

APPENDIX 2- Table showing qualitative participants' characteristics (names have been changed to ensure confidentiality)

Study ID	Study name	Profession	Ethnicity	Age	Number of patients involved with who had H2H CC	Field notes (if any)
HP1		ILD Consultant	White other	37	18	
HP2		ILD CNS	White British	31	32	
HP3		Community Matron	Philipino	30	2	Involved in the care of 2 patients that died at home as planned. Although consented to interview, this subject was very hesitant to make any comments that might be perceived as negative.
HP4		Community Palliative Care Nurse	White British	31	1	
HP5		GP	Asian British	42	1	GP very keen to take part in interview and feedback his views. GP for 34 year old patient with IPF.
P1	Alfred		White British	64		Patient with advanced IPF (no carer) on transplant list. Patient admitted for trial of NIV. Happy to take part in interview.
P2	Michael		White British	63		Advanced IPF with no carer. Patient unhappy with the state of NHS. Interviewed at home.
P3	Peter		White British	63		Advanced IPF with carer. Interviewed on day unit. Patient wearing oxygen. Struggling at times with SOB
P4	Stephen		White British	81		Fibrotic NSIP. Patient interviewed at home. Wife also interviewed as carer. Both interviewed separately.
P5	Mary		White Irish	84		Patient (NSIP) interviewed at home- relatively well at time- daughter interviewed
C1	Ann		White British	72		Wife of P4- interviewed at home.
C2	Sue		White Irish	48		Daughter of P5. Interviewed alone.
C3	Rachel		Black Caribbean	47		Daughter of 75 year old patient with IPF (not interviewed). Sole carer for patient.
C4	Leslie		White British	54		Wife of Ted- patient 55 year old patient with IPF. They have a 23 year old son with cerebral palsy which Ted is the main carer for. Interviewed at home with husband present.
C5	Penny		White British	63		Wife of 67 year old patient with IPF. Interviewed alone. Patient not interviewed

Recruitment for the qualitative study was conducted between May 2013 and November 2013. 5 patients, 5 carers and 5 health professional participants were recruited. Health Professionals (HP) recruited were an ILD Consultant, ILD CNS, community matron, community palliative care nurse and a GP. The qualitative results will be discussed in the following themes: 1) *Support in the community* 2) *Individual care plans and practical problems addressed* 3) *Co-ordination of care and efficiency* 4) *Crisis management* 5) *Palliative Care and psychological support* 6) *Symptom control* 7) *Empowering HP* 8) *Advance care planning* 9) *Feasibility and acceptability of intervention*.

Examples of quotes have been used to illustrate themes. Names have been changed to ensure confidentiality.

Theme 1 Support in the community

Previous to the Case Conference (CC), both quantitative and qualitative data showed that patients and carers were poorly supported. Patients and carers interviewed received routine care from their primary care physician. However, no patient or patients looked after by carers had any other professional help. Importantly, as well as not receiving support from HP in the community, no patients or carer participants interviewed were aware of the services that were available to them. In addition, if the patient or carer participants needed help, they often relied on the specialist ILD centre. However, the distance to RBH often caused patient and carer participants concern. This was typified by Leslie, 54 year old wife of Ted who had advanced IPF:

“What was it like erm before you had the CC what sort of input and help were you getting?” (SB)

“nothing we weren’t getting anything not from (2) not locallyreally (2) anything we needed we had to either go to or phone London.....and it’s like so it’s a 2 hour [laughs] it’s a 2 hour round trip.....but (1) that was quite scary cause you sort of think you know it’s a long way away you know if we need (4) u:::m (1) so local support just wasn’t there.....” (Leslie, 54 year old wife of Ted who had advanced IPF).

Patient participants such as Stephen, a 81 year old patient with NSIP, had felt that prior to the CC they had not known what they were doing. Importantly, through the CC patient, carer and HP participants became more aware of the services that patients and carers were entitled to. All participants reported that through the CC, patients and carers received support from a variety of community HP. Patients and carers commented that they were regularly contacted by community HP to check that they were “okay”. The community HP would not necessarily visit every week but would phone to touch base with the patient and carers. Patient and carer participants commented on how it was reassuring that someone was checking on them and that this made them feel “safe” and how they were grateful for all the help that they were now receiving.

“I think] I’m very lucky....I didn’t think that help was there” (Mary, 84 year old with NSIP)

Carers felt happier to have access to a support network in the community. For example, carers such as Ann, 72 year old wife of Stephen who had advanced NSIP, reflected on how they had felt isolated and were required to muddle through before:

“I was bit nervous before hand you didn’t have anyone to turn to really.....we have one son in xxxx but he’s far away and (2) I have a sister in xxxx which phones me up every day but [coughs] otherwise that’s I felt alon:::e” (Ann, 72 year old wife of Stephen who had advanced NSIP)

“and how do you feel now?” (SB)

“I feel better..... ‘cause I have all the phone numbers and people phone me up....” (Ann, 72 year old wife of Stephen with advanced NSIP)

Patients like Peter (63y with advanced IPF) were grateful for having been involved in the study and receiving support which he felt he would not have got if it had not been for the CC. Touchingly, he reflected on those who were still not receiving support. He stated:

“.....because before that [CC] erm well I say they they wouldn’t have known about me anyway erm (3) but (2) its [coughs] for people that are maybe not coming her:::e erm they they can be sitting indoors erm with no no help and not

knowing where to get it which is a shame” (Peter, 63 year old with advanced IPF).

Theme 2 Individualised care plan and practical problems addressed

Through the CC, an individualised care plan specifically meeting the patients’ and carers’ palliative care needs was developed. Using the evidence based guidelines, symptom control issues were addressed. Specific action points were allocated to each HP codifying responsibility. After the CC, the H2H CNS contacted the patient and followed up with the HP to ensure tasks were completed. In addition, in the care plan patients and carers had the contact details of how to contact each of the HP directly if there were any issues. This process is illustrated by the Community Palliative Care CNS:

“[the H2H CNS] contacted us afterwards to check everything we had said we were going to do we’d done which we had erm::: and we had her number to be able to contact if he had any problems as well so::: erm it went all quite smoothly really...” (Community Palliative Care CNS)

Many patients and carers had practical problems that needed to be addressed. Both patients and carers expressed how quickly after the CC these practical issues were attended to especially as many patients had been waiting a long time for these issues to be addressed. Rachel (47 y), whose mother had not received any care prior to the CC, reflected on how after the CC things moved very quickly. She said:

“...the district nurse she was just making sure that erm mum is comfortable er:::m cause at the I think that was the time when they all came mum was suffering with bed sore:::s.....so that was erm (2) a problem and I mean (1) it was dealt with fantastically because erm (3) xxxxx (2) made sure that a bed (1) hospital bed was delivered within two three days...” (Rachel, 47 year old daughter of patient with advanced IPF)

The GP felt that as responsibility was codified and patients/carers had contact numbers for all HP on the care plan, HP were more likely to follow through on tasks.

Importantly, the individualised care plan holistically focussed on the needs of the patient, carer and where applicable, other family members. Patients and carers during the qualitative interviews reported how beneficial this was. Quantitative data also showed a significant change in patient POS (measuring holistic palliative care needs of the patient) score for the FT group at week 4 and the WL group at week 8. Leslie discussed how the CC allowed their concerns for their son (which were at the forefront of their minds and fundamental to improving their quality of life) to be addressed by the social worker attending the CC:

“our erm (2) youngest son’s got cerebral palsy.. so erm after that meeting [CC] it was put in place for him to have erm (4) er counselling erm (3) and to explain to hi:::m (2) erm what was happening... and so he has a better understanding now erm (2) because it’s difficult to know you know you need somebody really from the erm (2) special nee:::ds to (2) to get through to them in in in the way that needs to be done rather than (1) so we had that put in place as well after the meeting [CC]” (Leslie, 54 year old wife of Ted who had advanced IPF).

Theme 3 Co-ordination of care and efficiency

Before the CC, patients and carers stated that there was a lack of co-ordination and efficiency in the care that was delivered. Stephen, a 81 year old patient with NSIP, expressed his frustrations with the lack of effectiveness of the health system:

“there was a lot of people didn’t know what to do with me a- quite I I suspect um I I can’t say for sure [deep intake of breath] and it seemed to be I’ve (1) been pushed from one to another or pushed round and round in circles I was taking a lot of er (1) tests (2) and they were all being sort of duplicated” (Stephen, a 81 year old patient with NSIP)

Post CC there appeared to be some improvement; Alfred, 64 year old patient with advanced NSIP and no carer felt that the CC allowed everyone to “sing from the same hymn sheet” improving efficiency of the care delivered. In addition if an admission did occur, the care plan gave clear

information about who was involved in the patient's ILD care. Carers such as Sue felt that having the care plan cut down a lot of time as she could just hand the care plan to any HP if needed.

Prior to the CC, HP participants such as the ILD Consultant recognised that there had been poor communication and a lack of joined up thinking. HP were in agreement with patient and carer participants about inefficiencies prior to the CC and that the CC had improved communication across the primary and specialist care setting:

“actually quite nice we don't generally get those we generally get you know the referral and then we have to ring up and get more information and find out you know do they know their (1) their prognosis and you know has his advanced care planning been discussed etc etc so having to like tease all the information out and then sometimes when we get there actually bring up it they say that it hasn't been discussed even though sometimes the hospital say it has so it [the CC] was very helpful in that respect” (Community Palliative Care CNS)

All HP were in agreement that having the patient and carer at the CC, involved in planning and fully aware of treatment plans for the future, was very helpful and allowed concerns to be prioritised focussing on the patients' and carers' needs. The ILD Consultant felt that as the specialist centre, they did not have time to address palliative care needs in busy clinics. As a result, these needs had dropped to the wayside. He was grateful for H2H. He stated:

“certainly knowing that that aspect of the care was being taken care of it's not (1) its just so difficult to provide that sort of level of fine detail in this hospital with so many patients coming through and as a referral centre that there just isn't the manpower to be able to focus on that sort of (1) erm specific symptom control and again knowing that you guys are doing it is a is a is sort of (1) often then it removes that from something we need to worry about.....” (ILD Consultant)

The many different ways of referring to community palliative care teams and the variance in the community support received was seen as a barrier to referral by the ILD teams. Patients receiving H2H had the H2H CNS making all the referrals to the appropriate community HP. She would also try

to ensure that the care remained co-ordinated by checking in with the patient at 2 weeks, one month and 2 months after the CC. Patients, carers and HP could contact the H2H CNS if there was a breakdown in care which she would try to resolve. This was reflected on by the GP who felt that co-ordination of care for patients who weren't involved in the study was "patchy" and "haphazard". The GP expressed that it was an unknown for patients, carers and HP as to which HP may be involved in the patient's care and a lottery as to which HP would subsequently visit the patient at home. He stated:

"if it wasn't for this (2) I can see a completely different scenario where this guy would be lost in the communityhe::: would be trying to find out who::: the respiratory nurse is [laughs] trying to get out who's the oxygen supplier trying to find out from his GP which one's going to be in charge of his care in the general practice which one's going to be helping him with his symptoms (1) you know it it would have become a hug:::e hassle and I don't think he::: realises how lucky he is actually to be part of this trial (2) because everything's there for him (2) there's no other issue..." (GP)

This was reiterated by the ILD CNS who felt that having the H2H CNS co-ordinate care and be available if needed gave extra support to patients and added an extra layer of support for the patient and carer to turn to if there was a breakdown of care in the community.

During the CC, HP were codified responsibility to address issues raised at the CC. In doing so, contact numbers were available to both the patients and carers for each HP and their allocated task. HP participants commented that having contact numbers of HP involved in patients' care clearly documented on the care plan was helpful. HP participants such as the community matron reflected on how she wasn't aware how to get in contact with the specialist teams prior to the CC and as a result would not have done. She felt that the contact numbers on the care plan facilitated approaching the specialist centre if needed and as a result improved care. Community HP interviewed also felt that having the H2H CNS at the CC fostered the relationship between the specialist and community settings and made it more likely that they would approach the specialist centre if needed for advice on how to manage the patient's care.

Interestingly, being involved in the study led to recognition by HP of the serious nature of the disease. As a result, not only did patients receive more HP input but patient participants and patients looked after by carer participants stated that they also gained easier/priority access. Carers such as Sue, 48 year old daughter of Mary who had NSIP, expressed that prior to the CC, she would often try to contact her GP at the local surgery which was often a time consuming and long process. However, post CC, things had improved immensely:

“the practice nurse has a system where something will come up where erm it’s noted it will flag up that mum’s in this home to care [H2H] process.....she can bypass a lot of the (1) the red tape” (Sue, 48 year old daughter of Mary with NSIP)

This was also recognised by the HPs interviewed. The GP commented that as a result of the study, patients had received FT access to all HPs. The GP reflected that this was empowering for the patient and carer. He stated:

“the patient is in charge of their own care:::for somebody like this yea:::h I think it’s really useful for them because then (1) they can sort of direct their questions to the right people cause they’re they’re fully aware” (GP)

Theme 4 Crisis management

Carers such as Penny (63y wife of patient with IPF) felt that prior to the CC, they would have rung 999 if her husband needed help out of hours. All patient and carers expressed relief that the CC had set out clear crisis management plans with direct contact numbers for HP 24 hours a day:

*“that’s right (1) um (3) one of the things that I do (2) imme:::diately was that (2) as soon as I had the telephone number of one of the (1) people I contact, was straight into the into the telephone d- line, dial in directly (2) ah (2) both my old telephone [laughs] and my (1) mobile, so its its there so I can contact them.”
(Alfred, 64 year old patient with advanced NSIP and no carer)*

As did Peter, 63 year old with advanced IPF, who felt that having access to contact numbers and a clear crisis management plan was a vast improvement:

“and now I've got all erm (2) they as I say they phone and I've got er a whole list of numbers that I can phone any time day or night erm if I need to, you know” (Peter, 63 year old with advanced IPF).

“do you find that helpful?” (SB)

“definitely] erm (1) it gives you (1) definitely gives you peace of mind, definitely” (Peter, 63 year old with advanced IPF).

“... Do you think that er you would know what to do in a crisis no:::w, so if something went wron:::g?” (SB)

“ oh yes yeah and (1) and (2) as I say I've got erm the telephone numbers... of of people that I can phone erm 24 seven which is ideal I mean before that erm the most I could do was dial 999” (Peter, 63 year old with advanced IPF).

In addition, HP such as the GP and ILD Consultant felt that having access to all the contact numbers was likely to help prevent hospital admissions.

Theme 5 Palliative Care and psychological support

Patients and carers felt that they had not been able to access palliative care prior to the CC. The main barriers to referral were misconceptions of what palliative care is and a misunderstanding of which patients were suitable for referral:

“our doctor we did speak to him (1) about (1) local care but our doctor actually said to us that they don't look at palliative care till you're bed ridden [laughs] (4) erm (4) but you need the support a long time before that (2) erm” (Leslie, 54 year old wife of Ted who had advanced IPF)

HPs were not the only ones that had preconceptions of palliative care. Patients and carers expressed that prior to the study they thought that a hospice would be somewhere where the “walking dead”

attended. Despite being involved in a palliative care study, some patients and carers were surprised to be contacted by the local hospice:

“we were a bit surprised er er to hear from the hospice (1) you know I mean er first first reactions when somebody (1) erm (1) one second [clears throat] wants to get a hospice involved you think like you've got to go in and er [laughs] you're not coming out” (Peter, 63 year old with advanced IPF).

Because of these misconceptions, patients and family members required repeated clear explanations of the remit of palliative care during the study. The appropriateness of palliative care/hospice teams in supporting patients for symptom control and psychological support throughout the disease journey was explained on entry to all patients and carers but needed to be repeated, especially if other family members became involved/attended the CC.

Interestingly, both patient and carer participants who had been hesitant of palliative care/hospice involvement at the start of the trial, subsequently expressed how much they valued the support they received from attending the day hospice and receiving regular palliative care input.

“I must say to everybody (2) definitely it is it's (2) I don't know how long I've got left but (2) whatever time I've got left (3) this palliative care is going to make that time better for me and it's better and if it's better for me it's better (2) for us as a family....I've been telling everybody (2) how important (3) you know I just wish I could get GPs in to buy into the (2) palliative care cause its makes such a difference (2) made such a difference to me” (Ted, 55 year old patient with advanced IPF)

In fact, being involved with the study and receiving community palliative care was seen as beneficial for both patient and carers in improving psychological symptoms. Sue commented that prior to the CC, her mother had been depressed. She felt that focussing on current and future care needs through the CC and accessing a support network had focussed her mother and improved her mood. Ted expressed that attending the day hospice allowed him to talk about his feelings if he wanted to:

"I I have weeks when (2) er like last week I wanted to talk about (3) you know (2) my illness and stuff...and they're there then (2) for me to be able to tap into.. which I am happy for because (3) when you're in in my my sort of position when you know your life limited (1) is your life is limited often at home (3) you tend you live a lie say to people you live a lie I think because say how do you feel you just say I feel fine but because you don't want to be worrying people all the time but (1) when you've got a palliative care team round you you can get that out of your system which is something we didn't have for the first 18 months two years of this disease" (Ted, 55 year old patient with advanced IPF)

"do you mean that then you can be honest about how you feel?" (SB)

"yeah I can I they cause sometimes it's just about releasing it.... it's not it's not necessarily who you even talk to [laughs] it's yeah it's just somebody who cares but that means then I can come home and life is better at home" (Ted, 55 year old patient with advanced IPF)

Importantly, there was recognition that the disease affected the whole family and that support for loved ones and carers was needed. Support from the palliative care teams for carers was appreciated by both patients and carers:

"I started to go the day hospice once a week for 6 weeks and also er which I thought was a very good thing erm (1) they asked my wife if she wanted to go over there erm once a week erm (1) to a carers (1) erm (1) sort of meeting and er (1) also (1) erm (2) they they what else are they doing for her oh they do a she (1) tends to get swollen a ankles quite a bit erm and they (1) they massage them" (Peter, 63 year old with advanced IPF).

Theme 6 Symptom control

During the CC, the evidence based guidelines on managing the palliative symptoms of patients with ILD were distributed to all HP involved in the patient's care (whether attending the CC or not) and also

to the patient and carer. HP, patients and carer participants found these guidelines helpful. HP participants such as the GP felt the evidence based guidelines were useful in improving symptom control with clear options of what to prescribe patients if they deteriorate. The community palliative care CNS also felt that the intervention improved symptom control through increased confidence in their current practices and allowing community HP ready access to specialist teams in the hospital if needed. She stated:

"I think it was helpful to get because obviously we don't get a huge volume of these types of patients and er and therefore our knowledge isn't as as great as as some of other knowledge on other patients that we get a lot of it was quite nice to know erm the exact plan for them really....it's quite nice to speak to a specialist and say you know what what what particular drugs do you think work better you know we know what you use for ours but is there anything in particular and there wasn't anything hugely different but it's just nice to have somebody who specialises a bit more in the you know because the the diseases" (Community Palliative Care CNS).

ILD HP participants such as the ILD Consultant also felt that the intervention had been helpful in improving symptom control. He stated:

"we would start er symptom control in hospital whether that was a little bit of Oramorph or lorazepam and then it was really we wouldn't often see the patient for another 3 or 4 months time and it was then back to the GPs hands to sort of titrate and change that as needed um and it it didn't always go successfully the things weren't re-prescribed or wrong doses were given but knowing that er (1) you and your team are now doing that again we've had patients say that it's been very useful for them to have sort of continuity of care and someone taking overall view of that...." (ILD Consultant)

Carers such as Sue expressed that as a result of the CC she was made aware of all the options of delivery of care available to her mother. For example, she was not aware that if needed, her mother could have intravenous antibiotics at home so an admission to hospital was not always necessary. In

addition, having a documented clear strategy on how to manage each symptom within the care plan was seen as invaluable by all participants. Carers felt that it allowed them to manage their loved ones symptoms better and sometimes prevented hospital admission.

Theme 7 Empowering HP

The CC was seen as empowering by both the specialist and community HP participants interviewed. The ILD CNS commented on how a large part of her job as an ILD CNS was to deal with end of life issues and it was helpful to see how end of life conversations were handled by the H2H CNS. Being involved in the CC guided HP participants in how they ought to be conducting conversations around advance care planning:

“it's certainly enhanced my practice, um, certainly there's an huge (1) element of my job which is dealing with um the palliative care and end of life of patients, and I think, seeing how palliative care interact with patients and bring up (1) uncomfortable::: (2) subjects for us as health care professionals, certainly has enhanced my practice....We need to::: (1) understand that these aren't necessarily subjects that patients don't want to discuss...sometimes some of the anxiety around the issues can be discussing what the future is, discussing, (1) you know, having those uncomfortable conversations. I think, H2H has facilitated that, helped patients be more organised and think around what they're doing and also highlighted to us how to go about those conversations, and that those conversations are (1) ok to have.” (ILD CNS)

All patients attending the Royal Brompton were given routine 3 monthly out-patient appointments in the ILD clinic. Previously, these patients had been reliant on attending these appointments, especially as there was little support being accessed in the community and patients did not have confidence in community HP in managing their disease. Through being involved in the study, patients and carers were linked in to their local community health services. Patient and carer participants reflected that they had started to develop support networks locally. This appeared to cause a change in the

relationship with the specialist centre where patients and carers began to question the aim of attending hospital appointments that were now viewed as stressful and burdensome:

“we are getting to the stage now (1) where (5) we won't be going to London so often I mean already xxx has to go by (1) ambulance cause he's having 6 litres of oxygen... erm (3) and obviously as he gets more poorly you know the trips just really aren't going to be (3) erm (3) beneficial to to him.. but that's no because already now they're they're just really a chin wag across the table .. to and cause they can't do anything now.. so (2) to know that you've got what you need here now in xxxxxx you know right her:::e (2) is what we need:::d you know not hundred miles down [laughs] the road” (Leslie, 54 year old wife of Ted who had advanced IPF).

This was also recognised by the ILD HP participants in the specialist centre:

“stratifying actually what (1) erm, (1) what hospital appointments patients are going to attend...has been very useful.....patients feel that they have to attend and then it's very stressful for them to ma-, you know make that trip in, so it's been very good for that angle as well.” ILD CNS

However, even though patients and carers recognised that there wasn't anything that the specialist centre could do, they still preferred to have the option of being able to attend RBH (ie keeping it as a “safety net” if needed). Patient's and carers' confidence in the community teams was a gradual thing which seemed to develop over time as patients and carers had more contact with the HP. As confidence in the community teams grew, this affected whether they felt the need to attend out-patient appointments and investigations at the specialist centre. Appointments were often moved to 6 monthly and tests cancelled as patients and carers gained trust in the community HP and felt better supported. However, the “door was always left open” which was important for maintaining hope and patients' psychosocial wellbeing:

“patients when can't practically offer them any more treatment they're very reluctant to be discharged whether they've had a bad experience with their local

hospital or they (2) you know they think ok there might a new drug coming up round the corner” (ILD Consultant)

The initial CC with the H2H CNS was reassuring for GP and the other HPs. The community matron expressed that having a “specialist” (the H2H CNS) offer to give their mobile number and welcoming contact was very empowering to the community HP and instilled confidence in their abilities. The Community Palliative Care CNS reflected on how she hadn’t always felt confident in dealing with these patients and how the CC helped in directing her in delivering appropriate care:

“we don’t get a huge volume of these types of patients and er and therefore our knowledge isn’t as as great as as some of other knowledge on other patients that we get a lot of it was quite nice to know::w erm the exact plan for them really...” (Community Palliative Care CNS)

The GP also commented that having easy access to specialists also made them more confident in delivering care as they knew that if there were any “issues, they had access to experts in the field”.

Theme 8 Advance Care Planning

Previously, the two specialities of ILD and palliative care were not seen to run alongside each other and it was usually an either/or scenario. H2H appeared to help to assist in that transition and allowed palliative care to be introduced alongside attendance at the specialist centre whilst active ILD management was ongoing. In fact, patients were often still on active treatment such as pirfenidone when they were referred to the trial. The ILD Consultant recognised that the shift between discussing ILD treatment options and palliative care was one that was difficult to do therefore difficult conversations about palliative care were often avoided:

“because of the nature of this unit I don’t think we deal that particularly well when we’ve run out of treatment options (2) to then put them onto a palliative care pathway and whether that’s because they see different people and in different adm- you know different clinic visits (2) or if we ourselves as as health care professionals just don’t like dealing with that kind of stuff...” (ILD Consultant)

ILD HP participants also recognised that important discussions surrounding advance care planning (such as preferred place of care and death) were not something that were done well by the ILD teams even though there was recognition that they were likely to prevent unnecessary hospital admissions. It was appreciated that the CC facilitated these discussions.

Through the CC, frank and open advance planning discussions were conducted. Prior to the CC, the H2H CNS (with a background in palliative care training) would ascertain with the patient whether they were happy to have discussions surrounding preferred place of care (PPC) and preferred place of death (PPD). Not all patients were ready to talk about PPC or PPD at the CC. However, patients and carers participants interviewed were grateful to talk about these issues- especially to find out more information about all the options available to them. Interestingly, the CC became a vehicle to facilitate frank and open discussion with family members which may not have occurred otherwise. The GP felt that the CC empowered patients to have conversations about end of life and to make sure that their views were communicated to their loved ones and the HP involved in their care.

Rachel whose mother had been going in and out of hospital for the last 2 years found the discussion and communication of the decision at the CC difficult:

“mum has made up her mind that she doesn't want to go back to the hospital erm mum wants to stay hom:::e so erm I have decided as much as this is very hard I've decided not to::: fight against my mum's wishes (1) er:::m (1) I do understand that my mum's (2) condition (2) is (3) far gone” (Rachel, 47 year old daughter of patient with advanced IPF)

However, there was a realisation that even though the conversations were difficult, they needed to occur: Ted touchingly commented alongside Leslie on how the CC forced him to open up to his grown up children about the future:

“...and that was the thing with the (2) I mean I did get upset at the initial (4) thing sitting round the table but that was the first time and it was probably as much because it was the first time (1) I'd had my children (3) the children were there (3) but they're not children but my my children (2) there::: erm I was able to say anything (3) and tell them let them know how I really felt so that's why and you

feel a bit weepy because you think (1) should be hiding it as a father you think (2) but it's not not (4) you know it's not you're not pre-programmed to (1) be talking about your own death...so (3) it's not an easy one to (1) discu:::ss...so (2) that's the only (3) but I don't I think the (1) the way (1) you've brought everybody together is fine because you're also getting a shock to the system like I found but I'm just talking in front of [laughs] my children and kids so be completely open about it." (Ted, 55 year old patient with advanced IPF)

"and looking back (2) do you think that was a good thing?" (SB)

" oh definitely it was a good thing cause [it made]" (Ted, 55 year old patient with advanced IPF)

" I don't think] you would have (2) opened up [to them]" (Leslie, 54 year old wife of Ted who had advanced IPF).

" I don't think] I don't think I ever would have I don't think I ever would have opened up without (2) you setting (1) that (2) in place that's the thing (2) I don't I still think I would have been (2) yeah I'm feeling I'm not feeling very good or I'm feeling you know I'm feeling alright I still don't think I would have really faced up to it" (Ted, 55 year old patient with advanced IPF)

Leslie also reflected on her experience of advance care planning at the CC and the appropriateness of the timing of these conversations:

"for us it was a bit traumatic you know everything being coming to life that actually these things are happening I think you can go to hospital appointments and still sort of brush it aside that you know [laughs] erm (2) but once everybody was sat round the table and we talked about DNRs ...and erm (4) advanced directives and all this sort of stuff it did bring it home and it did get a little bit (3) upsetting but (3) I I still do believe that it was better at that point than when (1)

somebody's actual laid on their bed and you think it could be any da:::y and (2) erm (1) you know I think you can deal with it better at that stage" (Leslie, 54 year old wife of Ted who had advanced IPF).

Interestingly, as patients developed closer relationships with community HP and especially the community palliative care team, this led to more discussions about end of life preferences and changed preferences. This may have reflected an increased confidence in the community teams and development of relationships with the community palliative care teams over time after the CC.

Theme 9 Feasibility and acceptability of the intervention

The timing of the intervention was thought to be appropriate and the earlier in the disease process it occurred, the more perceived benefit there was:

"it is (1) better (3) than (3) later you know if all these things happen once you're bed ridden (2) erm (3) you know you've got people coming in (2) that you don't know at least you know this way I mean we kno:::w the nurses...you know we know them first name terms erm you know you you feel comfortable with them erm (5) you know I do thinks it's definitely it nee- it needs to be done that way erm and that much earlier." (Leslie, 54 year old wife of Ted who had advanced IPF).

The length of questionnaires was deemed to be acceptable. In addition, the interval between questionnaires was also deemed to be appropriate; a 4 week interval between questionnaires was felt to be adequate to capture any changes in symptom control or quality of life. In addition, the questionnaires used were also felt to assess change satisfactorily by patients, informal caregivers and HP with the right outcome measures being used. One patient (Alfred) had felt that there was some repetition between questions in outcome measures and had become confused at times as some measures had asked about experiences over last 3 days (POS) and others over last 2 weeks (SGRQ).

Patients and informal caregivers alike did not feel that the questionnaires caused distress. There was a recognition that questions about death and dying were necessary but patients and informal caregivers alike did not feel that these caused suffering.

At the CC, patients and informal caregivers as well as the HP were given the evidence based guidelines. Both patients and informal caregivers were grateful for the guidelines (even though they weren't specifically tailored to the lay person). Patients such as Alfred felt that they encouraged him to research areas that were not familiar but found it encouraging that he was using the right things in other areas.

All HP were extremely grateful for the guidelines. For example, the ILD Consultant found them very useful and he felt they allowed systematic evidence based symptom control rather than ad hoc delivery of symptom control as he had previously done. Generalists such as the GP found them invaluable and specifically appreciated having guidance from specialists which again reassured him and instilled confidence that he was doing the right thing and guided him on aspects of symptom control he wasn't sure about.

Patients and informal caregivers interviewed did not feel that there was any problem with the FT design. One informal caregiver in particular (Penny, wife of a 67 year old patient with IPF) did not feel it was a problem to have to wait one month for the intervention as she did not feel that her husband's prognosis was so short that waiting would matter. However, the Community Palliative Care CNS did feel that it mattered especially if a patient was particularly unwell, she felt the wait could affect the care:

"I do think with some of them that it would cause problems. Erm I think that it would have been too late particularly if they're very poorly.... and you can't necessarily predict that with everybody and actually some of them (1) 4 weeks (2) would be too much without all that help...." (Community Palliative Care CNS)

However, there was an understanding from those with a research background such as the ILD Consultant that 4 weeks was a reasonable time period for the WL group to wait before receiving the intervention as it often took longer than that to set up support in the community.

All patients and informal caregivers interviewed were grateful for having taken part in the study:

"...just to say I'd like to thank you erm (1) for giving me the opportunity to go on this in- like on this survey [study] and to get the help that I've I've now got I really do appreciate it....." (Peter, 63 year old with advanced IPF).

"I think the study's excellent" (Stephen, a 81 year old patient with NSIP)

In addition, HP also felt extremely positive about the CC and reported that patients and informal caregivers had fed back to them about their experience:

"we've had good (1) er quite a lot of good feedback from patients as well that it's been very useful for them with regards to symptom management and having someone coordinate their overall care" (ILD Consultant)

"on every level I found it very very (3) er::: (4) useful.....I think it's brilliant..."
(GP)