NHS
North West Coast Clinical Networks

NHS England North West

Supporting the Identification of People in the Last Year of Life with 'EARLY'

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History

- Development over approx. 5 years
- Collaboration between palliative care and primary care
- Several pilot studies to refine
- An aid/tool, not a full solution

What we know

Around 75% of deaths are ‘expected’ and therefore there is likely to be a window of opportunity to engage in conversations around

end-of-life care and to plan ahead

Effective planning means that ideally, people need to be proactively identified as being in the last 12 months or so of life, rather than through a reactive approach during crises and rapid deterioration, when it is much harder to make informed choices and plan

Identification is more straightforward in some cases eg cancer, and harder in many of more chronic conditions eg COPD, dementia due to trajectories of decline

Why identification is so important

Earlier identification of patients who may be in the last 12 months of their life is important because this provides an opportunity for them (or next of kin / carers) to be involved in planning for their future care, and increases the likelihood of wishes and preferences being met at the end of life

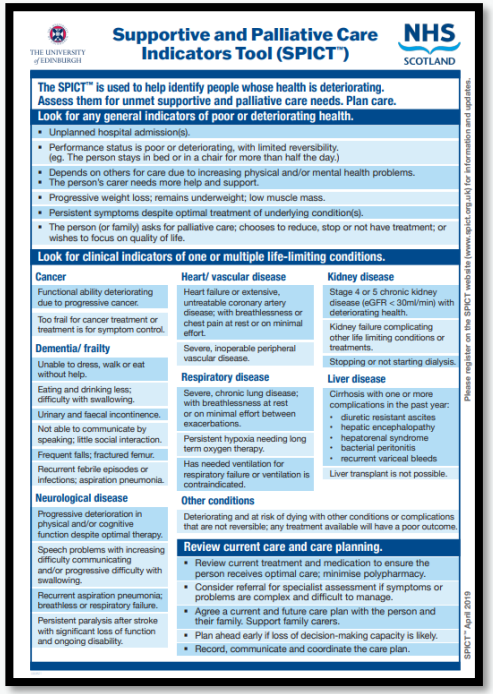
The offer may be declined but can be revisited, is voluntary etc, it is about us offering the opportunity and supporting people to explore

Planning might include thinking about the type of care they would like or would not like, where they would like to be cared for, who should be involved in their care etc. There may also be an opportunity to consider anticipatory clinical management planning

Tools to support identification

A number of tools already exist to help identify people in the last 12m of life, e.g. SPICT, GSF Proactive Identification Guidance (PIG)

[Supportive and Palliative Care Tool |]



Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer
Functional ability deteriorating due to progressive cancer.
Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty
Unable to dress, walk or eat without help.
Eating and drinking less; difficulty with swallowing.
Urinary and faecal incontinence.
Not able to communicate by speaking; little social interaction.
Frequent falls; fractured femur.
Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease
Progressive deterioration in physical and/or cognitive function despite optimal therapy.
Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.
Recurrent aspiration pneumonia; breathless or respiratory failure.
Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease
Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.
Severe, inoperable peripheral vascular disease.

Respiratory disease
Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.
Persistent hypoxia needing long term oxygen therapy.
Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions
Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

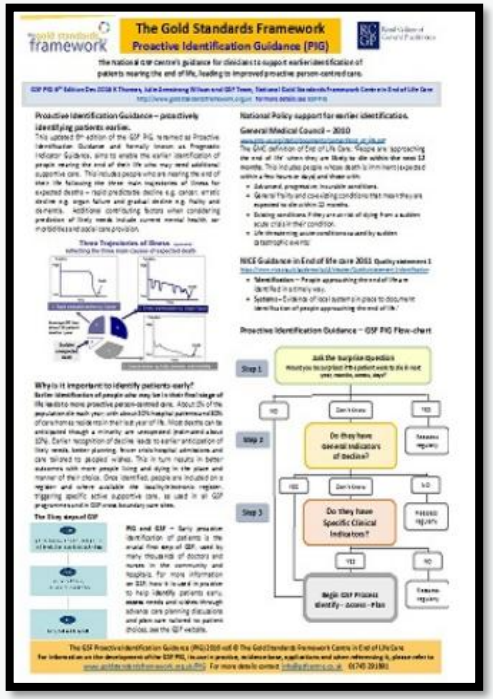
Kidney disease
Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Kidney failure complicating other life limiting conditions or treatments.
Stopping or not starting dialysis.

Liver disease
Cirrhosis with one or more complications in the past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Review current care and care planning.
- Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.
SPICT™ April 2019



The Gold Standards Framework
Proactive Identification Guidance (PIG)

[Proactive-Identification-Guidance.pdf]

However, the above rely on health care professionals remembering key features of deterioration, which may not always be apparent nor feel relevant at the time.

What is ‘EARLY’

EARLY Tool |

EARLY is an acronym for:

E - Early identification

A - Advance care planning

R - Record

L - Look again

Y - You can continually improve

EARLY Search

The EARLY toolkit includes a search which can be run in GP clinical system

The search is based on key elements such as disease coding, number of admissions etc

The list produced is divided into broad ‘disease’ headings

The individuals on the list **MUST** then be clinically validated as being in the last year of life as the search is **not** 100% sensitive

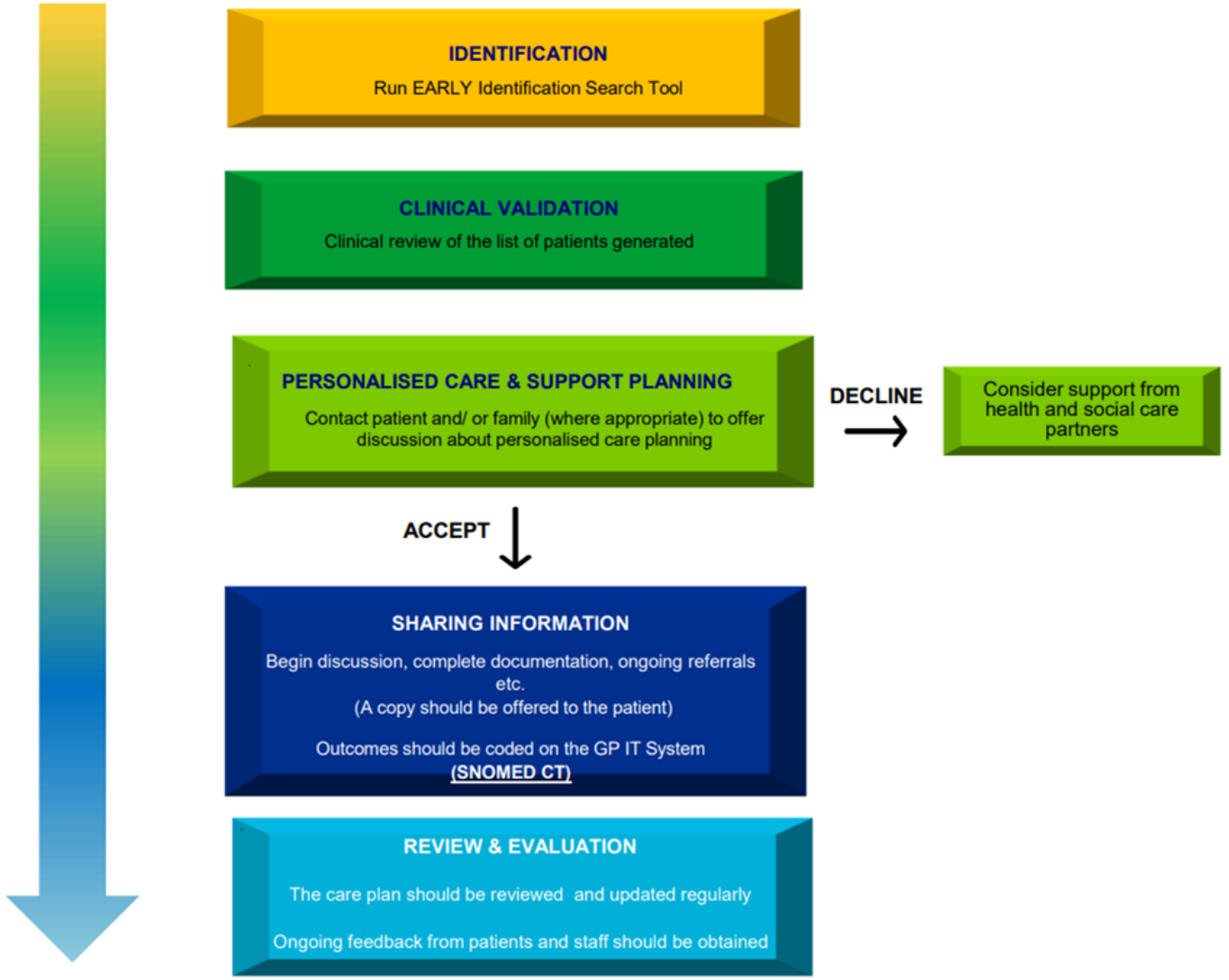
EARLY Searches in GP clinical systems

Like ANY clinical searches EARLY searches are highly dependent on coding so may under or over identify
Will pick up metastatic cancers – but these may be stable e.g. breast and bone metastasis – so may not be appropriate to pursue end of life discussions
May also pick up end stage renal disease where people are on transplant waiting list
Will pick up those prescribed high doses of opiates where indication is not palliative care

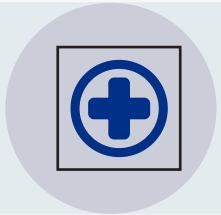
All of the above examples highlight why

clinical validation is a critical and essential step

5 Step approach



- How can EARLY Support PCNs and the wider system



It can help support identification in all disease areas, when used alongside proactive identification during clinical contacts

It can help focus in discrete disease areas

In a practice of 6000 patients 118 patients were identified in the EARLY search; this may feel overwhelming

Name	Population Count	%	Last Run	Search Type	Scheduled	Code System
x Linked searches						
Combined list of patients to be reviewed	118	2%	12-Mar-2025	Patient		N/A
Combined list of patients to be reviewed Auto Report	118		12-Mar-2025	Patient		SNOMED CT
Patients NOT on Palliative Care Register	5754	99%	12-Mar-2025	Patient		N/A
1. Cancer	14	1%	12-Mar-2025	Patient		SNOMED CT
2. Heart Failure	0	0%	12-Mar-2025	Patient		SNOMED CT
3. COPD	20	1%	12-Mar-2025	Patient		SNOMED CT
4. Kidney Disease	3	1%	12-Mar-2025	Patient		SNOMED CT
5a Hepatocellular Carcinoma	2	1%	12-Mar-2025	Patient		SNOMED CT
5b Liver Disease	2	1%	12-Mar-2025	Patient		SNOMED CT
6. Motor Neurone Disease	0	0%	12-Mar-2025	Patient		SNOMED CT
7. Frailty and Dementia	87	2%	12-Mar-2025	Patient		SNOMED CT
8. Idiopathic Pulmonary Fibrosis	1	1%	12-Mar-2025	Patient		SNOMED CT

But the 118 patients are helpfully subdivided into disease areas within the search in EMIS

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Choosing a disease area

Consider choosing one disease area to focus on, rather than the total list.

This may be influenced by:

- clinician capacity at your practice
- disease areas of unmet need
- high hospital conveyances for specific disease groups
- low GSF registrations, etc.

In the example here 20 patients with COPD will require clinical validation and are chosen because the practice is already working on the clinical optimization of patients with COPD

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What next…

Clinically validate the list – *'Would I be surprised if this patient died in the next 12m'* – this can be performed over a period of weeks/months according to clinical capacity

Decide if appropriate to approach end of life care discussions and if so, offer the opportunity to engage

Conversations may then develop into planning, ACP, anticipatory clinical management plans, etc.

Clinical validation beyond the 12m question…

The following general prompts will help you to consider the application of personalised care support planning in individual patients (note that the list is not exhaustive)

- Increasingly frequent attendance at GP Surgery?
- Has the patient had 3 or more encounters with emergency and out of hours services in the past 6 months?
- Has the patient had 3 or more admissions into hospital in the last 6 months?
- Does this patient already have a personalised care plan? If yes, has the pre-existing care plan been reviewed within the last 3months?
- Does the patient have pre-existing, long-term condition(s)which means that they are likely to deteriorate?
- Does the patient receive 24-hour care?
- Does the patient have a frailty index of moderate or severe?
- Is the person known to palliative care or end of life services?
- Has the person had recurrent falls?
- Does the patient have cancer that has progressed despite anti-cancer treatment, or cancer where there are limited treatments to save or prolong life?
- Has any specialist team or other professional involved in the patient's care identified that this patient may be in their last 12 months of life?
- Has the patient been considered for organ transplantation?

Patient example -

- John was identified in the list of 20 patients with COPD
- 77yrs, lived with his wife, 71yrs
- He had been admitted on 3 occasions over a period of 16 weeks, required ITU on one occasion for the treatment of pneumonia with acute kidney injury
- Hospital agreed DNAR order at last admission in context of poor physical health and unlikely to survive resuscitation. No ACP discussions or similar took place
- BMI 18
- Also had CKD with eGFR 20
- Housebound and barely mobile at home
- SOB at rest
- On maximum meds and had been under the care of the respiratory team
- Approached John with respect to failing health and optimal/appropriate care
- Had recognised himself the need for a different approach to his care
- Detailed discussions with patient and family. ACP agreed, respiratory team involved with referral to district nurses, EPACCS template completed, and information shared

What happened next?

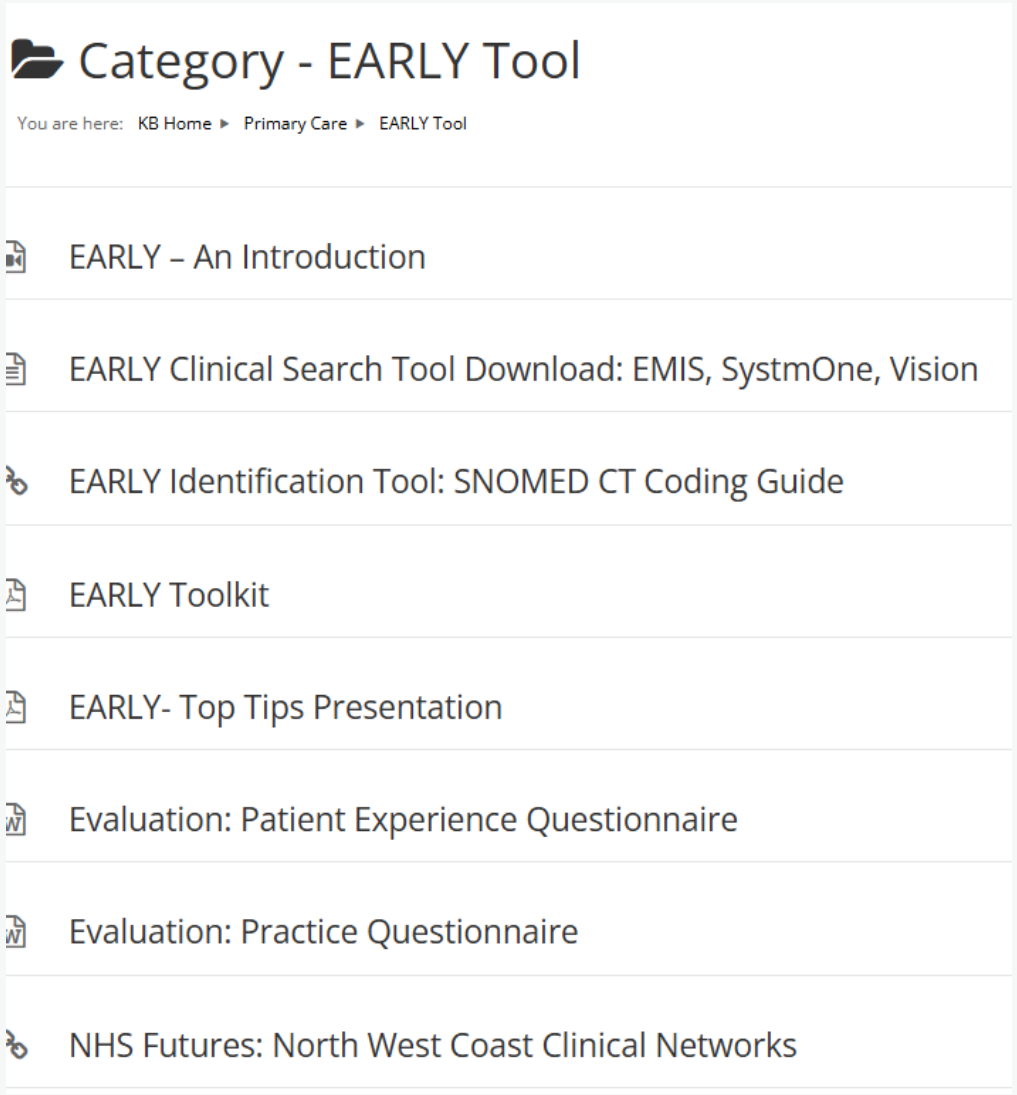
- John continued to live at home with carer support x3 a day
- He received 2 courses of oral antibiotics for a chest infection . Unfortunately, he continued to deteriorate
- In accordance with the ACP, escalation treatment plan and his wishes John was not transferred to hospital
- John received supportive care at home with the provision of symptom control medication
- He died 7 weeks after the initial conversation regarding end-of-life care

Additional Information

- Instructions regarding uploading the search and running the search are available on the Resources slides (to follow)
- If you have any specific IT issues, please contact your local IT support provider
- Any general enquiries can be sent through to england.early@nhs.net

We are aware that localities both locally and nationally are exploring other IT solutions to identify people in the last year of life. No tool will be 100% accurate and caution should be applied where searches potentially use data where either practices and/or patients have opted out of data sharing. This may exclude significant numbers of patients and compound inequalities

EARLY Toolkit



Web Link:

EARLY Tool |

Resources

North West Coast Clinical Network web page containing more information:

NHS England — North West » EARLY Identification in Primary Care (EARLY toolkit)

EARLY (NHS ENGLAND) email contact: england.early@nhs.net

Any questions?

Thank You

@nwcscnSenate

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