clothing					
The amount of information patients and	their family w	vould like prior t	o discharge	e from the v	ward waries	Dental check up/Oral health care Diet/eating					
considerably. This Patient Concerns Inve						Mobility		H		H	Н
family raise issues that they want to talk at ward round. Tick as many or as few as						My normal				ō	
concerns you would like to discuss with o						Sleep					
Discharge related:	Day:	Adm-2	3-5	6-8	9+	Voice/communicating					
Length of hospital stay						Weight loss/gain					11
Reasons for staying in hospital						Psychological, emotional an Dealing with frustration	a spirituai v	vesi-being;			PT.
Complications to anticipate						Intimacy		H			H
What to be concerned about						Mental well-being				ō	5
Appearance of my normal						Passing time					
Responsibilities at home					2	Personality and temperament					
Care at home Care of surgery site						Processing the surgery					
Surgery site other than head/neck			ö	H		Sexuality Spirituality/religious aspects		8			
Purpose of medications			Н			Social care and social well-	heina-	4			
How to take medications			Б		H	What I will need at home	Jenny.	O			
Recovery time at home					ō	Who will visit me at home	4	H	H	ä	n
When do I come back to hospital						Managing at home		ū			
Follow-up and reasons why						Finances					
Who to contact if concerned						Explaining changes to others					
Engaging in employment or social	regular acti	ivities 🗌									
upon men											
Patient (D)						Parient (C)					
Patient ID:	2					Patient ID:					
Admission date.	3					Admission date.					
A STATE OF THE STA	3					Monte of the last					
Admission date.  Main concerns:	3			7		Admission date.					
Admission date.  Main concerns:	3			3		Admission date.					
Admission date.  Main concerns:	3					Admission date.					
Admission date.  Main concerns:				3		Admission date.					
Admission date.  Main concerns:				3		Admission date.					
Admission date.  Main concerns:  Main concerns for visitors:						Admission date.					
Admission date.  Main concerns:  Main concerns for visitors:  Here is a list of professionals on the you. If you need to know more above.	ut their role	s and how the		port you	olease ask.	Admission date.					
Admission date.  Main concerns:  Main concerns for visitors:  Here is a list of professionals on the you. If you need to know more about the population of the youngeness of the population of the youngeness of t	ut their role slow) and		y can sup		olease ask. advisor	Admission date.					
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Main concerns for visitors:  Main concerns for visitors:  Here is a list of professionals on the rou. If you need to know more along the concerns of the conce	ut their role allow) and perapist al therapist	- Oncologist/ Radiotherapis	y can sup	- Financial - Chaptain - Clinical pr - Emotions	olease ask. advisor sychologist il support	Admission date.					
Main concerns:  Main concerns for visitors:  Main concerns for visitors:  Main concerns for visitors:  Main concerns for visitors:  Seech (sw. objects)  Oral rehabilitation (ream - Naming state (Vetician - Audiologist - Naciologist - Naming state (Vetician - Audiologist - Naciologist - Naciologi	ut their role allow) and perapist al therapist	s and how the - Oncologist/ Radiotherapis - Clinical Nurse Specialist	y can sup	- Financial - Chaplain - Clinical p	olease ask. advisor sychologist il support	Admission date.					
Main concerns for visitors:  Operator of the concerns for visitors:  Audiologist of the concerns for visitors:  Nursing state of the concerns for visitors:  Audiologist of the concerns for visitors:  Nursing state of the concerns for visitors:  Operator of the concerns fo	ut their role sllow) and serapist al therapist	s and how the  Oncologist/ Radiotherapis: Clinical Nurse Specialist Social worker General practil	y can sup t Soner	- Financial - Chaplain - Clinical p - Emotions therapist	olease ask. advisor sychologist il support	Admission date.					
Main concerns:  Main concerns for visitors:  Jental hygienist  Openist longuage the Occupation team  Openist longuage the Occupation team  Openist longuage the Occupation team  Physiotherapist Surgeon  Thank you for your time. All information is express issues	ut their role sllow) and serapist al therapist	s and how the  Oncologist/ Radiotherapis: Clinical Nurse Specialist Social worker General practil	y can sup t Soner	- Financial - Chaplain - Clinical p - Emotions therapist	olease ask. advisor sychologist il support	Continuation sheet:					
Main concerns for visitors:  Main concerns for visitors:  Here is a list of professionals on the rou. If you need to know more about the concerns of the conce	ut their role sllow) and serapist al therapist	s and how the  Oncologist/ Radiotherapis: Clinical Nurse Specialist Social worker General practil	y can sup t Soner	- Financial - Chaplain - Clinical p - Emotions therapist	olease ask. advisor sychologist il support	Admission date.					

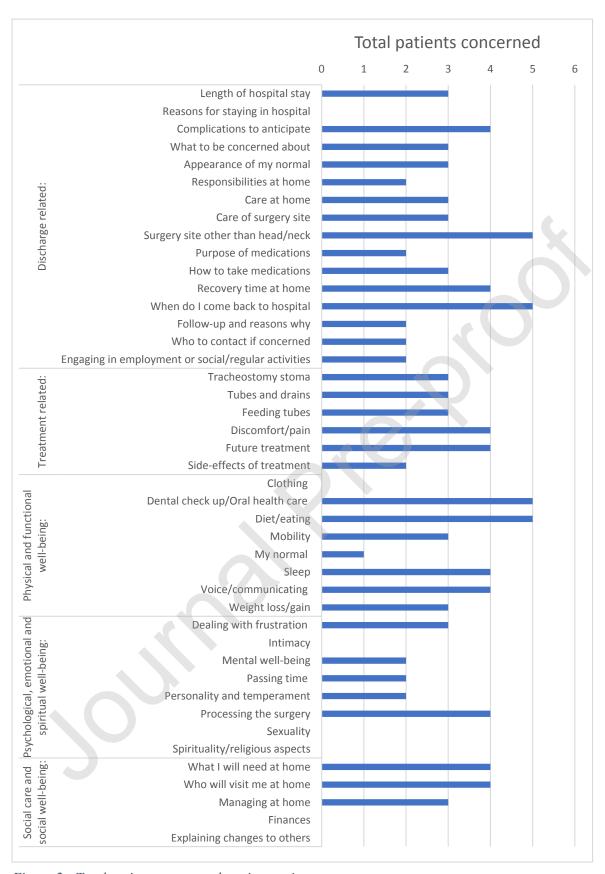


Figure 2 - Total patients concerned against patient concerns

		Commence of	Discharge related:	Concern?	Discussed
Aintree Unive	rsity Hosp	ital NHS	Tracheostomy stoma		
PCI Aintree Unive	PCI Aintree University Hospital				
		1.75	Feeding tubes	0	
		11020	Discomfort/pain	i ii	
		and the same of	Future treatment		0
Head and Neck - Wa	ird Dis	charge	Side-effects of treatment		
			Physical and functional wellbeing:		
Patient Concerns In	vento	ry PCI	Clothing		
his Patient Concerns Inventory (PCI) is a prompt-list to be o	ompleted during yo	or hospital stay. It is to	Dental check up/Oral health care		
nticipate anything that may prevent you from being dischar	ged when you're m	sedically fit to do so.	Dietleating		
Sease use this to highlight any potential issues that you or y			Mobility		
fectors, numes or any other staff at daily ward round. Please correspond with concerns you wish to discuss. The red prom			My normal	0.	
ealthcare professional to place a tick in once the concern h		ner yourset or a	Sleep		
Discharge related:	Concern?	Discussed	Voice/communicating	0	
ength of hospital stay	The state of the s		Weight loss/gain		
Reasons for staying in hospital	-		Psychological, emotional and spiritual w	rell-being:	
Complications to anticipate			Dealing with frustration		
What to be concerned about			Intimacy		
	Lai .		Mental well-being		
Appearance of my normal		4	Passing time		
Responsibilities at home	14:		Personality and temperament	0	
Care at home			Processing the surgery		
Care of surgery site			Sexuality	10	-
surgery site other than headineck.			Spirituality/religious aspects	0	
Surpose of medications			Social care and social well-being:		
flow to take medications	0		What I will need at home	B	
lecovery time at home	0		Who will visit me at home		
When do I come back to hospital			Managing at home		
follow-up and reasons why			Finances		
Who to contact if concerned	-0		Explaining changes to others		
Engaging in employment or social/regular activities					
Admission date:		States Model	Admission date:		States street.

Figure 3 – Prompt-list modification suggestion

Treatment related:	Tracheostomy stoma	New
	Tubes and drains	Modified
	Feeding tubes	Modified
	Discomfort/pain	Modified
	Future treatment	Modified
	Side-effects of treatment	Modified
Social care and Social well being:	What I will need at home	New
	Who will visit me at home	Modified
	Managing at home	Modified
	Finances	Modified
	Explaining changes to others	New
Psychological, emotional and spiritual well being:	Dealing with frustration	Modified
	Mental well-being	Modified
	Passing time	New
	Processing the surgery	New
Physical and functional well being:	Clothing	New
	Dental check up/Oral health care	Modified
	Diet/eating	Modified
	My normal	New
	Sleep	Modified
	Voice/communicating	Modified
	Weight loss/gain	Modified
Discharge related:	Length of hospital stay	New
	Reasons for staying in hospital	New
	Complications to anticipate	New
	What to be concerned about	New
	Appearance of my normal	Modified
	Responsibilities at home	Modified
	Care at home	Modified
	Care of surgery site	New
	Surgery site other than head/neck	New
	Purpose of medications	New
	How to take medications	New
	Recovery time at home	New
	When do I come back to hospital	New
	Follow-up and reasons why	Modified
	Who to contact if concerned	New
	Engaging in employment or social/regular activities	Modified

Table 1 - Items new or modified from PCI-At Diagnosis to PCI-WD

Table 2 - Current design change considerations and considerations for future development

### **Current design change considerations**

- 1. Separation of the columns with a clear division.
- 2. Alternate shading of rows for each point to allow easier discrimination of items.
- 3. Inclusion of documentation area to ensure concern addressed.
- 4. Rewording of the phrasing at the top of the document and underlining or highlighting that patients only need to fill out what they are concerned about.
- 5. Gather specific figures for length of hospital stay to allow for comparison in future to assess if the PCI-WD has resulted in an improvement.
- 6. After the patient has been admitted and run through the PCI-WD pre-operatively, consider retaining the PCI-WD and recommencing once the patient has returned from ICU.
- 7. Patient prompts at regular intervals, or prompt-list given to patient following 7 days post-op.
- 8. Designated pigeon-hole on the ward for PCI Ward Discharges to be placed into when notes are returned for filing, along with ensuring admin staff are aware of the PCI Ward Discharge.

### Considerations for future development

- 1. If over time it is felt the PCI-WD is too complex, more benefit is likely to come to the patient if the design is simplified to just a single time-point during the patient's stay.
- 2. Introduction of a digital PCI-WD Ward Discharge through use of a cased interactive tablet. This could help facilitate patient reminders and allow them to complete their concerns on a daily basis. Use of a survey platform could allow for data analysis and highlight a patient's concern to be addressed and a soundboard for communication and reassurance.
- 3. Consideration for use of voice notes by patients (provided speech is not greatly hindered by the surgery).
- 4. Further adaptation of concerns on the prompt-list.