THINK TALK ACT

An initiative from Pilgrims Hospices

‘TALK’

POST PILOT REPORT

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Executive Summary

Many patients and their families may not yet require specialist palliative care services but they could benefit hugely from raising awareness about future planning of their care and wishes at the end of life and enabled access to other support offered. Patients and their families are referred hospice services late and this often presents as a crisis management scenario rather than an advance plan of care with early support for patients.

To look to address this Pilgrims Hospices have piloted a project known as THINK, TALK, ACT. This report outlines the findings from an evaluation of the 'Talk' part of the pilot. We collaborated with two GP surgeries in the East Kent area to run the 'Talk' pilot. A cohort of their patients identified through the EARLY search tool as potentially in their last year of life were invited through their GP practice via co-designed letter to attend a 'Talk' clinic appointment at their practice.

The aim of the pilot was to understand how the 'Talk' programme was working to refine the future roll out of the programme and evaluation methods. Methods of data collection were from patients - surveys with attenders and non-attenders and case review of patient notes; from staff - survey, observation and consultation with GP staff and hospice practitioners.

The EARLY tool produced a list of 470 patients (1.11%) of the GP caseload as expected. After validation 253 invitations were sent out. 34 appointments were booked (13%) of those invited. 30% of those who booked did not attend. Of those who did attend just over half (52%) were referred to Pilgrims wellbeing services. No patients were referred into the 'Act' part of the pathway.

The programme didn't engage with and provide hospice support to as many patients as intended. It was of benefit to those for whom it did help, who mainly have non-cancer conditions, a key group for referral earlier. Patients found the 'Talk' appointment and therapy/ wellbeing sessions useful, particularly the 'Planning for the Future' session. This and the observations from staff in indicate that a move to cover advance care planning (ACP) in 'Talk' sessions would be welcomed. However, covering both ACP and IPOS discussions in one appointment would be difficult. There were similarities between the 'Think' and 'Talk' patients generated from the list so there could be scope to consider combining the programmes for both sets of patients with this focus

Observations from the data collection from GP surgeries showed that further consideration is needed in any further roll out of 'Talk' to review the patient letter and communications to support with patient engagement, explore further how the patient lists are validated, and consider dedicated staff and booking systems to support the programme.

Integration with the programme with hospice services is also required, e.g. that staff receiving 'Talk' patient referrals are aware and trained on the referral pathway for these patients; that wellbeing programmes on the practitioner tool for referral are running and available.

Overall, the 'Talk' programme and it's evaluation method are recommended for further roll out with some amendments as described above. A larger evaluation of the roll out of the amended programme to other areas and over a longer time to follow up patients would be recommended to understand if the 'Talk' programme has a positive effect on patient outcomes relating to addressing their needs, ACP and end of life care.

Contents

Introduction and Rationale for Think Talk Act

Introduction

It is known from a demographic perspective that 1% of the population will die each year, which in the area we serve equates to approximately 7500 people and Pilgrims support approximately 2500 of these people.

Many of these patients and their families may not yet require intensive support services but they could benefit hugely from raising awareness about future planning of their care and wishes at the end of life and enabled access to other support offered, such as sessions provided by the hospice therapy centres. There is also likely to be unmet need amongst this group for the expert services the hospice provides.

Starting with this pilot, Pilgrims Hospices plan to roll out a project known as THINK, TALK, ACT, with the aim of enabling GP Practices to identify and support relevant patients, and introduce proactive personalised care planning for everyone identified as at risk of being in their last year of life. This will enable more people to be made aware of their situation at an earlier stage so they have the mental and physical capacity to take time to think through what they would like to happen and put plans in place, and access services earlier. This initiative will also be an important link into the Single Point of Access programme in Kent and Medway ensuring these earlier identified group of people have the right access at the right time.

This report outlines the findings from an evaluation of the 'Talk' part of the project pilot.

Rationale for 'Think Talk Act'

Pilgrims Hospices in east Kent plays a significant role in the support and care of patients and families facing the challenges of terminal illness; especially in the last year of life.

There is a growing body of evidence to support the need for 'earlier recognition and referral' for patients and their families to receive palliative care (GMC 2010) and that early support leads to better outcomes at the end of life, including less emergency admissions into hospital (Qureshi et al 2019).

Currently, families are usually referred to our hospice service in the last 10 weeks of life and this referral is mostly generated by the hospital oncology teams. Evidence suggests this late referral is the same in other hospice settings, particularly for patients with non-cancer conditions and older age groups (Allsop et al 2018). This often presents as a crisis management scenario rather than an advance plan of care with early support for patients. This therefore limits the hospices' ability to be equitable and effective in offering support to as many people as possible when it could be most beneficial (Murray et al 2017).

There is nothing new in GPs being tasked to produce lists of patients with different health challenges but it is the 'so what happens next' that the THINK TALK ACT programme is designed to support.
The 'Think' sessions are not designed to replace the patient/doctor consultation but to allow the GP to prescribe a social intervention. We envisaged that the project save GPs time in identifying the right patients plus enabling more efficiency by working along-side them to create cost effective and timely plans that meet the individual's needs, via the 'Talk' element of the intervention. This new service will also support GP's to meet their contractual obligations for End of Life management as outlined in the January 2019 NHS England GP Contract and will be a vital link to the new Single Point of Access service that is planned for the future in Kent and Medway.

What is the 'Talk' programme?

The aim of the 'Talk' programme is to proactively identify the 1% of patients at GP practices, who are at risk of being in their last year of life. This identification is possible by using an established screening tool of GP patient records; the EARLY tool: https://www.england.nhs.uk/north-west/north-west-coast-strategic-clinical-networks/our-networks/palliative-and-end-of-life-care/for-professionals/early-toolkit-for-primary-care/ .

This electronic record screening tool is based on the Gold Standards Framework and Supportive and Palliative Care Indicators Tool (SPICT tool) and research has shown that such tools perform better than clinician intuition alone (Mitchell et al 2017).

These identified patients were then invited to attend a 'Talk' clinic at their GP surgery where they were reviewed by a hospice practitioner to discuss their symptoms and concerns. The symptoms and concerns were assessed using the Integrated Palliative Care Outcome Scale (IPOS) a validated tool currently used in clinical practice in the hospice (Murtagh et a 2019). The IPOS will help to identify needs of the patient and their family and appropriate hospice input will be discussed and prescribed e.g. Pilgrims Therapy Centre wellbeing programmes. A 'Talk' wellbeing prescribing tool has been designed to support the practitioner to identify the appropriate referral to hospice services (e.g. wellbeing programme or other support) depending on their individual item scores on the IPOS.

It may be that patients identified in 'Talk' may require our more intensive support offered by our community multi-disciplinary team or inpatient unit which is the 'Act' part of the hospice service pathway. If patients are identified as needing urgent hospice input or referral back to their GP this will be arranged on completion of the 'Talk' clinic.

The aim of the 'Talk' intervention was to raise awareness of the existing support Pilgrims Hospices offer, which we anticipated will increase the number of referrals to the Pilgrims Therapy Centre wellbeing programmes in particular, and at an earlier point. It is hoped this phased introduction to Pilgrims will dispel some of the fears people have with regard to hospice care. e.g. only being a place where you go at the end of your life.

It aims to enable healthcare providers to identify and support relevant patients and introduce the idea of proactive and personalised advance care planning. The process will also enable closer working between hospice, primary care and frailty teams where there is a clear overlap in the services offered and improved understanding of each other's systems, pressures and services will result in a smoother patient journey; and more importantly a journey that will be more in line with the patient wishes.

In summary the 'Talk' programme aims to:

- support GP practices to identify the 1% of patients at risk of being in their last year of life on their case load who could benefit from palliative care services.

- understand needs of patients and their families that may not otherwise have been identified by services.
- acting on this knowledge by offering to discuss these needs and, enabling patients to access appropriate palliative care services at an earlier stage (or access at the point of need, leading to better outcomes for patients).

The ‘Talk Clinic’ pilot

We collaborated with two GP surgeries in East Kent to run the ‘Talk Clinics’, referred to as Surgery A and Surgery B in this report. These were the same surgeries that had participated in the ‘Think’ pilot conducted a few months before (Marks et al 2022).

Surgery A

Surgery A has a population size of **24,790**, the EARLY tool produced a list of **230** eligible patients (**0.93%**).

The list was then validated by the Practice Manager and any patients that were in care homes were removed which left **183** patients who were sent an invite to attend one of our ‘Talk’ Clinics.

13% (24) booked an appointment and **67%** (16) of these attended.

From the attendees, **50%** (8) were referred into our Wellbeing Services to a prescribed programme/s, many were referred into a selection of different programmes.

Of the referred patients into our Wellbeing services 75% were female and 25% were male.

Surgery B

Surgery B has a population size of **17,602**, the EARLY tool produced a list of **240** eligible patients (**1.36%**).

The list was then validated by the GP and any patients that were in care homes were removed which left **70** patients who were sent an invite to attend one of our ‘Talk’ Clinics.

14% (10) booked an appointment and **70%** (7) of these attended.

From the attendees**, 57%** (4) were referred into our Wellbeing Services to a prescribed programme/s, many were referred into a selection of different programmes.

Of the referred patients into our Wellbeing services there were an equal number of male v female – 50%

Summary

Combined surgeries have an approximate population of 42,392 patients.

The EARLY tool produced a list of 470 patients= 1.11%

After validation at total of 253 invites were sent

13% booked an appointment to attend a ‘Talk’ Clinic.

68% attended their appointment.

52% of these were referred into our Wellbeing Services.

The following programmes available for referral into were:

Strengthen and Balance, Breathlessness Management, Planning for the future, Energise Exercise, Living Well Group, Wellbeing Café, Sit Down Get Fit and Time to Create.

Summary of the Talk Process

The process from identifying the 1% cohort to referral after attending ‘Talk’ a appointment is outlined below in Box 1. Both of the surgeries adopted different approaches to implementing ‘Talk’ within their practice.

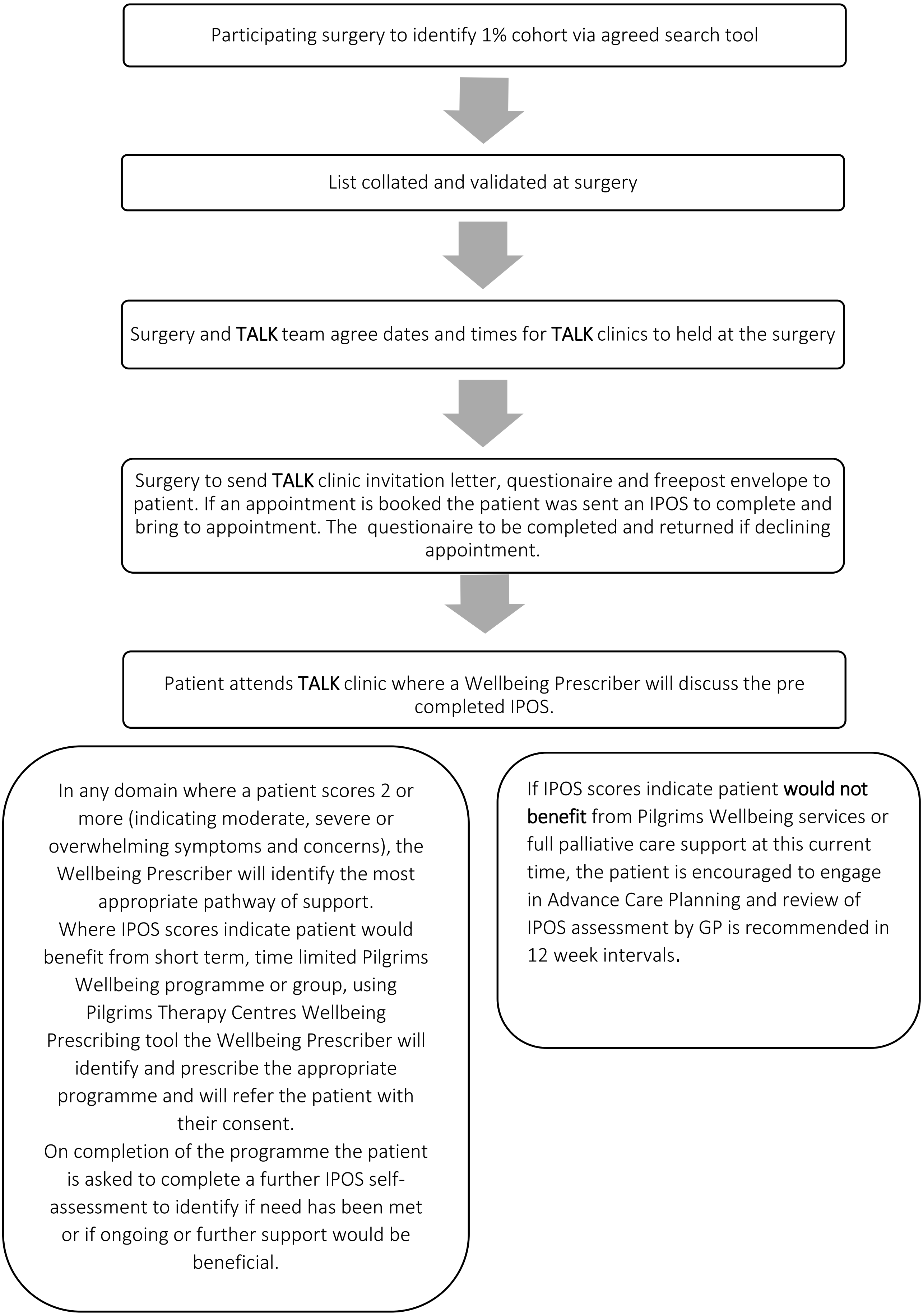
Both surgeries had input into the development of the process, including the patient letter, the method for booking patients in and subsequent referrals to Pilgrims Wellbeing programmes. Both surgeries had a day a week allocated for a ‘Talk’ clinic, with six appointments at 45 minutes each available each day.

Both surgeries opted for the bookings for these appointments to be made via phone call directly to the surgery as they wanted control of the process and felt people may engage more if it was via the surgery rather than the hospice. They opted for different approaches to validation of the “1%”patient lists that were generated, and also in the process of providing the referral information to the hospice:

Table 1: Surgery Talk processes & procedures

Surgery	List Validation	Referral process
Surgery A	Validated by the Practice Manager They mainly removed patients that were in care homes, inviting 80% of the patients identified on the list.	Referral info prepared after ‘Talk’ clinic and those needing referral given to ‘Talk’ Practitioner the following week
Surgery B	Validated by the GP Removed a number of patients they felt were not suitable, inviting 29% of the patients identified on the list.	Referral info prepared in advance of the ‘Talk’ clinic for all patients. ‘Talk’ Practitioner able to collect on the same day.

Figure 1: TALK Clinic Process Flow Chart



Participating surgery to identify 1% cohort via agreed search tool

List collated and validated at surgery

Surgery and **TALK** team agree dates and times for **TALK** clinics to held at the surgery

Surgery to send **TALK** clinic invitation letter, questionaire and freepost envelope to patient. If an appointment is booked the patient was sent an IPOS to complete and bring to appointment. The questionaire to be completed and returned if declining appointment.

Patient attends **TALK** clinic where a Wellbeing Prescriber will discuss the pre completed IPOS.

In any domain where a patient scores 2 or more (indicating moderate, severe or overwhelming symptoms and concerns), the Wellbeing Prescriber will identify the most appropriate pathway of support.

Where IPOS scores indicate patient would benefit from short term, time limited Pilgrims Wellbeing programme or group, using Pilgrims Therapy Centres Wellbeing Prescribing tool the Wellbeing Prescriber will identify and prescribe the appropriate programme and will refer the patient with their consent.

On completion of the programme the patient is asked to complete a further IPOS self-assessment to identify if need has been met or if ongoing or further support would be beneficial.

If IPOS scores indicate patient **would not benefit** from Pilgrims Wellbeing services or full palliative care support at this current time, the patient is encouraged to engage in Advance Care Planning and review of IPOS assessment by GP is recommended in 12 week intervals.

Summary of ‘Talk’ clinic attendance

The total number of Talk patients booking appointments was **34**, across eight clinics between the two GP surgeries. This was **13.4 %** of the number of patients invited **(n: 253**). Further details of clinic activity per surgery is in **Table 2** below.

30% of patients who had booked did not attend (no shows) but no reason was given for why they did not attend. A final clinic was arranged to accommodate previous non-attenders at surgery A. Only one attended of the three who rebooked, but again it was not known why the other two non-attenders didn’t attend. They did not cancel their appointments and it is not known if the reason for this was due to the busy phone line of the surgery or not, understandably people may not call to cancel. This could be an argument to move the booking line to a separate line, potentially to the hospice in a future roll out.

Of those who did attend **(n:23), 52%** were considered to have needs where they were suitable to refer to at least one Pilgrims Wellbeing programme.

Attendance of the booked appointment was slightly better for surgery B compared to surgery A, **78%** and **66%** respectively. The same was true with referrals with 50% of patients being referred from surgery A and **57%** from surgery B. It is not clear if the different approaches to the $1^{\%}$ list generation and validation may have had an impact on this or whether it was due to a difference in the patient groups at the two surgeries. Demographic information of characteristics of the patients on the two lists was not provided.

Table 2 Clinic schedule and take up

Surgery A			
Clinic No.	**PATIENTS BOOKED**	**ATTENDED**	**REFERRED**
1	5	3	1
2	5	5	3
3	5	2	0
4	6	5	4
5	3	1	0
Surgery B			
Clinic No.	**PATIENTS BOOKED**	**ATTENDED**	**REFERRED**
1	5	5	3
2	3	1	1
3	1	1	0
TOTAL			
DATE	**PATIENTS BOOKED**	**ATTENDED**	**REFERRED**
	34	23	12

Pilot Evaluation: Aims, Objectives and Methodology

Aims and Objectives

Aims:

In the pilot the aim of the evaluation was to:

1. understand how the 'Talk' intervention works in a small number of GP pilot sites
2. understand how the evaluation methods work to inform a future larger roll out of 'Talk'.

Objectives:

- Do the identification, validation and invitation processes work. Is this acceptable to GP practices? Is it picking up the right patients?
- Assess the take up of 'Talk' clinics. Whether people are willing to engage having been identified by screening. Who attends.
- Assess patient acceptability, views and experiences of the programme: Their evaluation of being approached for and attending the TALK clinic and its usefulness. What are the outcomes of the clinic e.g. referral to therapy centres accepted and used, whether could result in advance care plan discussions in the longer term, whether involving palliative care had made a difference to their quality of life and any symptoms or concerns they may have,
- Assess clinic practitioner acceptability, views and experiences of running the 'Talk' clinics
- Assess the resource required to deliver the service ready for up-scaled.
- Assess the methods used in the evaluation and what may need to changed or added based on the findings from the pilot.

Methodology

Data collection from service users:

Firstly, survey questions were used to gather information from patients to understand why they did not take up the offer of a 'Talk' clinic. Clinical outcome, referral and demographic data will be collected from those taking up the session from their hospice care record, to understand the needs of the patients and see what impact attending the clinic and any subsequent programme had on patients outcomes in terms of any symptoms, concerns, quality of life, subsequent health care use.

A feedback survey will be used to understand what the clinic attendees thought of the intervention and their views on care.

The patient sample was the full cohort of patients identified from the EARLY electronic record screening tool by the two GP practices and invited to attend a 'Talk' clinic. A one page questionnaire was included with the invitation letter, inviting patients to complete if they decided not to attend a TALK clinic to understand their reasons why. A pre-paid envelope was provided to send this form back to the TTA programme manager.

Patients attending a 'Talk' clinic were invited (at the end of the session/or after by post) to take part in the evaluation of the TALK pilot, by asking for their consent to use their data from their clinical record (referral information and IPOS data from the clinic and at the completion of their episode of care e.g. wellbeing programme). Further information about the IPOS measure is available at: https://pos-pal.org/maix/ipos_in_english.php. They were also invited to complete a survey after they attended their Talk clinic, and those referred to hospice wellbeing programmes were also sent a follow up survey after they completed their programmes.

The patient survey included 'Views on Care' (VoC) questions. This a validated measure that a can be used as a supplement to IPOS to understand palliative care patients quality of life and wellbeing after they have accesses a service: https://pos-pal.org/maix/ipos-views-on-care.php. The survey also included questions on their views, experiences and acceptability of being invited and attending the 'Talk' programme, and their experiences of being a 'Talk' patient at the Pilgrims Therapy centre. Consent was assumed if a survey was returned. Questionnaires were sent out by post (with a pre-paid envelope). A Qualtrics link was also offered as an alternative option to complete the survey online for the first survey but all responses were by post and this was not used for completion.

Data collection from staff:

Survey, observation and consultation methods with staff one-to-one were used to understand the acceptability, views and experiences of staff directly involved in the Talk programme. This included Hospice practitioners who supported 'Talk' patients and staff from the two GP surgeries involving in the Talk programme.

GP practice staff involved in the process of identifying, inviting and booking patients into clinics were invited to complete a short survey by email (distributed via the Practice Manager). Consent of GP staff was assumed with return of the questionnaires.

Observation was to be undertaken at both GP practices on a clinic day with agreement from the GP surgery to understand the processes/workflow of 'Talk' and any barriers/enablers. This will include:

- observation of the 'Talk' clinics with the agreement of the hospice practitioner and patients

- consultation with those involved in 'Talk' at the practices e.g. practice manager and those who ran/validated the lists (for 'Think' as well as 'Talk' to understand patient inclusion/exclusion), and the hospice practitioners.

The observation element is considered consultation or process learning and data will not be collected. Therefore a formal informed consent process was not required.

Unfortunately clinic appointment observation was only available from one GP practice as the clinic day arranged to be observed for the other had low numbers attend for which the patients cancelled.

Public and Patient Involvement

Public and patent involvement advice was sought on the ‘Talk’ programme content (including the ‘Talk’ invitation letter) and evaluation from the Centre for Health Services Studies ‘Opening Doors to research’ PPI group at the University of Kent and from our Hospice research volunteer.

Data Analysis

Descriptive analysis was performed on the quantitative data (non-attendee questionnaire, ‘Talk’ attendance and patient referral info, and patient survey data using SPSS and Excel software packages.

Notes were written for the observations and staff consultations and summarised in this report.

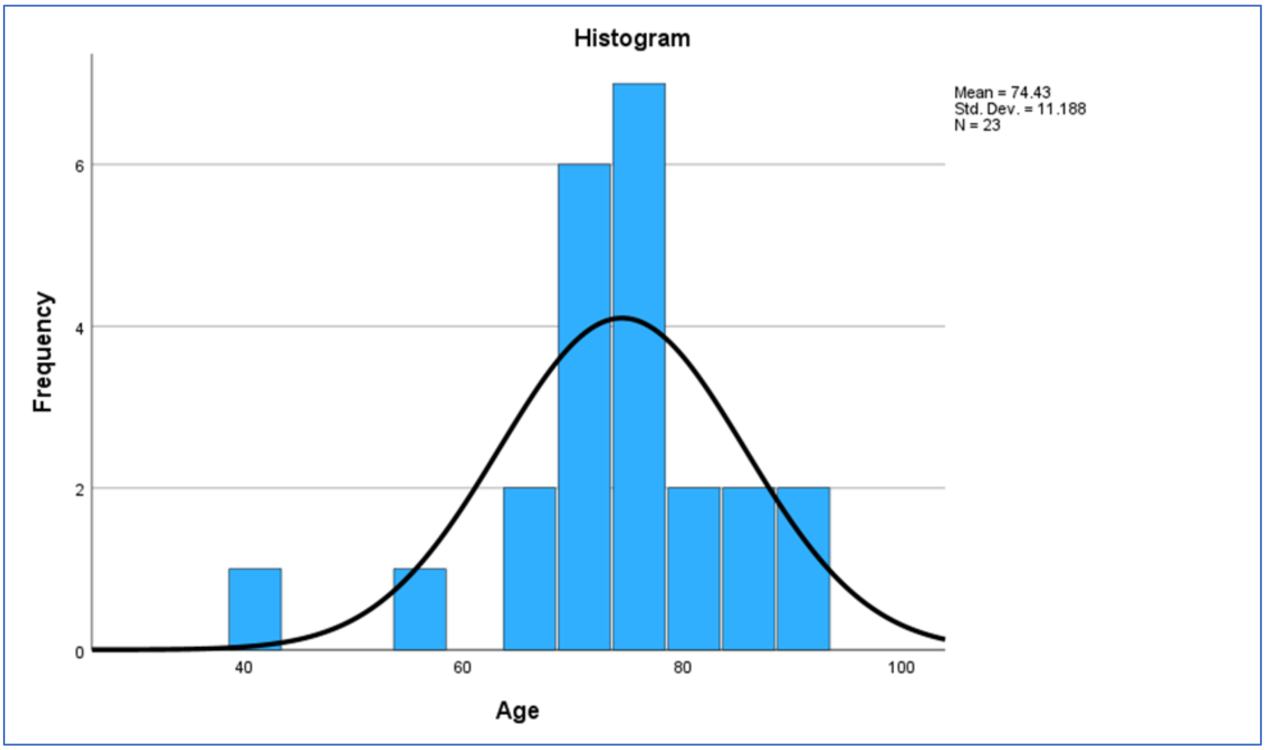
Evaluation Findings

Case Review of Patient Records

Overview of Talk Patients and Referrals

Of the **23** patients who attended a Talk clinic **70% (n:16**) were female and **30% (n:7)** were male. The mean age was **74** (median **77**), with ages ranging from 41 to 92 years old. **Figure 2** highlights the distribution of their age:

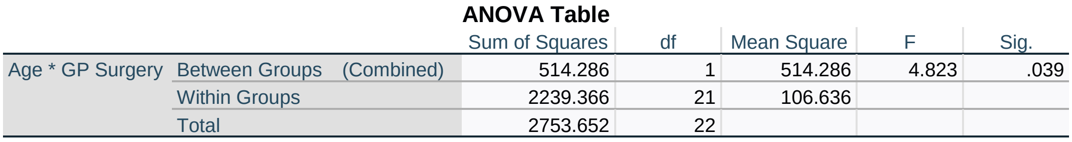
Figure 2 Age of Talk clinic attendees



Unfortunately the patients' diagnosis was not available on the outcome form for the patients attending the Talk appointments, so we only have this information for those twelve patients who were referred on to Pilgrims wellbeing services but not for the 11 patients who were not referred. Of these twelve referrals, **42% (n: 5)** had a cancer diagnosis, but more, **58% (n: 7),** had a non-cancer diagnosis, which included COPD, heart failure, frailty and dementia. For this group, it shows that Talk enabled more patients with unmet needs with non-cancer diagnoses to be referred to the hospice early, which is a key group that are referred late to palliative care services. Unfortunately we did not have the demographic information of the whole list that was generated from the tool screening by the GP practices, This would have given an insight into what proportion of patients with cancer/non-cancer diagnoses the lists were generating and whether this translated into take up of 'Talk' appointments and subsequent referrals of this group.

For these demographic characteristics (age, sex and diagnosis) there was no statistically significant difference between the two surgeries, apart from age (p-value 0.39) which can be explained by some 'outliers' of surgery B having two patients who were under the age of 60 (**Table 3**):

Table 3 Comparison of mean age of Talk patients by GP surgery



ANOVA Table

			Sum of Squares	df	Mean Square	F	Sig.
Age * GP Surgery	Between Groups	(Combined)	514.286	1	514.286	4.823	.039
	Within Groups		2239.366	21	106.636		
	Total		2753.652	22			

All patients that were referred to Pilgrims Hospices following a 'Talk' appointment were referred to at least one wellbeing programme. None of the patients at the point of referral were deemed to be in need of services in the 'Act' part of the patient pathway e.g. more intensive support from our multidisciplinary clinical/allied heath professionals. Although one patient did go on to receive individual support from a hospice physiotherapist after receiving hospice therapy centre support. One was referred onto the service's walking group which wasn't included on the prescribing tool.

Table 4 below shows the prescribed wellbeing programmes that were referred into as a result of attendance at the Talk clinic for all twelve patients. Each programme was referred into for at least one of the twelve patients. Strength and Balance, Planning for the Future, and Breathlessness Management were the most referred in to programmes for 'Talk' patients for their identified needs.

Table 4 Overview of prescribed wellbeing programmes from the Talk clinic

Patient	Planning for the Future	Breathlessness Management	Relax & Restore	Exercise Energise	Living Well Group	Strengthen & Balance	Living with Fatigue
1			*				
2		*	*	*			
3	*	*	*		*	*	*
4		*					
5						*	
6			*		*	*	
7	*						
8	*	*				*	
9	*					*	
10		*				*	
11	*	*				*	
12	*						

Time from the ‘Talk’ appointment to referral, took an average of 2.3 weeks to reach the hospice. It was 3.1 weeks for surgery A and 0.7 on average for surgery B.

The length of time that a referred ‘Talk’ patient spent in the Pilgrims Hospice service (from the ‘Talk’ appointment to discharge) was an average of 16.1 weeks (12.5 for surgery A; 23.5 for surgery B). The number of weeks in the service was higher for surgery B, which had a shorter waiting time for referral in place. The delays to starting were due to the patient’s own personal circumstances, which the hospice accommodated. At the time of the Talk pilot, the Pilgrims Therapy Centres had not long reopened after Covid-19 and the service was short staffed. For example, there was a long wait for ‘Planning for the Future’ which is only available once per month. To ensure ‘Talk’ patient received what they were referred for some exercise classes were offered as a 1-2-1 rather than as a group.

As **Table 5** demonstrates:

Surgery A had a longer wait for their referral being received into Pilgrims Hospices Wellbeing Services due to not having the data available to complete the process on the date of the clinic, this data often had to be collected the following weeks giving an average wait time of 3.1 weeks for these patients.

Surgery B had a different approach and prepared data ready for the clinic and any referrals received were added to Pilgrims Hospices systems within a week of the clinic date.

We had 4 patients not complete their wellbeing programmes due to varying reasons, such as unable to attend due to a decline in health, one patient had a bereavement so we referred them into our separate bereavement services so were able to support them via another one of our pathways.

We had some issues inhouse with our own referral pathway, as this was a pilot project it complicated our usual process.

When a referral was received, a Consultant added the diagnosis onto our system, this caused some complications very early into receiving our ‘Talk’ Clinic patients as these patients were for Wellbeing programmes only and were not palliative. This issue was speedily resolved.

We had also designed a different referral form just for the pilot and this had not been shared with our admin teams which also caused some confusion, again this was resolved straight away..

This highlighted the need to ensure we were fully ready to receive these patients, with every member of staff fully updated with sight of any new style forms.

Table 5 Referral times into service and discharge

Patient	Talk Clinic Appt	Referral onto PH systems	Talk appt to referral onto PH system (weeks)	Wellbeing Programme Completed	PH Discharge date	Talk appt to PH Discharge (weeks)
SURGERY A DATA						
1	30/11/22	13/1/23	6.2	NO	15/3/23	15
2	7/12/22	23/12/22	2.2	YES	10/5/23	22
3	7/12/22	23/12/22	2.2	NO	12/1/23	5.1
4	7/12/22	23/12/22	2.2	YES	7/3/23	12.6
5	4/1/23	25/1/23	3	YES	23/5/23	19.6
6	4/1/23	25/1/23	3	YES	7/3/23	8.6
7	4/1/23	25/1/23	3	YES	7/3/23	8.6
8	4/1/23	25/1/23	3	YES	2/3/23	8.1
SURGERY B DATA						
9	1/12/22	6/12/22	0.6	NO	17/5/23	23.6
10	1/12/22	6/12/22	0.6	NO	31/5/23	25.6
11	1/12/22	6/12/22	0.6	YES	17/5/23	23.6
12	8/12/22	14/12/22	1	YES	4/5/23	21

Case studies of ‘Talk’ patients

For ‘Talk’ patients who gave us consent for use of their patient record data we provide case studies of their journeys through the ‘Talk’ process. There are four case studies outlined below:

- all four were female patients,
- The age range if the four was 67 to 77
- two were cancer and two non-cancer diagnoses,
- three were referred to Pilgrims Wellbeing programmes, one was not.

Case study 1:

Patient 1. completed the initial IPOS and attended the ‘Talk’ appointment where they reported shortness of breath to be their main concern, but they also reported a severe lack of energy, mobility, and anxiety about their illness and others worrying about them. After a discussion at the ‘Talk’ appointment they were referred to Planning for Your Future; Breathlessness Management Group; and Strengthen & Balance Class.

They attended all three of these groups, and all sessions, only accepting the strengthen and balance class once they had completed their current physio treatment for back pain. They were also given Macmillan and Calming Hand information.

After completing the breathlessness management group their VAS score and IPOS scores had remained the same, and hadn’t worsened. Two weeks later their breathlessness had improved by 1 point on the IPOS.

They participated well in the strength and balance class, and they saw their mobility improve by 1 point on the IPOS by the end of the exercise sessions.

At the end of their time attending Pilgrims Wellbeing sessions they had a vast improvement relating to their anxiety about their illness and they reported that they didn't feel anxious at all the worry of others at the end of the programme.

Case Study 2:

For Patient 2. family; health; faith and friends were most important. Their main goal was to improve their mobility, but breathlessness was also a problem. After discussing their concerns at the 'Talk' appointment they were referred to Planning for Your Future; Breathlessness Management Group; and Strengthen & Balance exercise class.

They attended the groups, but had to miss two of the exercise sessions, there was also misunderstanding of the date/time of the classes which were emailed to them. They were also given Macmillan and Calming Hand information.

Breathlessness and mobility IPOS scores were much the same and VAS score unchanged at the end of the programme. They were finding the relaxation CD helpful. They were very thankful and appreciative of the care received by Pilgrims, commenting that they had a 'lovely welcome' on their first visit to the hospice, and they were pleased with the speed of service received. At the end of their programme they said 'Thank you so much for all the wonderful care I have been given during my time here'.

Case Study 3:

The main problem for patient 3 was their mobility, and this was the area they wanted to improve. During the 'Talk' discussion they appeared to have short term memory loss alongside their illness. They did also have Alzheimer's disease. They were referred to the Strength & Balance exercise class.

This was one of the first 'Talk' patients referred to the Pilgrims Wellbeing and the referral was delayed due to the referral going into the wrong inbox at the hospice. This was realised and flagged up by the 'Talk' Programme Manager who was tracking the progress of 'Talk' patients. For this reason the referral to Strength and balance didn't happen until 10 weeks after their 'Talk' appointment. On calling the patient to book their sessions, their mobility had deteriorated further since the 'Talk' appointment due to their dementia. The Strength and Balance programme was deemed no longer appropriate by the hospice, and the family were finding it difficult to cope. Their situation was discussed with the hospice Physiotherapist and the family were called back to offer referral to the Acute Response Team (ART). This was declined as they wanted to wait for a social services assessment. Two further follow up phone calls were made by the Physiotherapist to see how they were getting on and offer advice before they were then discharged from the service. Offer of referral to ART was declined again.

Case Study 4.

On attending the 'Talk' appointment patient 4. had very few symptoms, they were very active currently and felt well supported by their oncology team. It was most important to them to know and understand about what services were available to them in the future should things change quickly. The hospice services were discussed in detail, including advance care planning, at the 'Talk' appointment. They were not referred to any Pilgrims Wellbeing services at this time.

The case review of the patient records and individual case studies gave us good insight into the processes of the outcomes of the 'Talk' appointments, the process of subsequent referral and the outcomes for patients in terms of what sessions they attended and how they felt about those sessions for the staff written notes.

At the time of writing this report all 'Talk' patients had completed their sessions and had been discharged from the service as they did not require any other hospice service at this point. A couple were signposted to other services were there was identified needs e.g. such as social services and our stepping stones bereavement service. At the time of discharge, a letter was sent to the 'Talk' patient's GP to make them aware. This letter states that should the patient require our services in the future we would be happy to accept a further referral. What we will not know is what the longer term impact will be for these patients and whether their Talk experience will enable them or their GP to refer them again at the right point of need. In the future evaluation of any roll out of Talk we plan to do a further follow up to assess patient outcomes, or seek consent to collect data at a later point as part of a follow on study to analyse referral trends.

Findings from the Patient Surveys

Non-attenders survey

The non-attenders survey was sent out to the 253 patients with the 'Talk' clinic invitation letter. As 23 patients booked a 'Talk' appointment there was potential to receive 230 responses from non-attenders who had chosen not to take up the offer of a 'Talk' appointment.

35 responses were received from non-attenders (a response rate of 15%). They were asked to give reasons for why they decided not to take up the offer of a 'Talk' clinic and given the opportunity to write further comments.

Of those who responded:

- **14 (40%)** said that they were not interested in attending
- **11 (31%)** said they did not feel it was relevant to them
- **7 (20%)** said they were not physically able to attend
- Only **2 (6%)** were concerned to attend due to COVID-19.
- **6 (17%)** gave other reasons.

The other reasons included: they were receiving or had just received treatment, such as scans and chemotherapy; one had dementia and wouldn't be able to join in with conversation. Another didn't like the idea of attending groups and similarly, another said ' I just want to be a basic patient with the surgery and doctors'. Another said their husband attended with their daughter already. Therefore it may be possible that this was misunderstood to be the same programme as 'Think' (the earlier programme offered).

The other comments received covered themes around accessibility, understanding and appropriateness.

Accessibility:

Five comments related to this theme, which are given below. These respondents commented that they decided not to take up the offer of a 'Talk' appointment due to age, ill health or mobility issues. The pilot was conducted over the late autumn and winter period and this did not suit one respondent in terms of travelling in the dark. Other alternatives to face-to-face appointments at the surgery might be considered to enable these patients to benefit from the appointment. A virtual appointment via Zoom was suggested by one respondent. However, what we do not know is whether the patients would have been prepared to attend groups at the hospice that could have been offered as a result of attending the 'Talk' appointment. One key outcome though is that this patient is identified.

- *I am not well enough at the moment to commit to any meetings- Zoom might help.*
- *I'm 97 it's too much for me now, like to watch telly and I see my family. They come to me every day.*
- *First of all. I would like to thank you for this invitation, but at this time of year, I don't drive and experience extreme difficulty getting home after dark & do not want to put myself in any more difficult situations.*
- *At the present time I am suffering from a broken wrist and also a very heavy cold.*
- *Disabled and rely on my husband for help and to use toilet constantly.*

Understanding:

Six comments related to the theme of 'understanding' around the purpose and relevance of 'Talk' to them. As mentioned above one respondent thought that they had already attended (possibly 'Think'). Another felt it would be about talking about future care and wishes and felt they already had this covered. The others felt they were not at a stage of their illness where support was needed or they considered themselves to be in relatively good health. This could either be a lack of understanding of what a hospice service could offer them or conversely it may be the sensitivity of the EARLY tool identification and validation process which could have included more relatively well patients who feel they would not benefit, which could be explored further.

- *My husband attended with our daughter already, Thank you.*
- *I already talk about this with my next of kin and they know what I want done. Thank you*
- *Not relevant at this point in time.*
- *Thanks for showing interest, it sounds very good and maybe further along the line but for the time being I'm doing fine.*
- *Maybe when I am older or have a condition that is causing me to struggle with life.*
- *I have signed the A.L.D form my daughter knows of this. I usually have a walk (weather permitting) every day. I go to Zumba class 3 times a week, gardening in the summer months.*

Perceived Appropriateness:

As indicated above some patients were invited who were relatively well and didn't see that attending was relevant or would be of benefit to them (four comments)and are considered in the 'perceived appropriateness' theme. There were a further two comments that related to appropriateness of being invited to attend 'Talk', which are below. One respondent said they had three years to live. The second comment relates to a patient just finishing chemotherapy who said their cancer treatment was for curative intent, and thought it inappropriate and insensitive to receive this letter at this time. These comments do not necessary mean that they were inappropriately identified as at risk of being in their last year of life, but highlights that further research is needed into who the EARLY tool is identifying and the validation process that follows.

- *I have been given 3 years to live*

- *Not at this time in my treatment. I received this letter the day after I finished my Chemotherapy and found it quite insensitive to invite me to plan my end of life care when I'm led to believe that my treatment has a curative intent. I totally understand the idea behind the clinic but feel the wording could be more sensitive.*

The above comment was the only comment to provide negative feedback on the receiving of and wording of the letter. This demonstrates the learning and improvements that have been made to the letters first used in the 'Think' pilot. However lower overall engagement with 'Talk' may mean that the letter should be considered further. There was one other negative comment by one respondent to say that they found the survey form 'offensive'.

'Talk' Patient Feedback Survey

The baseline survey was sent out to 14 participants after they attended their 'Talk' appointment. Twelve of these were the patients whom had been referred to Pilgrims following their appointment. The remaining two were patients who were not referred but were given a 'consent to contact' form to return with their address or email address for us to be able to contact them.

Five responses were received (36% response rate) – these were all from referred patients who all chose to return the postal version of the survey given rather than complete it online. With low numbers, results should be interpreted with caution. The baseline survey found the following:

- **40%** (n:2) felt comfortable receiving the letter inviting them to the 'Talk' session. 20% (n:1) said they did not feel comfortable. The rest neither agreed or disagreed that they felt comfortable.
- The majority felt they understood what 'Talk' was going to be about (**80%** n:4).
- **80%** (n:4) said they found it easy to book the 'Talk' appointment.
- All respondents felt there was enough time to discuss their issues and concerns at the 'Talk' appointment, and didn't feel rushed (**80%** n: 4 strongly agreed; **20%** n:1 agreed).
- No one had a feeling of disappointment after the 'Talk' appointment (**80%** n: 4 strongly agreed; **20%** n:1 neither agreed or disagreed).
- **80%** (n:4) agreed that they understood more about planning for their future care after the 'Talk' appointment, one **(20%)** disagreed.
- **80%** were glad that they attended the 'Talk' appointment; one **(20%)** neither agreed or disagreed.

Respondents were also asked about their quality of life and main issues/concerns before the 'Talk' appointment, and how they felt that had changed after attending the appointment. This was based on the 'Views on Care' questionnaire questions used in clinical practice.

Respondents were asked to rate their quality of life on a scale of 1 to 7 - 1 being very poor and 7 being excellent. For ratings both before and after the appointment the responses ranged from a minimum of **2** and the maximum **6**. Before the appointment the average rating was **4** (median & mean) which decreased slightly to **3.60** (mean)/**3** (median) after. When looking at the change in individual scores quality of life had worsened for 2 respondents (**40%)** by one point and there was no change recorded for three respondents **(60%).**

It should be noted that ratings for their quality of life after the appointment asked how they were doing 'today' which could have been weeks after the appointment as the questionnaires were posted out afterwards. It is suggested that if this method is used again in a future roll out that giving the questionnaire out at the time of the appointment should be considered to increase the accuracy of the rating.

40% (n:2) felt that over the last week (when they completed the questionnaire) that their main problems and concerns had got better. Another **40%** (n:2) felt there had been no change and **20%** (n:1) felt things had got a little worse.

One respondent (**20%)** felt the support of the Pilgrims Wellbeing team at the 'Talk' appointment had given them a lot of benefit on how things were going at present. It had given a little benefit for two **(40%)** and a further two **(40%)** felt it hadn't made much difference.

Two of the respondents did write some further comments about their experience of 'Talk' which highlighted their uncertainty about why they had been chosen based on their need/stage of illness and made them reflect on their illness/condition when they received the letter. They reported positive outcomes as a result of attending the appointment, both in the care they received and the programmes offered:

> *I wasn't exactly sure what to expect or why I was there. My 'Talk' person was really lovely to talk to and , perhaps I did not fit into any particular category, though I am not sure what they were, if any. I was a little confused. One positive was to be notified when I could join a group for walking and really look forward to that.*

> *Receiving the letter regarding the help you were offering made my condition more real. Even though the letter stated that receipt wasn't to do with the stage of my illness, it still felt as though it was.*

'Talk' Patient Feedback Survey – follow up:

All twelve patients who were referred to Pilgrims Hospice Wellbeing programmes after their 'Talk appointment were sent a follow up survey after they completed or nearly completed their programmes. Five questionnaires were returned (a **42%** response rate). As above the results should be interpreted with caution due to low numbers.

They were asked which wellbeing programmes they attended. Some attended one or multiple programmes.

Three of the respondents attended Breathlessness Management Group, three attended 'Planning for your future' (looking at ACP).

One respondent attended Strength and Balance class, Energise Exercise group, Living Well Group, Wellbeing Café, or Walking group (which was an option not on the wellbeing programme prescribing tool).

The survey found the following in relation to the referral process and attendance at the programmes:

- All respondents found the process of referral to start their Pilgrims Wellbeing programme(s) straightforward (**80%** n:4 strongly agreed/**20%** n:1 agreed).
- **60%** (n:3) strongly disagreed with the statement that it took a long time to wait to start their Wellbeing programme(s). One agreed **(20%)** and another neither agreed or disagreed **(20%)**
- All patients felt comfortable attending the Pilgrims Wellbeing programme(s), (**80%** n:4 strongly agrees/**20%** n:1 agreed).
- **40%** (n:2) strongly agreed that they understood more about planning for their future care after completing their Pilgrims Wellbeing programmes. Both of these attended the 'Planning for your future group. Another (who also attended the group) neither agreed or disagreed that they

understood more (**20%** n:1) . Others who didn’t attend that group either disagreed (**20%** n:1) or said they didn’t know (**20%** n:1).

- All respondents strongly disagreed with the statement that they had a feeling of disappointment after completing their Pilgrims Wellbeing programmes.
- All respondent said they were glad that they attended Pilgrims Wellbeing programmes (**80%** n:4 strongly agreed, **20%** n:1 agreed).
- **80%** (n:4) felt confident to ask their GP to be referred back to hospice services when they felt they needed them. One (**20%)** neither agreed or disagreed.

Respondents were asked the same ‘Views on Care’ questions again that they were asked in the baseline survey. When rating their quality of life (1 being very poor and 7 being excellent, both the before and after the programmes the range of responses were a minimum of **2** and the maximum **6**. Before starting the programme(s) the average rating was **3.60** (mean)/**3.00** (median) and improved to **4.20** (Mean)/**4.00** (median) at the end of the programmes. When looking at the change in individual scores quality of life had improved for 2 respondents (**40%),** one of these by 1 point and the other by 2 points. There was no change recorded for three respondents **(60%).**

It should be noted that ratings for their quality of life after completing the wellbeing programme(s) asked how they were doing ‘today’ which could have been weeks after they finished in some cases, as all questionnaires were sent out at the same time for logistical reasons. It is suggested that if this method is used again in a future roll out that giving the questionnaire out at the end of their programme should be considered to increase the accuracy of the rating.

Findings from the GP Staff Survey

Four responses to the survey were received from staff from the two practices (two per practice).Half said they were involved in managing or overseeing ‘Talk’, generating and validating the 1% list or involved in mailing out the patient letters. A quarter said they were involved in taking appointment bookings, fielding enquiries e.g. over the phone, booking rooms for the ‘Talk’ clinics. No one who responded said they were involved in the referral process after the ‘Talk’ clinic.

Interpretation of the results should be treated with caution as the validity and reliability is questioned due to the lower number of responses. It is unlikely that we would have received responses from all staff involved in ‘Talk’ although we were not expecting a large number.

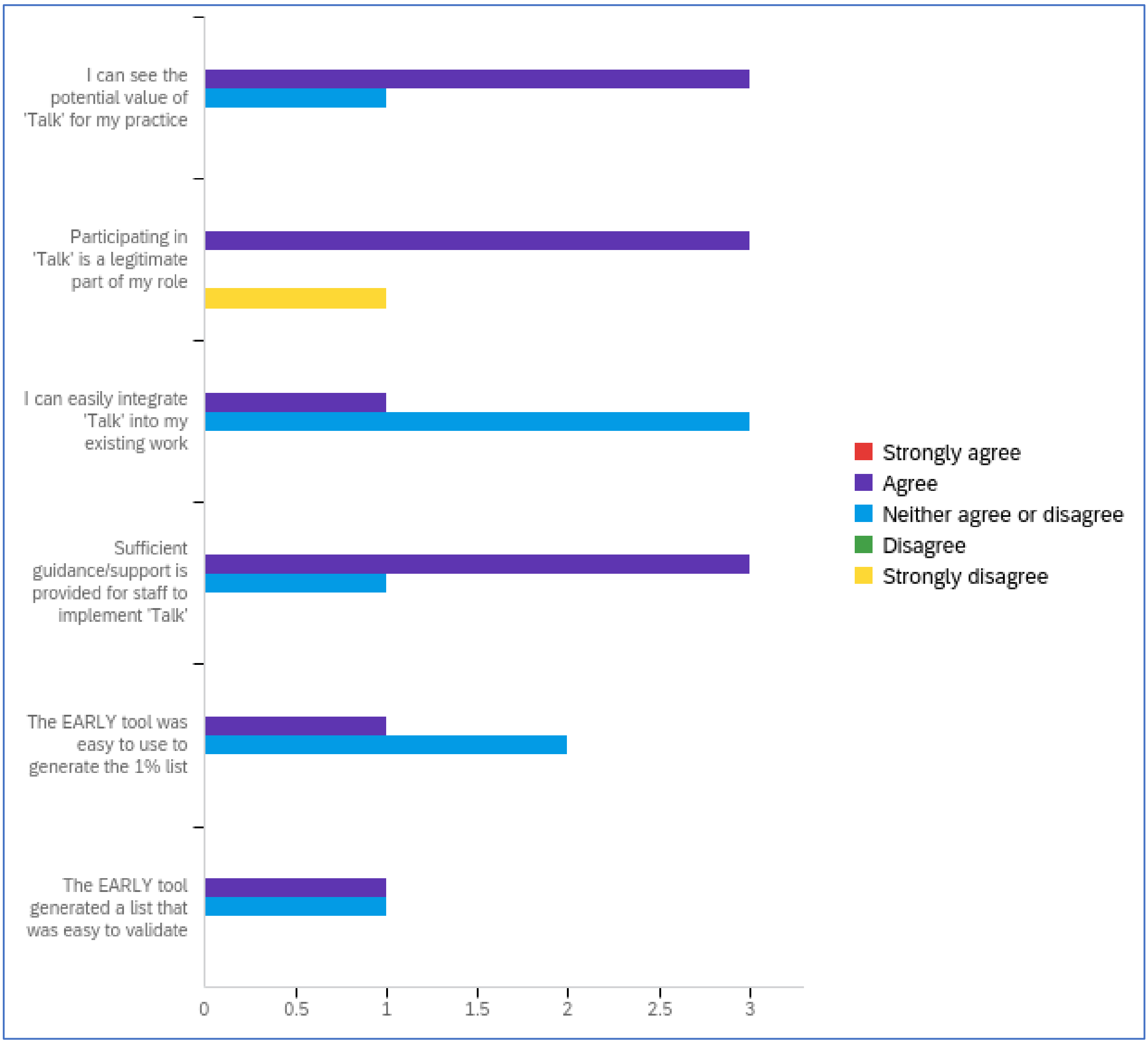
Three quarters of respondents saw:

- the potential value of ‘Talk’ for their practice.
- ‘Talk’ as a legitimate part of their role
- They received sufficient guidance/support with the implementation of ‘Talk’.

Although none of these felt strongly about these areas (**Figure 3**)**.** One respondent who described themselves as involved in managing or overseeing ‘Talk’, involved in generating and validating the 1% list, strongly disagreed that this was a legitimate part of their role. However, another in a similar role was more positive, in agreeing that it was legitimate.

Other statements received generated responses that were less clear, where responses were ‘neither agree or disagree’. Two thirds felt this for the statement ‘I can easily integrate ‘Talk’ into by existing work’ with one third agreeing with the statement. Two of the three responses neither agreed or disagreed that the EARLY tool was easy to use to generate the 1% list. The other agreed with the statement. Only two respondents answered the statement about the validation of the list. One agree it was easy to validate and the other neither agreed or disagreed.

Figure 3: GP practice staff responses to statements in the survey



The respondents were also asked to describe their experiences of taking part in the ‘Talk’ pilot, both positive or negative. One comment was received under the negative heading regarding the wording of the patient letter:

> *The letter that was generated to go out to patients wasn’t particularly received well by a large majority of the patients, I understand from a marketing prospective why the wording of the letter was constructed in that way but there is a fine line between generating return and engagement and undue concern amongst already emotionally vulnerable people* (Surgery A)

This further resonates with findings from the patient non-attendees survey that further work and consultation is needed on the content and marketing of the letter to support the understanding of why they have been invited, what to expect, and reassure about any fears relating to hospice involvement. As the cohort attending ’Talk’ were relatively well this may go some way to explain the patient reaction if the sample sent the letter where similar.

In summary, in the main findings from the small number of responses the feedback was generally positive, with some areas for consideration for future roll out with patient staff engagement. There were some negative or indifferent views and experiences of 'Talk' that need to be considered in the context that it was implemented during the time of winter pressures and after the same practices had recently taken part in the 'Think' pilot prior. Information about the usefulness of the EARLY tool was limited from the survey results.

'Talk' programme observation and consultation

Observation was conducted in one of the pilot practices (Surgery A). Observation in the second practice didn't happen due to further clinic dates needing to be cancelled.

Observation was carried out in the practice, both in the waiting area, and informal discussion with Practice Managers, admin, and reception staff. One of the talk sessions was observed and followed up with discussion with the 'Talk' practitioner.

In general, 'Talk' was very well received. For the administrative side of the pilot staff felt that;

- More clarity would be helpful at the start about all the tasks that would be involved.
- The letter caused confusion and further consideration could be given to how the appointments are presented to invitees.
- The database searches are easy and quick, but the validation takes time – changing the algorithm to make sure that care home residents were automatically excluded would be a benefit.
- Further discussion would be needed to clarify information sharing processes (with practitioners)
- No consideration had been given to repeat list searches – a system for coding would need to be developed, in order to ensure the same patients would not be invited in multiple rounds.
- Thought would need to be given to how often the list could be re-run.

However, although there are administrative questions to be addressed, all practice staff agreed that offering this service to their patients was a positive.

The 'Talk' Practitioner attended the 'Talk' clinical days whereby they had up to six appointments with 'Talk' patients a day at the surgeries. Each appointment was for 45 minutes as 15 minutes was needed for the associated admin between appointments.

A relationship was needed with the GP admin staff who were able to confirm who was attending when they arrived for the clinic day and prepare any referral paperwork to collect after the appointments. One surgery decided to prepare this in advance for all patients so any referred patents details could be given to the practitioner straightaway. The other decided to prepare the paperwork afterwards so they were only preparing paperwork that was needed. The downside to this was that the practitioner would then receive this a week later at the next 'Talk' clinic or even later , causing referral delays.

Talk could be seen as the only opportunity for people to see someone face to face, so difficult to be sure of the drivers for why people decided to attend, and whether it would be different under other circumstances. Many were not assessed as in need of referral to hospice services at this point from their IPOS. Some did have other needs to address e.g. emotional needs/ bereavement issues, which the appointment gave them the opportunity to support. Although not the purpose of the appointment, they did occur, and it was felt that any future practitioners in this role would need to be prepared and skilled to be able to deal with such situations during the appointment.

In terms of the process for 'Talk' appointment, the use of the IPOS and prescriber tool worked well to identify suitable programmes for patients in need. However, sometimes programmes weren't available once referred and patients had to wait a couple of months or a one-to-one session was considered.

A move to cover ACP in these 'Talk' appointment would be welcomed, but it would be difficult to cover this as well as the IPOS discussions for appropriate hospice referral. The issue with the focus on IPOS was that all concerns need to be addressed and there was no clear route for some of these after the appointment other than referring back to their GP.

We were able to consult with a Wellbeing Practitioner who had experience of supporting the 'Talk' patients referred to the Pilgrims Wellbeing programmes. They felt that management had kept them informed about the pilot and when it was going to start. There were separate identifiers on EMIS (the hospice patient record system) so they could see when there were referrals for 'Talk' patients.

In terms of the effect of the 'Talk' programme on their time and capacity day to day, the main impact was the additional admin time needed to contact the patients and book them into programmes. There was no difference in terms of time for running of the programmes compared to usual as 'Talk' patients were booked on to existing programmes. It may have meant however, that our usual patient group had to be put on a waiting list until a space became available for them.

The 'Talk' patients referred were relatively well patients and 'more able' compared to the usual group of patients seen. From their IPOS scores their main issues and concerns related to physical health – i.e. some needing walking aids etc, which could be an age related rather than illness related issue.

As 'Talk' patients were attending the same sessions as our usual patients there were issues in that patients find the sessions to be a space where they can talk to others in similar situations (i.e. nearing the end of life), and the 'Talk' patients were not in this same situation. Some 'Talk' patients struggled with knowing this would be them in the future, and could get them down in their mood, which the practitioners tried to elevate and distract from in the activities. Another way Practitioners tried to help address this during sessions was to identify who the 'Talk' patients were in the group. This could be tricky at times and had considered adding name badge stickers or different colours for them. They suggested that a separate group for 'Talk' patients might be worth considering if it were to be rolled out further to overcome this issue. Logistically, they felt there would be less of an issue of timing if a programme wasn't offered straight away to 'Talk' patients, and instead fill a separate 'Talk' patient programme that wasn't run as regularly.

'Talk ' patients attended the groups they were referred for, but a few didn't stay for the whole programme. Interestingly, they found that the 'Talk' patients attended other groups already e.g. Age UK organised groups, which the usual patients they see do not tend to do. Coming to the therapy centre meant some 'Talk' patients had stopped going to these other groups. The practitioners encouraged them to go back after their hospice programmes had finished.

At the end of their programmes the 'Talk' patients did not need to be referred on to anything else at the hospice, apart from one who was referred to physio. Discharge letters were sent to the 'Talk' patients' GP on completion of the programmes.

The feedback from 'Talk' patients, as for usual patients, is that they would have liked to have carried on once the 12 week programmes were up. Attending made them feel safe and protected. 'Talk' patients attending the 'Planning for the Future' (ACP) session found that most useful.

Main observations and necessary changes suggested:

- ‘Talk’ patients were different to usual therapy centre patients as they already attended other groups. It may be that they used to but stopped due to ill health and palliative care groups offer a space to engage with people going through similar things.
- Usual patients attending groups are more unwell compared to ‘Talk’ patients – separate groups was suggested, or a way to help identify if mixed.
- Need to consider staffing (additional resource) for the additional work more referrals would create e.g. admin and groups.
- ‘Talk’ patients liked the hospice environment when they were there. The word ‘hospice’ can put people off coming – the hospice is seen as ‘the end of the line’.
- People need to know about the work of the hospice and what they do more to not put them off. Some do sadly access services too late, but the issue of access too early is that they are then discharged if no further services are needed. Although ‘Talk’ patients were encouraged to contact in future when they need.
- Getting patients referred to Wellbeing programmes at the right time is important, and therefore it would be a good idea to ensure that we are not missing people who need the support out there.

Conclusion

For those patients who accepted a ‘Talk’ appointment the process was a helpful one. For those patients referred after a ‘Talk’ appointment their quality of life had improved after attending the programmes. ‘Planning for the future’ was the group that was perceived to give the most benefit to ‘Talk’ patients referred to Pilgrims therapy centre wellbeing sessions. The patient record reviews and consultation with hospice staff showed that ‘Talk’ patients appreciated being invited to the appointment, to have time to talk, and also to participate in the programmes. Respondents from the survey indicated that it gave them more confidence to discuss their wishes and future referral back to the hospice.

‘Talk’ enabled more patients with unmet needs with non-cancer diagnoses, which is a group that are referred late. Unfortunately we did not have the demographic information of the whole list that was generated from the tool screening , which would have given as insight into what proportion of patients with cancer/non-cancer diagnoses the lists were generating and whether this translated into take up of ‘Talk’ appointments and subsequent referrals of this group. However, the pilot was primarily conducted to see if the intervention worked as a process and further evaluation of the demographic characteristics of those involved is planned in the evaluation of any future roll out of ‘Talk’.

Despite these positive findings it should be noted that the ‘Talk’ appointment only resulted in just over half of the patients having needs that required a referral into hospices wellbeing services, none required more intensive hospice support (ACT). In any future roll out attention would need to be focused to identifying the characteristics of who the EARLY tool is identifying and on the processes and procedure being followed in the validation of the list, and who is validating it. The data received was limited, but from observations made by practitioners the characteristics between the patients identified by the Frailty Index for ‘Think’ and the EARLY tool for ‘Talk’ did not appear to be significantly different. If the roll out of ‘Talk’ continued to identify patients that are ‘relatively well’ and are similarly discharged after their sessions it would be worth exploring what ‘flags’ could be in place though the GP to ensure that they are referred again at the point of need in the future, or are we seeing patients too early as opposed to the 'right time' and the screening criteria could be reconsidered.

In addition, the engagement with Talk was lower than initially anticipated, with lower numbers accepting the offer of a 'Talk' appointment. There could be many reasons for this. The feedback from GP staff was that although they saw the value in the programme they felt the invitation letter wasn't received well by many patients that received it. The non-attenders survey indicated that people invited were 'doing fine' and didn't need it, but it is possible some may not have understood the relevance/appropriateness for them. This may mean that further work is considered around who is invited and/or the invitation itself, with people having preconceived ideas about what the hospice does and who they support, to help engage 'harder to reach' groups.

Other reasons for low attendance may have been the time of year, which was wintertime, health and mobility of people invited which means that timing and also how the further engagement with this patient group could be delivered differently, e.g. virtual appointments were suggested. Finally difficulties could have been due to the booking system itself. People had to call the surgery to make an appointment which may have put people off, particularly as they had to use the main surgery numbers for which the line can often be busy. However, this was not indicated as a problem in the non-attenders survey.

From the GP staff survey and consultations, the need for adequate staffing for the 'Talk' process to run smoothly was also noted. e.g. appropriate staff (ideally GPs) having time to run and validate the list, enough admin time to prepare and send the invitation letters and other forms, field phone calls and provide the information in a timely manner for patients that were being referred to the hospice following their appointment. In terms of the referral process, this worked best when the surgery organised the referral paperwork so it was ready to collect on the day of the clinic rather than a later date (i.e. the 'Talk' clinic the following week).

Appropriate training of hospice staff is needed for any future roll out. Firstly, the 'Talk' practitioner requires skills and competencies to deal with the range of issues that patients presented with at the appointment. Secondly, that the hospice staff receiving the referrals are trained on how to handle this different type of referral on their systems.

Hospices should ensure they have adequate resources to cope with the additional demand on the service that 'Talk' will generate. The after effects of COVID-19 pandemic meant there were still some staff and capacity issues for the hospice. Some wellbeing services were still not back to being fully operational at the time, both in terms of sessions available and staffing, which caused delay in some 'Talk' patients receiving the programmes prescribed. Any future roll out should ensure the readiness of the service to accommodate the sessions prescribed if they are included on the prescriber tool, or for the prescriber to be aware if there may be a wait for a place to become available.

It is important to note that all patients involved in 'Talk' who were referred to the hospice have since been discharged. However, it is hoped that in addition to any immediate benefits it may have had, the experience enabled patients to have a greater understanding of what services are available to them and enable conversations with their GP in future. We will not be able to see the longer term impact of whether this experience leads them to be re-referred to hospice services at the point of need or ACP conversations occurred/ACP put in place. A move to cover ACP in future 'Talk' appointments could help with this but it was observed that it would be difficult to cover both ACP and IPOS discussions in one appointment. It is also important to consider the signposting routes of those 'Talk' patients who were not referred to the hospice but had other needs and were referred back to the GP.

Recommendations

- Given that the patients invited for 'Talk' were not hugely different from those invited for 'Think' further research on the identification and validation on the EARLY tool in particular is recommended with any further roll out. It may be that the criteria for 'moderately frail' may need reviewing, to ensure we are capturing and not missing those with greater needs.
- Consider approaches for increasing patient engagement with 'Talk'. This could be different communication and outreach pathways for those people who are identified in the list searches who are either not interested or too ill/frail/etc to visit the GP surgery/other venue. This could be offering different formats such as virtual and (potentially) home visits in order to facilitate those too unwell to attend an in person appointment. Having face to face appointments was a positive part of 'Talk' and should still remain as part of the offering of the programme.
- Consider an increased focus on advance care planning in the 'Talk' appointment. The overlapping outcomes of both 'Think' and 'Talk' highlights the possibility to link the 'Think and 'Talk' sessions together e.g. offering 'Talk' to 'Think' attendees an promoting the wellbeing services of the Therapy centres as part of 'Think'. Likewise, 'Think' patients wanted to support with the next step of their advance care planning through a one-to-one appointment. A suggestion is that the 'Think' and 'Talk' list searches become a similar pathway (i.e. group events) with additional referral as appropriate.
- Consider further guidance to support GP practices to help integrate 'Talk' to become part of their regular work. Dedicated admin time is suggested to support with sending out the letters, appointment bookings/enquires if done internally, dealing with referrals to the hospice. Due to phone waiting times with GP surgeries, particularly during times of winter pressures, it is recommended that a dedicated phone line and team member to field calls/bookings is in place. This could be at the hospice.
- GPs would also need dedicated time to validate the lists and processes in place for how often to generate the list and to ensure patients are not repeatedly invited to attend. This may not be a problem per se, particularly for those who didn't attend at the first invite but may like to in the future. Perhaps an option for patients to decline being sent further invites could be included as part of this process. GPs may also need to consider what follow up conversations to have with patients around ACP or other unaddressed needs after 'Talk discharge'.
- In a future roll out avenues for communication between the 'Talk' team and the hospice services should be in place, to ensure smooth and timely referral, ensure that there is capacity to offer the sessions prescribed or raise awareness of wait times e.g. ensuring therapy centre classes are available and staffed before offering on 'Talk', or explaining to 'Talk' patient that they will go on a waiting list at the appointment so they do not miss the opportunity.
- Consider increasing the capacity of the Pilgrims Therapy Centre, in terms of staffing and available groups, to meet the increased demand for group attendance from 'Talk' patients. Consider the flexibility to offer 'Talk' only sessions to avoid other patients having a longer wait for sessions and difficulties that may occur with the 'mix' of palliative and non-palliative patients in the sessions.
- Preparation of hospice staff for referrals coming through 'Talk' – e.g. so admin and therapy centre teams know how to handle referrals that could be identified as non-palliative.
- For future evaluation of any further roll out, it is recommended that the evaluation data collection is integrated within the intervention to enable both easier collection of data and timely data collection to avoid missing data and the collection of more accurate data e.g. 1. patient questionnaires given at time of 'Talk' appointment and follow up on the completion of programmes. 2. Incorporate required data collection from GP practices as part of the intervention, e.g. demographic data from the 1% list, reasons for exclusion during validation, updates on any follow up with patients and ACP after discharge from the programme.

Disclaimer

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Please contact Karena Marks: karena.marks@pilgrimshospices.org for further information.

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