Palliative care telehealth: Patient & carer perspectives

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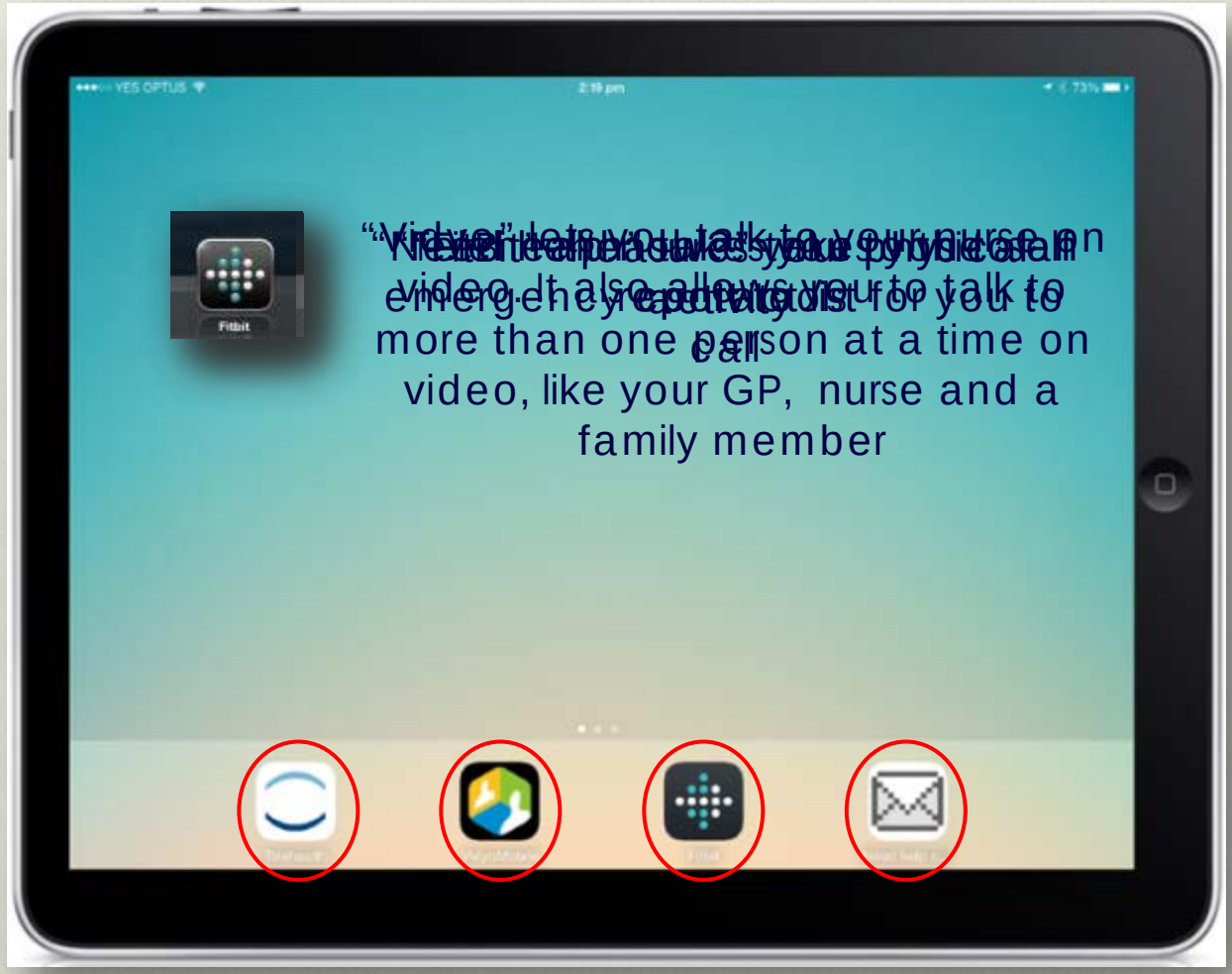
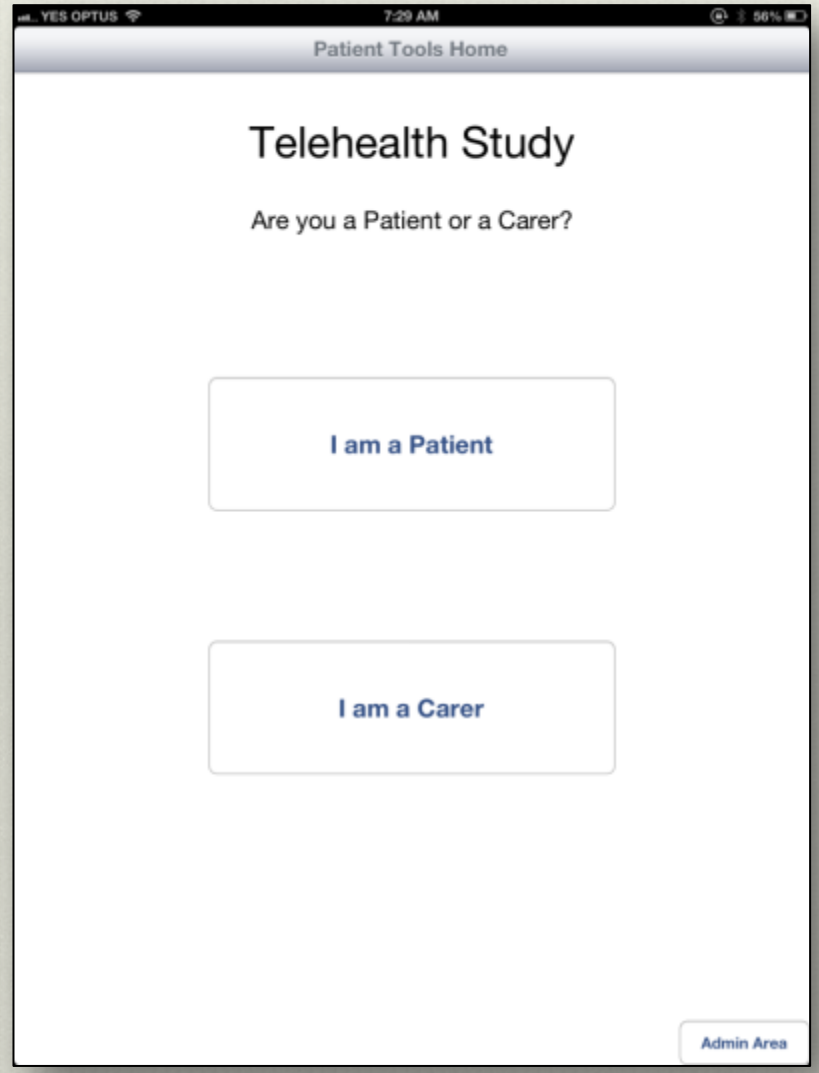
Aim

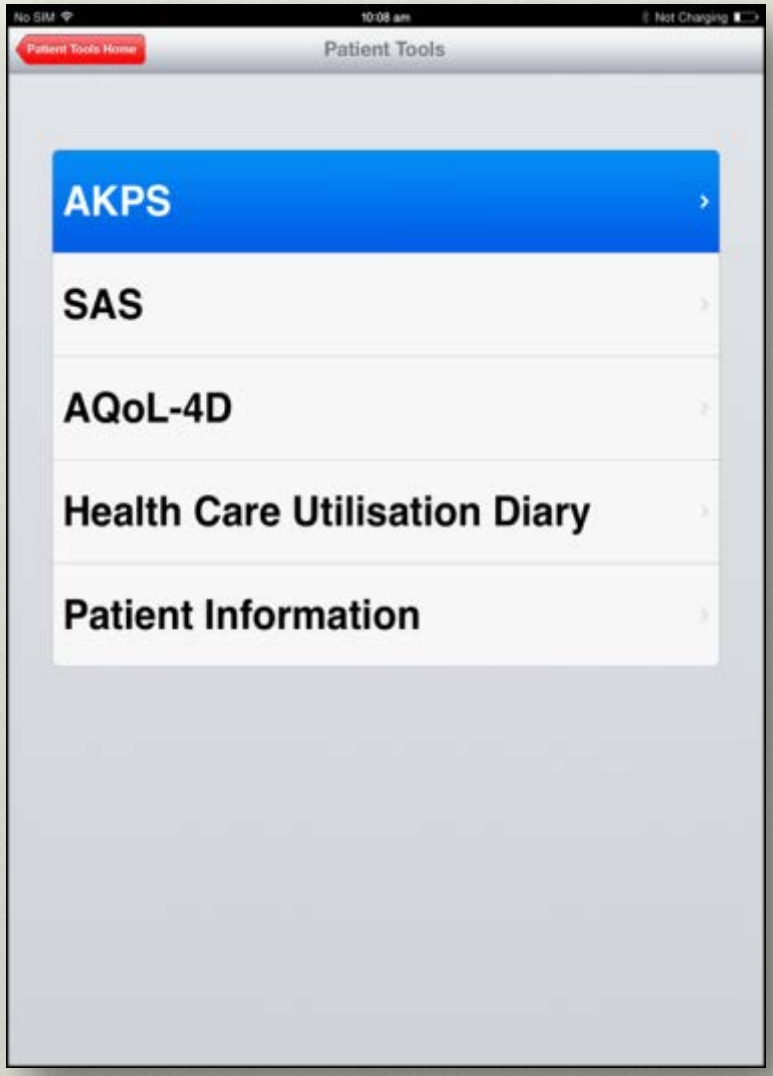
- To assess the feasibility & acceptability of a telehealth clinical intervention for patients & carers receiving community palliative care

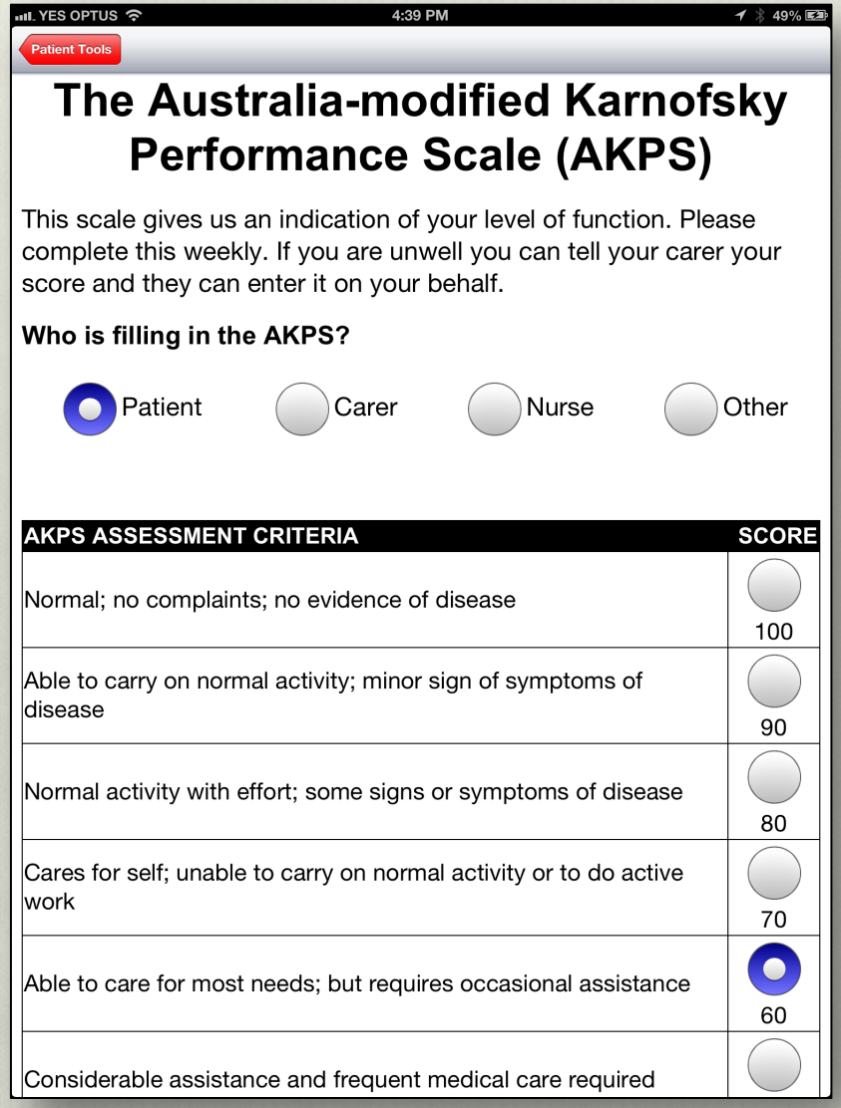
iWant
Fruit gums & jelly babies
Personal fanfare.
Brrrrm brrrrm button.
Carer needs
Video home visit
Art photo library.
101 instant excuses
Grunting sound.
Breathalyzer & yeehaa button
Pain, SOB
Digital bum scratcher.
Toilet paper end of roll warning.
Functional status
Fast food maps
Whooping sound.
... is all you need
Leunig

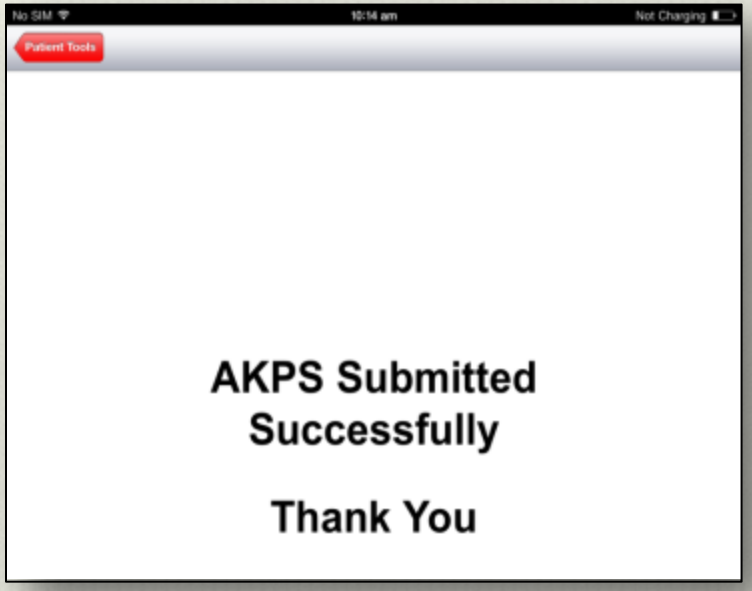
Applications

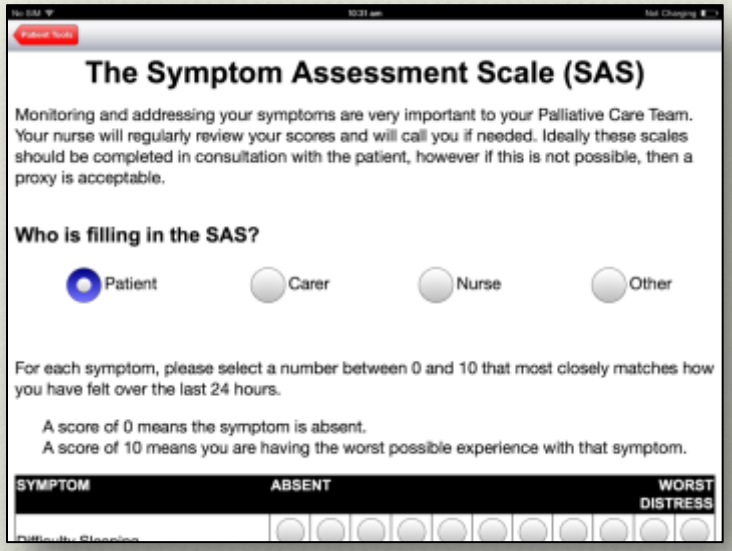



YES OPTUS
7:29 AM
56%
Patient Tools Home
Telehealth Study
Are you a Patient or a Carer?
I am a Patient
I am a Carer
Admin Area


No SIM
10:08 am
Not Charging
Patient Tools Home
Patient Tools
AKPS
SAS
AQoL-4D
Health Care Utilisation Diary
Patient Information


YES OPTUS
4:39 PM
49%
Patient Tools
The Australia-modified Karnofsky Performance Scale (AKPS)
This scale gives us an indication of your level of function. Please complete this weekly. If you are unwell you can tell your carer your score and they can enter it on your behalf.
Who is filling in the AKPS?
Patient
Carer
Nurse
Other
AKPS ASSESSMENT CRITERIA
SCORE
Normal; no complaints; no evidence of disease
100
Able to carry on normal activity; minor sign of symptoms of disease
90
Normal activity with effort; some signs or symptoms of disease
80
Cares for self; unable to carry on normal activity or to do active work
70
Able to care for most needs; but requires occasional assistance
60
Considerable assistance and frequent medical care required


No SIM
10:14 am
Not Charging
Patient Tools
AKPS Submitted Successfully
Thank You



The Symptom Assessment Scale (SAS)

Monitoring and addressing your symptoms are very important to your Palliative Care Team. Your nurse will regularly review your scores and will call you if needed. Ideally these scales should be completed in consultation with the patient, however if this is not possible, then a proxy is acceptable.

Who is filling in the SAS?

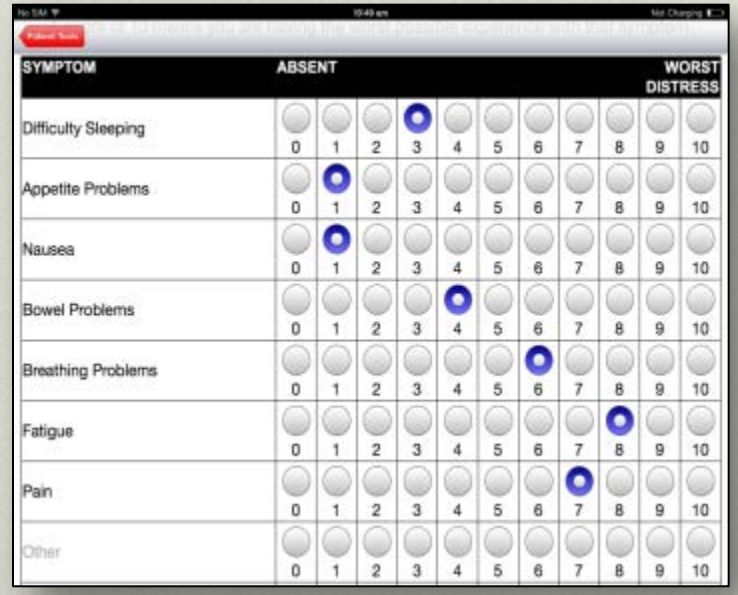
(•) Patient ( ) Carer ( ) Nurse ( ) Other

For each symptom, please select a number between 0 and 10 that most closely matches how you have felt over the last 24 hours.

A score of 0 means the symptom is absent.
A score of 10 means you are having the worst possible experience with that symptom.

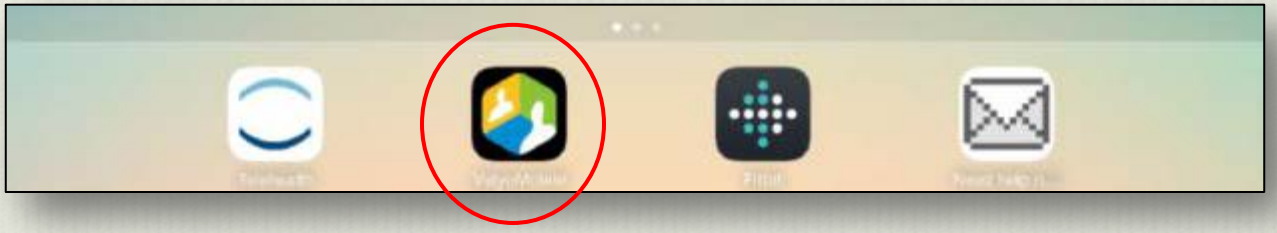
SYMPTOM	ABSENT										WORST DISTRESS
Difficulty Sleeping											

	0	1	2	3	4	5	6	7	8	9	10
Pain								•			
Other											
Other											

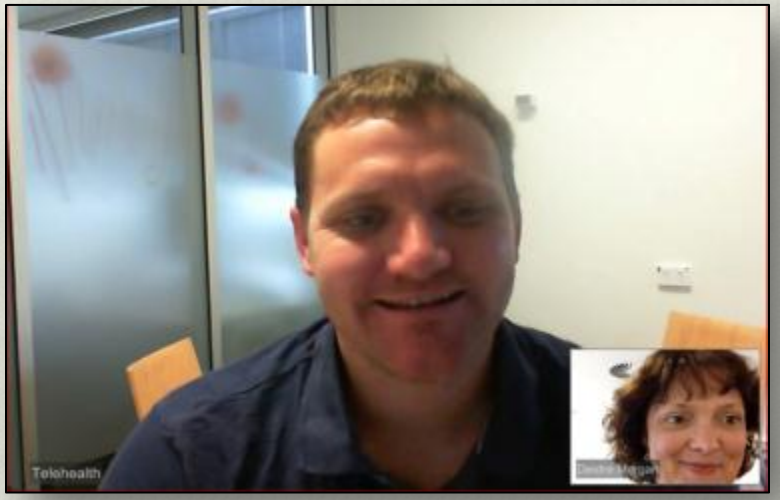


SYMPTOM	ABSENT										WORST DISTRESS
Difficulty Sleeping				•							
Appetite Problems		•									
Nausea		•									
Bowel Problems					•						
Breathing Problems							•				
Fatigue									•		
Pain								•			
Other											

	0	1	2	3	4	5	6	7	8	9	10
Fatigue											
Pain								•			
swollen legs										•	
worried											



Contacts
My Favorites
Decline
Answer


Telehealth

Methods

- 37 patient-carer dyads & 6 single patients in study
- 26 semi-structured interviews with
  - 20 patient-carer dyads
  - 2 patients without carers present
  - 2 single patients
  - 2 bereaved carers
- Interviewed about
  - their experience of palliative care telehealth
  - & GP case conferences (7)
- Audio-recorded, transcribed verbatim, thematic analysis

Interview Demographics

- Ages: 49 – 92yrs
- Patients: 12 8
- Carers: 13 5
- Diagnoses: urological, pancreatic, lung, breast, colorectal, other gastrointestinal, prostate cancers, cardiovascular disease, skin, bone/soft tissue, other non malignancy, haematological
- Patient AKPS at interview:
  30 (almost completely bedfast) through to
  80 (normal activity, some signs or symptoms of disease)

Themes

- Keeping in touch: remote care
- Willingness & motivation to participate
- Complexity & simplicity of reporting
- Strategies to manage challenges
- Palliative care here in our home

Keeping in touch

- Comfortable, confident, reassured they know

  "It makes sense & it gives you a sense of confidence because you know that, even though they don't answer, at least they are registering it." Caroline, 64 yrs

- More honest with clinicians, more honest with me

  "It is handy for me because over the last what, sort of three months, symptoms have been changing & moving around. So instead of me trying to remember all that when I am in there, I can do it as I go along." Mark, 49 yrs

- Critical importance of clinician follow up

  "It would be nice to have contact straight away, pretty well, when the numbers go up. Just to see what we can go & do... I don't press the numbers for no reason." Carl, 56 yrs

Willingness & motivation

- Computer familiarity, fears & friendship
  "when you first use it you are following the instructions & over...a short distance of time, that you don't have to look up the instructions anymore, you can memorise them & ...away you go." Neville, 78 yrs

- I should be looking after him!
  "I forget to come & do it. I am that busy looking after that kid over there... it is a pain in the arse." Alice, carer

- Not the same as a human
  "You are talking to a person instead of a machine." Richard, carer
  "And a person can think, you know. They can't think." Joan, 71 yrs

- Motivation to participate
  "I just sort of felt, I really need to let them know that there is something else wrong because he hasn't, I don't know if he had written it or not." Michelle, carer

  "so I am just a person who just gets on with it so I feel no need for it for my personal use." Julie, carer

Complexity & simplicity

- Complexity of self reporting

  "I think probably the hardest thing is working out maybe what, how high some of the symptoms should be." Joe, 64 yrs

  "Well the thing is in the morning, it can be real bad & then in the afternoon it has gone off. So how do you?" Frank, 70 yrs

- Where you put that extra bit in

  "I wanted to put in about the pressure because of the bruise, so I knew there was pressure there so I wanted to alert them to the fact that he was getting pressure." Teresa, carer

  "But nothing about depression on there & I thought there should have been. Because us old blokes we get depressed." Ian, 83 yrs

- You just don't want to know!

  "The trouble is when you are wide awake all night then you have to get on the iPad but you don't want to go on the iPad, you don't want to know nothing." Paul, 57 yrs

Strategies to manage challenges

- **I keep pushing different buttons**

  "You can't get rid of it but then all of a sudden like you keep pushing different things & it disappears." Frank, 70 yrs

  So now when I do his tablets in the morning & his injections, I get that done & then pull that (iPad) over…" Julie, carer

  "So we are trying to put that into the daily routine" Mark, 49 yrs

- **Logistics of self reporting**

  "It is very easy to give the correct direction to the point where you change over. Whereas your finger, goodness me,…it is far better than using the fingers." Mike, 78yrs

- **Strategies for managing drop outs**

  "The nurse talked me through it once and then we got stuck with him too. So he said, "Don't worry about it, I will call in." and that day he called in." Joan, 71 yrs

Palliative care here in our home

- Its personal – face to face
  "I can show him what is wrong with me. I can show them the nodes, like I did today... You are not a number. It is very, that is very important. It just seems more friendly and...more personal." Paul, 57 yrs

- Communication essentials via video
  "Dad's hearing & comprehension is a problem... So I think it is important that anyone that has a conference like this does have a family member who understands the person personally." Mary, carer

- Connecting clinicians
  "having everybody together on the same wavelength instead of 5 interviews we had last week…I think I counted up 9 hours." Mary, carer

- Managing care needs with minimum burden
  "The travelling's an absolute nightmare... It [videoconference] *saves me three to four days of agony. By the time I get back in my bed it feels like I have run three marathons. And I don't eat nothing, I don't drink anything. All I want to do is sleep."* Mark, 49 yrs

Conclusions

- People with advanced disease are willing & able to self report symptoms & function

- Willingness to participate is influenced by
  - experience with/attitudes towards technology
  - follow up on alerts by clinicians
  - reliability of connection
  - perceived value
  - reciprocity (benefit for others in future)

- Ability to participate is influenced by
  - an internet connection
  - timing of telehealth (too late – too sick, too early – no perceived benefit)
  - clinician encouragement, education, support & flexibility

Last words

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Questions?