

TRYING TO TRANSFORM CARE THROUGH RUNNING AN ELECTRONIC PALLIATIVE CARE COORDINATION SYSTEM (EPACCS)

DR STEVE PLENDERLEITH,

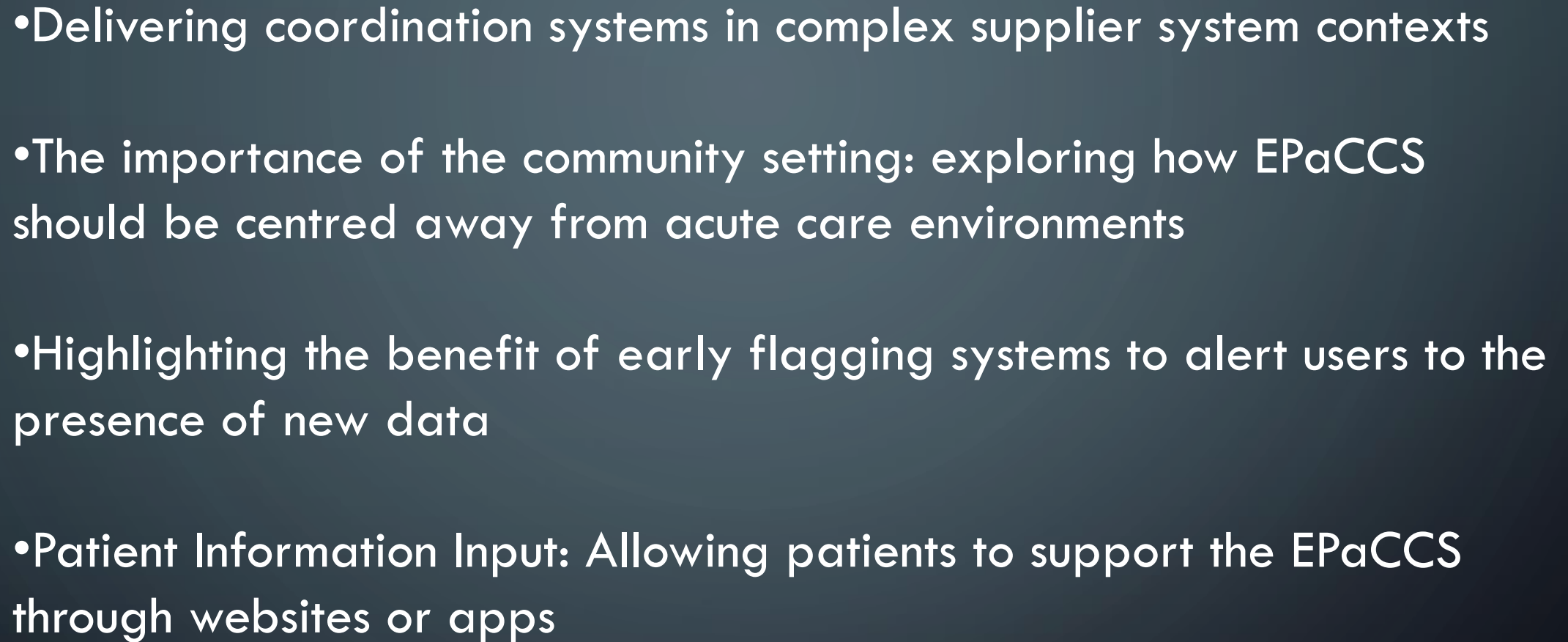
PALLIATIVE MEDICINE LEAD,

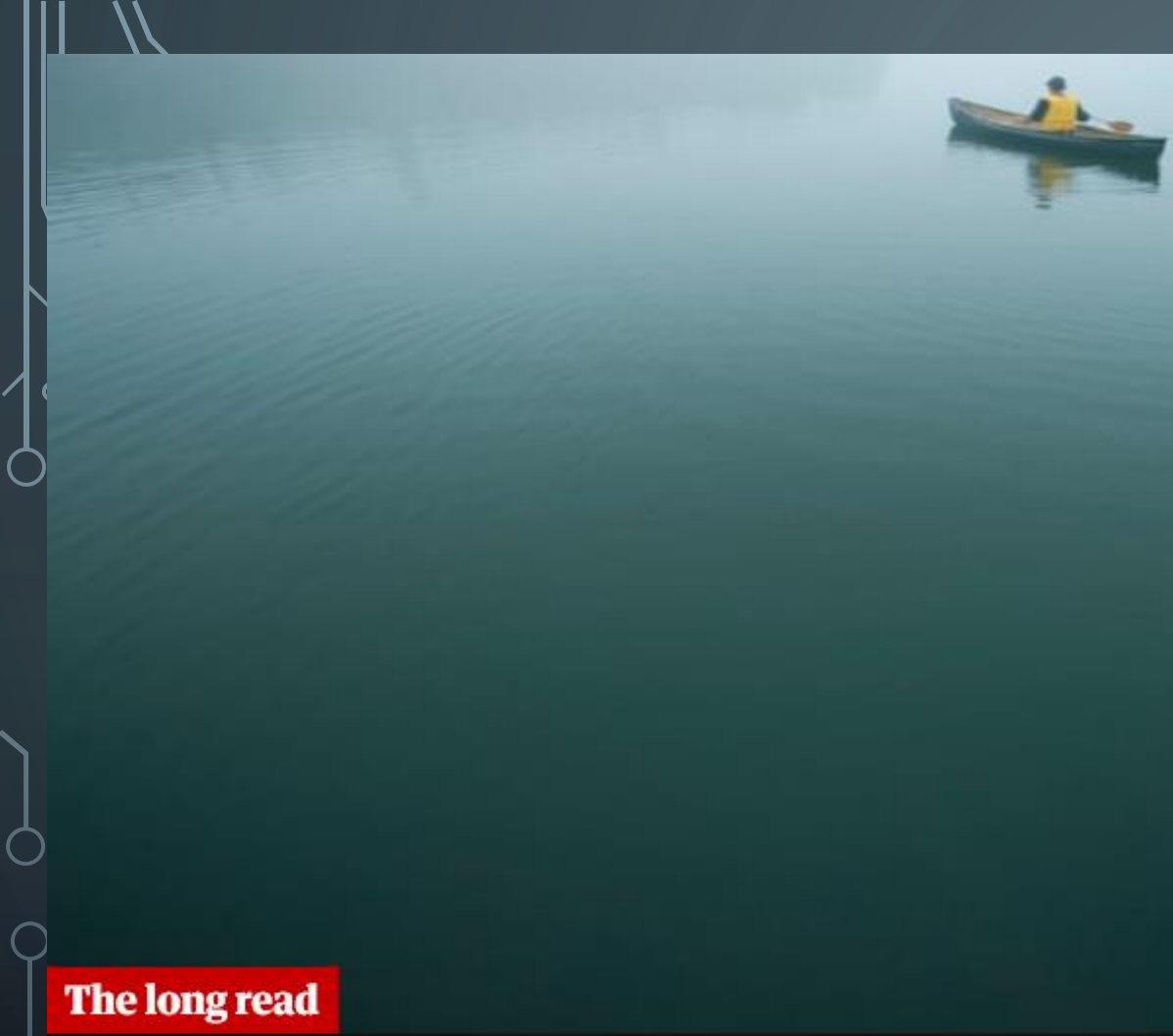
MEDICAL DIRECTOR (PHYSICAL HEALTH SERVICES), SE DIVISION

SOUTHERN HEALTH NHS FOUNDATION TRUST

Challenge Carbon Steel Digging Spade



- 
- The slide features a dark blue background with decorative white circuit-like lines in the corners. These lines consist of straight segments connected by small circles, resembling a network or data flow diagram. The lines are positioned in the top-left, top-right, bottom-left, and bottom-right corners, framing the central text area.
- Delivering coordination systems in complex supplier system contexts
 - The importance of the community setting: exploring how EPaCCS should be centred away from acute care environments
 - Highlighting the benefit of early flagging systems to alert users to the presence of new data
 - Patient Information Input: Allowing patients to support the EPaCCS through websites or apps



The long read

Letting go: my battle to help my parents die a good death

<https://email.rcplondon.ac.uk/1V12-7CECC-DMKIYG-4F6U0C-1/c.aspx>

My parents were determined to avoid heroic medical interventions in their dying days, even before the pandemic. Why wasn't anybody listening?

by [Kate Clanchy](#)

Delivering coordination systems in complex supplier system contexts

Will depend upon the size of your ePaCCS

Across Hampshire Portsmouth and Southampton – near 2million population

- 3 acute trusts all with MULTIPLE different clinical systems
- GPs in Hampshire all of EMISweb
- GPs in Portsmouth all on SystemONE
- GPs in Southampton 50/50 EMIS and S1
- 2 community Trusts
 - SHFT Hampshire RiO
 - Solent Portsmouth and Southampton SystemONE
- 3 councils Hampshire, Southampton and Portsmouth
- Also
 - Summary Care Record – all of England
 - CHIE (previously known as the Hampshire Health Record)

Which means this is a bit trickier than dealing with 1 (old world) CCG

POLITICAL FACTORS


- Does anyone have a;
 - bank account?
 - Tax account?
 - Pension pot/life insurance/mortgage?
 - Tesco/Coop/Sainsbury's card?
 - Amazon/Google/Apple account?

If so, and you rang the helpdesk or went into an office run by that service/company, would you expect them to be able to access your account to help engage with you?

POLITICAL FACTORS

So in the meantime we are left to;

- Setup Local Care Records (CHIE)
- Develop sharing (Wessex Care Record Project)
- Negotiate with companies. Some of whom say they will only follow national guidance
- Manage cyber security locally



I thought you
could all see my
medical record?

SO..... PREVIOUSLY

Experience from Hampshire. . .

- Big data store – Hampshire Health Record (Graphnet) now CHIE
 - Coded GP data dumped each night from both EMIS and S1
 - PDFs – OPD letters, discharge letters – stored and visible
 - Blood and imaging results uploaded and visible

However, post the 2012 CCG dictat . . .

- Separate ePaCCS. No PDS or other system links. Username & password.

Failed, as;

- Clinicians don't have time to do stuff twice
- No big network push hence no carrots and sticks
- £240k wasted for a tick box

SO..... CURRENTLY

As no more money . . .

- 1) ePaCCS template in GP systems.
 - Coded (READ2, CTV3 *& now SNoMeD CT) using SCCI 1580 & SCR codes
- 2) Same template in Solent Community Trust using S1
- 3) Matching but none coded template in RiO
 - But until now no way to get this info to CHIE or SCR
- 4) Acute Trusts
 - Developing Treatment Escalation Plans. Paper or electronic, but only visible in house. Though a ReSPECT PDF is visible in CHIE from one Acute Trust area.
- 5) Nursing Homes
 - Project to access CHIE ongoing

FUTURE PLANNING IN SYSTMONE

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Introduction & Patient Consent

For project information, template updates and additional resources. [Future Planning Website](#)
Project supported as part of an NHS and Hospice partnership. [Supported by](#)

The main purpose of this template set is to provide a **summary** of the patient's clinical information to the Summary Care Record (SCR)

Please keep free text succinct, understandable and relevant to the question asked / box title

By accessing the Summary Care Record during Emergency / Acute Care episodes:
- Ambulance Triage (999/111) and paramedic crews, GP OOH services, MAU, ED and any other hospital staff with an NHS smartcard, will be able to access this summary information to guide their clinical responses.

THIS IS THE MOST IMPORTANT CODE IN THE WHOLE TEMPLATE. [See more](#)

Enhanced consent to share - shows Additional Information updated to the Summary Care Record

The **"Enhanced Consent"** tick box above will enable **information from this set of templates** to show in the patient's national Summary Care Record. In addition, some other coded information from the GP record, including diagnoses and involved teams, will also be shared to the SCR.

Verbal or written consent is acceptable. Consent may also be gained by other clinical teams who should pass this info to the practice as, currently, only GP practices can record this code in the patient record.
If a patient has a persistent lack of capacity for giving this consent, then their legal representative (LPA for H&V, court appointed guardian) or an appropriate clinician (ideally with MDT backing) should, acting in the patient's best interests, add this consent code to the patient record.

Person giving consent and rationale if NOT patient

Add patient to a Practice Register ?

Register & ICR progress

May be used in some practices.

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Treatment Escalation Planning TEP

Who does the patient live with? [Future Planning Website](#)

Emergency contact details

Power of Attorney

Home access info & risks eg pets & other

Treatment Escalation Planning (TEP) Levels

Intensive: Transfer to hospital for treatment if appropriate. Critical care, intubation and ventilation should be considered.
Hospital: Transfer to hospital if appropriate, but not for critical care, intubation or ventilation.
Home: Treat with normal and rescue medications (orally, oral, med, SC (air syringe driven)) at home with support from GP. Admission to hospital to be avoided unless measures fail and following discussion with Palliative Care or other involved Specialist Team and GP.
Comfort: Palliative Meds via SC, oral or per rectal route, positioning, wound care and other measures to relieve symptoms. Admission to hospital to be avoided unless comfort measures fail and following discussion with Palliative Care Team.

Anticipated problems due to medical conditions **COVID-19 still at present notes below.**

Person giving consent and rationale if NOT patient

Has Advance Decision to Refuse Treatment (ADRT)

Where is the original stored?
Add a summary of relevant details

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Observations to be considered

If stable, usual B/R/range & response if abnormal

CO2 Retention Risk Factors (BTS guidelines 2012)

Known Chronic type 2 respiratory failure

Patients may be at risk of CO2 retention and the future respiratory depression with higher oxygen concentrations if:

- They have a past history of CO2 retention
- They have chronic chest disease, such as COPD, musculoskeletal disease or chronic neuromuscular conditions
- They have all 3 of the following risk factors:
 - long term smoker
 - >50 years old
 - unexplained exertional dyspnoea

Patients at risk of CO2 retention - please document

None CO2 reason for visit & acceptable O2 sat range

Face mask, nasal specs, any special equipment needs

Cardiovascular issues - record useful information

Patients usual heart rate & rhythm or any other abnormalities

Any longstanding abnormal signs or findings

FP Mx/Wishes leaflet patient info added

Please tick this box if information has passed to the practice using the Future Planning My Wishes form.

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

CARDIOPULMONARY RESUSCITATION DECISIONS

Future Planning Website

Patient CPR status

This record does NOT replace the need for a DNACPR or R/SPECT form

Awareness of CPR Decisions or Decisions

- Discussion about DNACPR choice decision
- Care if removal of CPR clinical decision
- Family member involved in CPR choice decision
- Not aware of DNACPR clinical decision

Select all that are relevant

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Future Planning: My Wishes

Please use the Future Planning My Wishes booklet to help patients/families take forward their views between your visits.

Checklist aspirational patients and families towards the Age UK. Let's talk about death and dying booklet [Age UK Direct](#) [Age UK Direct](#) may also be helpful.

Considerations for ongoing care

Patient Family/Wish wishes & preferences for care

Preferred place of death

Status of internal cardiac defibrillator

Considerations for care after death

Wishes & requirements following death

Referral to coroner required. Please give details

Wishes to be issued donor. Please give details

Support Available

Other involved specialist teams

- Under care of community ecop/teams (D&M)
- Under care of cardiologist (D&M)
- Under care of diabetes specialist nurse (D&M)
- Under care of community ecop/teams (D&M)

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Frailty Assessment

Named accountable GP

To calculate the GSF score for patients in your practice please see the SystemONE electronic 'Frailty Report in Reporting - Miscellaneous Records'

NHS Scotland [Get data in Practice](#)

polypharmacy medical review (Ongoing Episodes)

Number of falls in the last 12 months

NICE 2019 - Multifactorial Falls Risk Assessment

Risk factors for falls

Frailty Assessment Conclusion

Frailty Review - meeting dates and date

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

Prognosis & GSF Meeting

Awareness of Prognosis

GSF Stage - possible prognosis

MOST IMPORTANT CODE FOR THE PRACTICE

adds patient to the GSF/End of Life register

Please record additional information in the Treatment Escalation and Future Planning TABS as appropriate.

GSF Stage - Blue (>1 year)

Discussion/Info around advance care planning

Under care of social services

GSF stage - Green (Months)

DS 1500 Disability living allowance completed

Future equipment needs considered

GSF stage - Yellow / Amber (Weeks)

NHS continuing healthcare fast track funding applied for

Referred to community care team for care needs or introduction

Hospital bed, mattress & continence equipment in place, if needed

GSF stage - Red (Days)

Package of care in place sufficient for needs

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

Future Planning GP Version 3.3

Introduction & Patient Consent | Treatment Escalation | TEP Observations | CPR Decision | My Wishes | Frailty | Prognosis & GSF Meeting | End of Life

End of Life / GSF Register

Named accountable GP

End of Life / GSF Review - meeting notes & date

Etiology, Diagnosis or Diagnoses

Palliative care Phase Of illness

Attends Hospice Daycare or other supportive service

Hospice/specialist palliative care team involved?

FP End View1 view cannot be shown when previewing a template

KARNOFSKY SCORE CRITERIA

- 100% - Normal; no complaints; no evidence of disease
- 90% - Able to carry on normal activity; minor signs of symptoms of disease
- 80% - Normal activity with effort; some signs or symptoms of disease
- 70% - Capable of self-care; unable to carry on normal activity or to do active work
- 60% - Able to care for most needs; but requires occasional assistance
- 50% - Considerable assistance and frequent medical care required
- 40% - In bed more than 50% of the time
- 30% - Almost completely bedfast
- 20% - Totally bedfast and requiring extensive nursing care by professionals and/or family
- 10% - Comatose or barely rousable

Australian modified Karnofsky Performance Status scale

VERSION 3.3 of the Future Planning Template - January 2020 © Copyright reserved. Southern Health NHS Foundation trust

SO..... WHAT DO WE ACTUALLY STILL NEED

ePaCCS “requirements” are huge.

1. Read only access for Ambulance, 111, OOH services & ED.

- Is an emergency the time to be doing ACP ? No, but it is a trigger point.
- Hence, *My Wishes* leaflet for Paramedics to leave on site.

2. Patient access

- Developing Treatment Escalation Plans. Paper or only visible in house

3. Care Homes & Hospices

- Need to be able to add to care plans
- 100 different care plans all currently on paper or in CH e systems

Need to focus on TEP (of which CPR is just one)

The importance of the community setting: exploring how EPaCCS should be centred away from acute care environments

1. End of Life patients average 4 admissions in their last year of life

These are trigger points, but who recognises them?

- GP or Hospital computer systems?
- A hospital specialist team, if aware of the admissions?
- Community teams – CCT, Care Home, GP, Long term condition Clinical Specialist

90% of that year is spent at home

- No matter who initiates the conversation – building the picture and updating should be ongoing, so increasingly fall to community teams.
- Patient, relatives and friends rarely attend OPD, dialysis, chemo, frailty assessments together.

Highlighting the benefit of early flagging systems to alert users to the presence of ~~new~~ any ePaCCS data

The need for this depends upon your ePaCCS solution.
And who you are.

1. Ambulance Centre Call handler – called about a collapse, should be looking for a DNACPR. Does a flag add anything if the CPR decision is already recorded (& accepted) electronically
2. A paramedic on site – should be looking at SCR or LCR for meds and allergies for every poorly patient.
3. GP – in surgery about to see a patient. Knowing there is new info in ePaCCS from outside the practice. YES
4. All other involved social and care teams. DITTO
5. National Care Record Locator Service – may be coming to SCR in the future

Patient Information Input: Allowing patients to support the EPaCCS through websites or apps

Quite simply, YES.

- It already works via paper – My Wishes
- Emergency contact and access details
- Preferences and wishes for care before and after death
- PPD and 2nd PPD
- Religious and cultural requirements
- Tissue donation

However;

1. Certain sections, TEPs, need to be checked for clinical reality.
2. We need to ensure it is the patient or their legal representative recording the information.
3. Appropriate accurate guidance needs to be available.
4. Patients and families need to have confidence in the security of their data