System wide transformation – from local to National policy

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Care and support through terminal illness
Journey from local CPR policy to NHS Scotland DNAPCR policy and beyond…..

Cardiopulmonary Resuscitation (CPR) – a practical skill, mandatory training for most clinical staff in most care settings

Do Not Attempt CPR – NFR, DNR, DNAR, no consistent approach, a generalist issue, not talked about much in 2004!

Why have Specialist Palliative care leadership for a generalist emergency issue?
“Stay authentic but connect to wider picture as far as possible”

- Acute hospital issue – CPR policy (DNACPR paragraph, white dot!)
- Scottish Ambulance Service
  ➢ Problem for us too – (e.g., DNACPR written on canteen napkin)
- GPs & District Nurses – families who call 999, patients who want to die at home
- Police Officers – Sudden Death Guidance
- Care Home issue – “blanket” DNACPR policies or blanket “call 999” policies
- Patient and carer issue – medicalised death, no or poor communication etc

“Just letting you know your patient died this morning, we only shocked her the once….”

“His wife was so upset! It just wasn’t right to take his body to the police morgue so I stayed all night till the GP came at 8.30am

“The doc phoned me to say Mum was in from the care home with a chest infection and if her heart stopped did I think they should restart it – I felt like I had given mum a death sentence
Why have Palliative care leadership for generalist emergency issue?

DNACPR - not a palliative care specific issue but is relevant for every patient with identified palliative care need in every care setting

Remember 1 in 3 patients in the acute....... 

Prevalence study in-patients in 25 Scottish hospitals (n=10,743)

• 10% died during their current admission
• 29% died within 12 months

Clark et al (2014) Imminence of Death Among Hospital In-Patients
Pall Med 28(6)474-9
Evolution of a National DNACPR policy

2004 – CPR policy review St John’s Hospital Livingston
2006 – Integrated DNAR policy NHS Lothian
2008 – Scottish Government Public Audit Committee recommendation
2010 – Integrated Adult NHS Scotland DNACPR policy and Children and Young Person’s Acute Deterioration Management Plan (CYPADM)
2014 – Tracey v Cambridge University Hospitals Trust – judgement
2014 – start of “light touch review” of NHS Scotland DNACPR policy
2014 – revised CPR decision-making BMA/RCN/RC(UK) guidance
2015 – start of work on Emergency Care and Treatment Plans
2015 – Winspear vs Sunderland NHS Foundation Trust – judgement
2016 – revised CPR decision-making BMA/RCN/RC(UK) guidance
2016 – revised NHS Scotland DNACPR policy
Naming of mismatch between good practice guidance and local practice (single hospital)

National policy + education + audit + QI

Regional policy + education + audit
and then when you think you are at the summit……………….

Media / comms strategy

Advance & Anticipatory Care Planning

Care Homes

Police

First responders

“Deteriorating Patient” – Scottish Patient Safety Priority

eHealth and digitisation

Research

Incapacity legislation

NHS 24

Legal changes

NHS Education for Scotland online modules, overlapping workstreams

Scottish input to national good practice guidance (GMC, BMA/RCN/RC(UK))
DNACPR Policy

**EDUCATION**
Patients, carers, clinical staff, volunteers, social carers, care home staff, police etc

**EQUITY**
Postcode, diagnosis, culture etc

**IDENTIFICATION**
of palliative need - SPICT, SPARRA etc

**HEALTH LITERACY** – trust, empowerment, enabling

**ANTICIPATORY CARE PLANNING**
National ACP, Key Information Summary, ReSPECT etc

**RESEARCH** – what works, patient experience, carer experience, sharing good practice

Marie Curie
Messaging and Health Literacy

“Health literacy is about people having enough knowledge, understanding, skills and confidence to use health information, to be active partners in their care, and to navigate health and social care systems.”

www.healthliteracyplace.org.uk

Perceptions of palliative care  Collins et al  PallMed 2017, Vol 31 (9): 825-832

• diminished possibility
• diminished choice – forced upon you by the healthcare system when no other choices remain
• place to wait for death,
• end to earlier hopes for survival & increasing dependency on others for care.
Messaging and Health Literacy

Loud Media messaging about DNACPR
- Cost cutting
- Clearing blocked beds
- Doctors and nurses playing God
- Having a treatment that would save your life withheld to save money

Health Literacy aim - bring patient and caregiver understandings in line with the evidence for what ‘good quality care’ really means in the context of serious illness (#RealisticMedicine)

WIFE’S FURY AT ORDER TO ENSURE NATURAL, PEACEFUL AND DIGNIFIED DEATH AT HOME……
……doesn’t have quite the same headline impact!!!
Don’t lose sight of who will benefit when a problem is solved

“Before NHS Scotland implemented the policy, there would be around 50 times every year when out of hospital expected deaths were dealt with inappropriately. Since the policy was implemented, and SAS produced its own associated policy, these have been largely eradicated. The effects on bereavement and recovery have been incalculable.”

Clinical Performance Manager
Scottish Ambulance Service
System wide transformation leadership - working with Pandora’s box

- Containment
- Coherence
- Connections
- Collaboration

www.comixgamer.deviantart.com
“This case was never really about the decision-making process, that didn’t really come up at all. It was - why didn’t they talk to my mum. Why didn’t they explain to her what was possible? Why didn’t she get the chance, when she so desperately wanted it, to talk about what was going to happen?”

Kate Masters – daughter of Janet Tracey – explaining why her dad pursued the case against Cambridge University Hosp Trust
“This is difficult for me to explain, so I brought a prop.”

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