A Quality Improvement Journey in Palliative Care: Enabling reliable person-centred care through *information reconciliation*

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Background

Recent research[1] identified that approximately 1 in 3 patients in Scottish hospitals is at risk of deterioration and dying during the current admission or within the next 12 months. These patients require anticipatory care planning (ACP) to ensure effective management of acute deterioration, appropriate in-hospital treatment and informed care post-discharge. A 2-year project commenced May 2014 to integrate ACP into routine clinical care and the local measurement framework for the Scottish Patient Safety (SPSP) Deteriorating Patient programme.

Aim

To improve the experience and outcomes of care for patients with advanced conditions and at risk of further deterioration and dying, via reliable person-centred anticipatory care planning and professional response to deterioration.

Approach

Quality improvement methodology includes the IHI Model for Improvement[2] to support clinician ownership, challenge assumptions and drive change. The Conversation Ready Healthcare Community[3] approach informed professional, patient and family engagement and review of processes and systems to support this. The Information Reconciliation model *(Figure 1)* provide the structure for testing a dynamic systems-wide approach to ACP:

Phase 1 = hospital care (pilot acute medicine and medicine of the elderly/stroke wards):

- Integration of core elements of ACP within routine clinical processes
- Identification of 'patients at risk 'of deterioration and dying
- Clinician, patient & family communication regarding goals of care including treatment options, benefits/burdens of interventions and their priorities & concerns
- Clear documentation of a multi-professional Goals of Care anticipatory care plan: Information Reconciliation *(Figure 1)*
- Reliable, informed clinician response to deterioration.

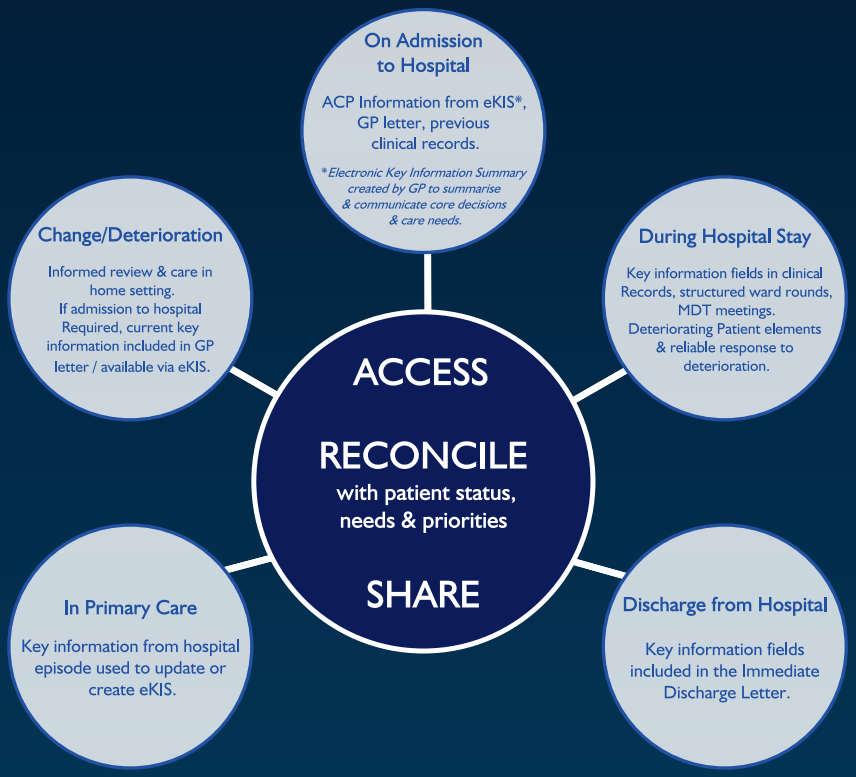
Data:

- Clinical documentation audit (n=105), observations of ward rounds, nursing handovers, team safety briefs and multi-disciplinary meetings. Observations of care (n=65) plus tracked outcomes at 6 and 12 months
- Semi-structured interviews with patients and nominated family members (n=20)
- Staff experience of ACP, conversations and reflections.

Key areas of testing Phase 1:

- Acceptability and feasibility of ACP in acute hospitals
- Anticipatory care planning (ACP) form - to prompt and record goals of care including decisions re: risk of deterioration, CPR status, escalation plans and communication with patients & families - What Matters to you?
- Terminology re ACP used by clinicians: agreed glossary of terms
- Approach to capturing patient and family feedback on ACP.

Figure 1 - Information Reconciliation Model



Findings Phase 1

- The proportion of patients for whom anticipatory care planning (ACP) is appropriate varies across specialties but was higher than has been reported[1] (48-80% of patients)
- 46% of patients in the first observation cohort died within 6 months. 69% of those died in NHS hospital care = importance of information reconciliation and ACP in community settings
- ACP form currently version 5. Reliability is improving *(Figure 2)* indicating that ACP completion, discussions with patients and families and documentation can be incorporated within the hospital culture and clinician workload
- Clinician feedback indicates the form efficiently communicates core information, including to out-of-hours services
- Comparative audit of time to access key ACP information in patient notes, including in the event of acute deterioration to support emergency care:

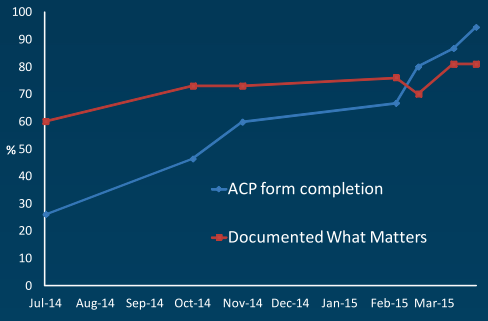
  At baseline: < 5 mins = 36% 5-10 mins = 42% > 10mins = 22%

  With ACP form: 100% accessed within 30 seconds
- The ACP form prompted clinician communication with patients & families. Significant improvement from baseline to discussions with 94% of patients and families and documented decisions including Cardiopulmonary Resuscitation (CPR) status. Frequency of discussions increased with no change in proportion of Do Not Attempt CPR decisions made
- Documentation of patient priorities including *What Matters* has increased from 60% to 81% following introduction *(Figure 2)*
- Discussions with patients and families about treatment decisions such as CPR need to be within the wider context of "Goals of care", including *What Matters* to the patient and family. Patients and families identified the importance of their involvement in ACP discussions, however with variation in preferences regarding extent of involvement in decisions, depth of discussion and perception of ACP issues. This includes receiving information about any uncertainty of recovery during the current episode or relevant to the future dying process. Patients emphasised coping through living for today.

"Give me a chance..." "I don't want to live as if I died a while ago..." "Knowing too much...would have sent me to a dark place..." "I want to live day-by-day..."

- ACP is professionally and personally challenging for clinicians. Education should support multi-professional competence and confidence.

Figure 2 - Correlation: ACP form completion & *What Matters* documented



Next Steps - Phase 2

- Testing of information reconciliation hospital to community interface: prompts and fields for ACP in the immediate discharge letter from hospital
- Optimise use of electronic Key Information Summary (eKIS) for ACP information on admission to hospital and out-of-hours
- Exploring methods to support patients with communication impairments to participate in ACP discussions (up 60% of patients in pilot areas)
- Addressing human factors, defining and testing a Conversation Ready Clinician skill set
- Inclusion of ACP in mandatory and core training for clinicians.

REFERENCES: 1. Clark *et al* (2014) Imminence of Death Among Hospital In-Patients. *Pall Med* 28(6)474-9 2. www.ihi.org/resources/Pages/HowtoImprove/ScienceofImprovementHowtoImprove.aspx 3. www.ihi.org/engage/initiatives/ConversationProject/Pages/ConversationReady.aspx

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