

National Cancer Survivorship Initiative

Developing Services for Those Living With and Beyond Cancer

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Survivorship: Living With and Beyond Cancer

- In last 30 years, 10 year survival rate has doubled
- 2 million people living with and beyond cancer in the UK
 - expected to rise by 3.2% a year
 - 10% of the over 65's are living following a cancer diagnosis
- As the number of those living with and beyond cancer increases, so will the pressures on the system
- Different approaches to care and support following treatment need to be identified and tested to inform commissioning and workforce agendas
- Patients and professionals want a service which meets the needs of patients as appropriate

The Cancer Story

some cancers are born chronic, some cancers
become chronic,

some cancer patients have chronic illness thrust
upon them by treatment

and some are not chronic at all

(apologies to W Shakespeare)

National Cancer Survivorship Initiative

- Partnership between Department of Health, NHS Improvement and Macmillan Cancer Support
- Objective of the initiative is to improve the quality, safety, effectiveness and experience of care through delivering the 5 key shifts:
 1. Cultural shift- focus on recovery, health, and wellbeing
 2. Shift towards assessment, information provision and personalised care planning
 3. Supporting self management/care
 4. Shift from 'one size fits all' to personalised care based on stratification of the person, disease and treatment
 5. Shift from measuring clinical activity to measuring experience and outcomes

NHS Improvement; What We Do

- Improvement resource within the NHS
- Working with clinical specialties to inform policy development and support policy delivery in practice
- Key priority is to maintain a focus on delivery and demonstrate measurable results through the application of robust, systematic improvement work

What Do We Know

2007 survey of perceptions and preferences for follow up

- A survey of 3000 patients & clinicians from Primary and Secondary Care
- Top 3 perceived reasons for follow up
 - To monitor early complications following treatment
 - To detect recurrence early
 - To detect late effects of treatment
- Differences in perceived reasons for follow up between professionals and patients
- Patients generally prefer what they have experienced

Patient Conference 2008

What patients want

- Better information to make informed choices and take control with confidence
- Rapid access to right professional first time when things go wrong
- Would be open to alternative methods of follow up if given appropriate information

2009 Rapid review of follow up across cancer networks in England

Main Findings:

- Traditional 'one size fits all' follow up practice
- Network pathways not always reflected locally
- Wide variation in of frequency of planned follow up over 5 years;
 - Breast 4 -14 visits
 - Colorectal 5 – 13 visits
 - Prostate 4 -18 visits
- Wide variation in duration of follow up - some offering routine follow up for life

Rapid Review Continued...

- Variation in type/duration of surveillance testing
- Limited patient choice on follow up options
- Some evidence of shared care models
 - mainly post treatment stable prostate
- Care plan discussed with 1/3 patients but patient copies not always given
- Variable access to specialist psychological support
- Alternative models of care - patchy

www.improvement.nhs.uk/cancer/documents/RapidFUReview.pdf

NHS Improvement Testing

Pilot testing of elements of potential new pathways of care and support

CYP (10 cancer centres for children):

- quality pathways delivering age appropriate and consistency of care
- New risk stratified models and pathways of care
- Hub coordinated service with care locally as appropriate
- Safe effective recall for surveillance

Adult (26 communities):

- System enablers; ACP, TRS, risk stratification, patient database
- Community led support through oncology CNS in community
- Living well support including information, rehabilitation and exercise
- Telephone support
- Stratified models and pathway development

Picker experience of care survey

- 85% patients found quality of care was excellent or very good
- 9% increase from baseline in those with a care plan however 61% reported they didn't have one
- 10% increase to 86% in patients knew who to contact if they had a concern
- Whole system change: positive experience of care compared to baseline
- Changing elements of care: less significant impact on experience of care from baseline

Assessment and Care Planning Evaluation

- Offered at diagnosis, end of treatment and other key points
- Needs to reflect current and future needs
- Requires dedicated resources (time, space, IT, training)
- Face to face, or telephone,
- Several screening tools tested to facilitated discussion – Distress thermometer or derivative was most popular
- Patient felt more positive and confident after discussion
- Staff recognised benefits and value to patients
- Recognised by the whole team as a key enabler to self management

Summary Treatment Record

- 80% GPs said useful or very useful
- 50% GPs said it would make a difference to how they managed the patient
- 70% wanted similar concise summary at diagnosis
- Ideally need to be interfaced with other IT systems
- Most found difficult to complete in clinic so does have resource implications
- Need to be tumour specific and electronic to aid completion
- Worked best where consultants *believe* in the value

Education and Information

- Tumour specific and generic post treatment courses well received by patients
- 1 day events, 4 - 6 week courses, residential with agenda tailored to patient needs
- One day events that include generic and tumour specific sessions worked well
- Peer support highly valued by attendees
- Requires resources (venue, admin support, refreshments, training)
- Written information on symptom management
- Lack of late consequences of treatment information
- A key enabler to self management

Emerging principles

- Risk stratified care pathways tailored to individual needs based on their disease, treatment and on them as an individual
- Personalised care plans that are developed and reviewed with clear outcomes that meet patient needs
- Improved information for GPs through treatment summaries
- Education, information and support that is appropriate to enable patients to exercise choice and control
- Systems for re-access that are safe, clear and timely. This includes quality assured remote monitoring systems

WHY CHANGE?

The Need for Change

- Increasing numbers of patients living beyond a cancer diagnosis
- Current model unsustainable and not meeting patient needs
- Consequences of treatment and recurrences don't just happen in first 5 years at the time of follow up appointment
- Individuals want choice and control to manage their own condition
- Ensuring changes in practice support QIPP and *'Equity and Excellence Liberating the NHS'*

Value Patients time!



HOW ARE WE LEADING THE REDESIGN AND TESTING OF NEW MODELS AND PATHWAYS OF CARE?

NCSI Prototype Testing Hypothesis

By introducing stratified pathways that meet patient needs and that enable patients to self manage where appropriate, we will be able to:

- Improve health outcomes***
- Improve the patient experience of care***
- Reduce follow up attendances by 50%***
- Contribute to reductions in emergency admissions***

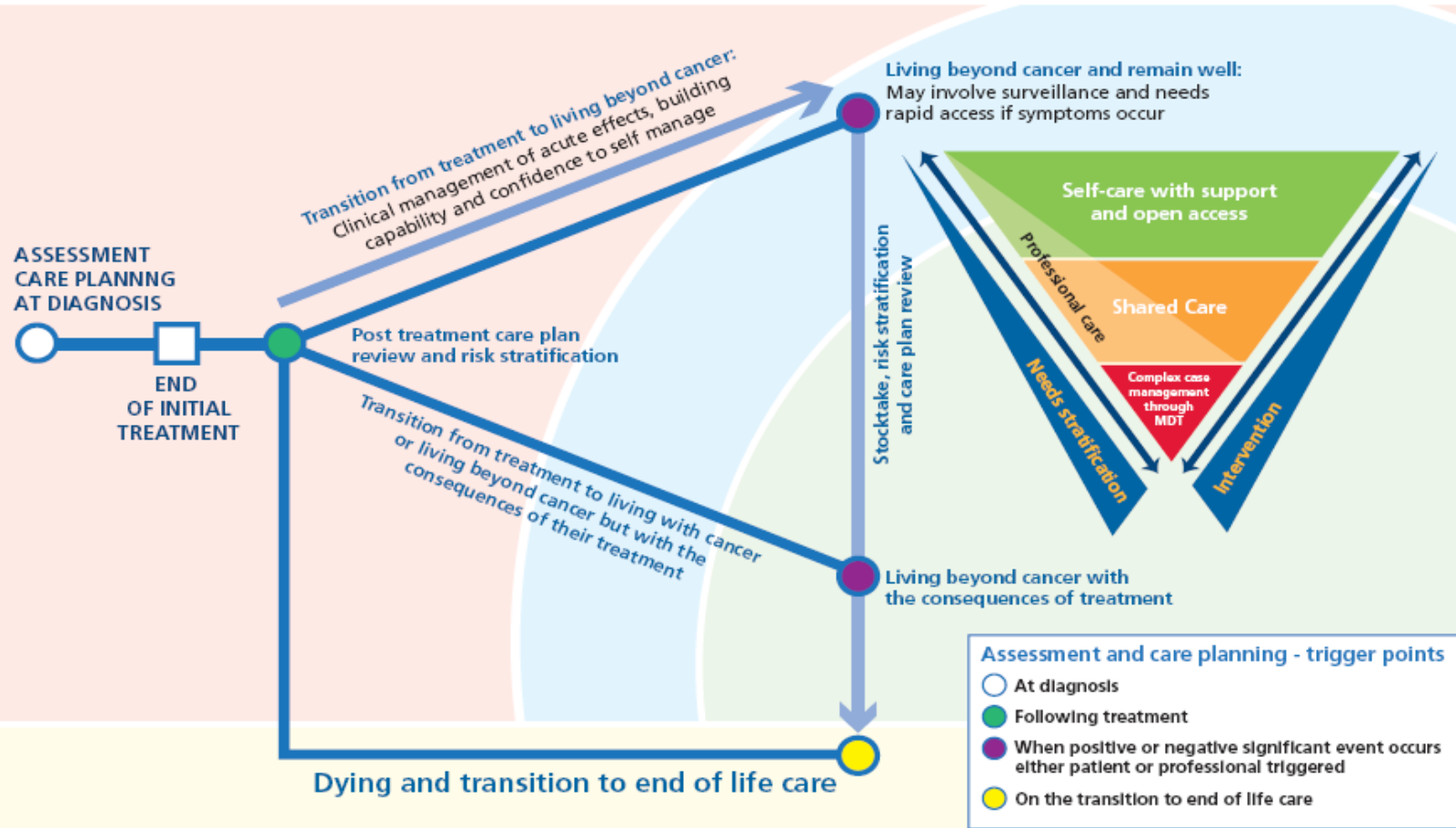
Prototyping test sites and tumour types

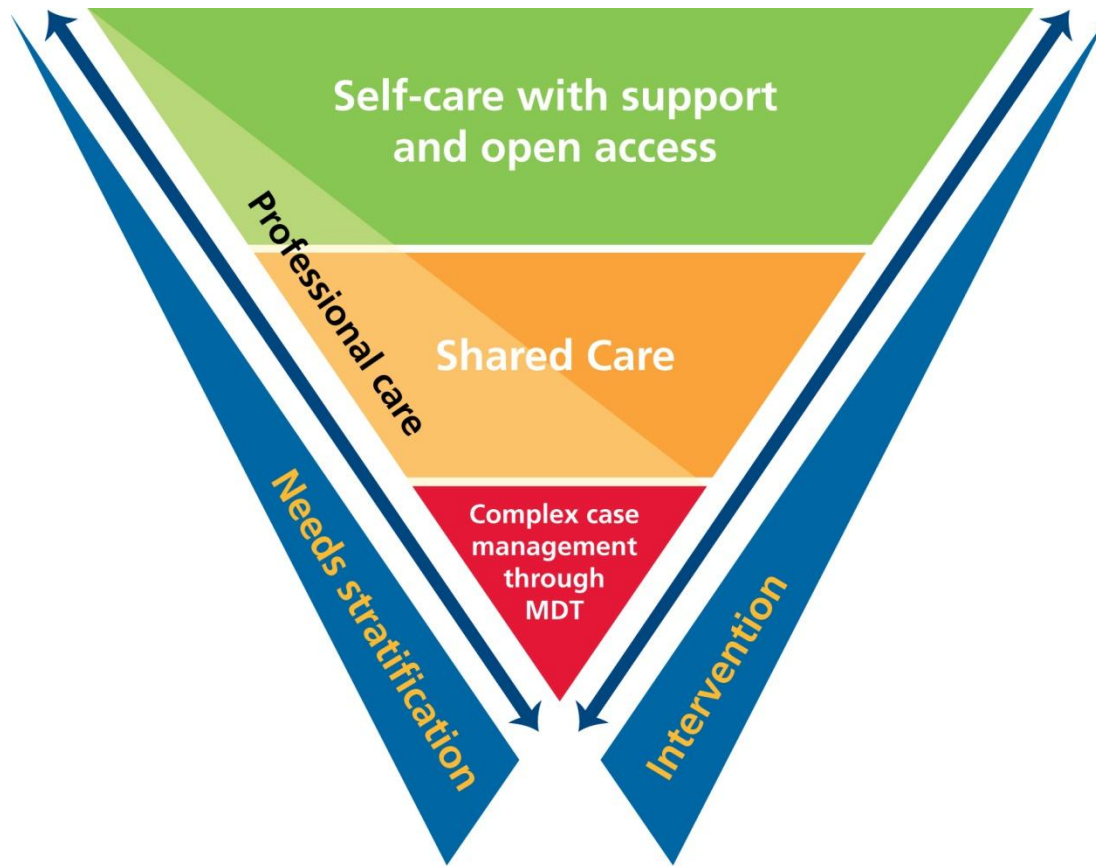
- 7 National Prototype sites
- Focus on 4 tumour types to provide the principles for future practice
- A year of testing to prove/disprove the hypothesis
- Disseminate the learning and principles to support commissioning and care/support provision for those living with and beyond cancer

Support Projects Within the NCSI

- Vocational rehabilitation
- Late consequences of treatment
- GP cancer care review
- Activity and lifestyle
- Supportive self management
- Health and Wellbeing Clinics

Model of Care: Living With and Beyond Cancer

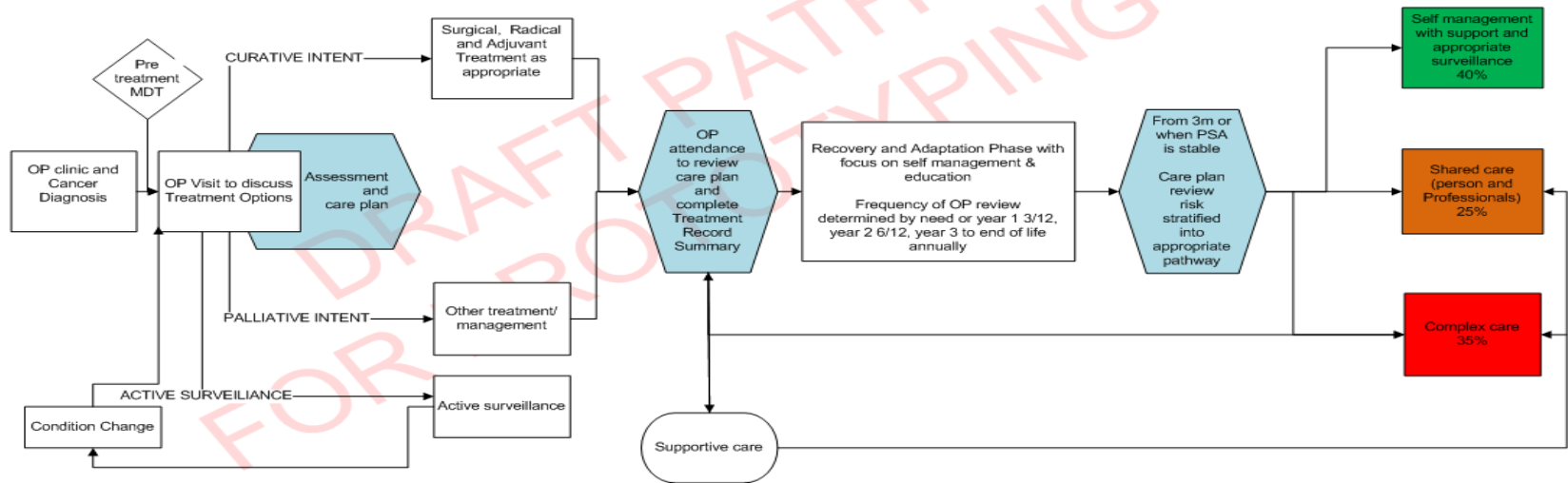




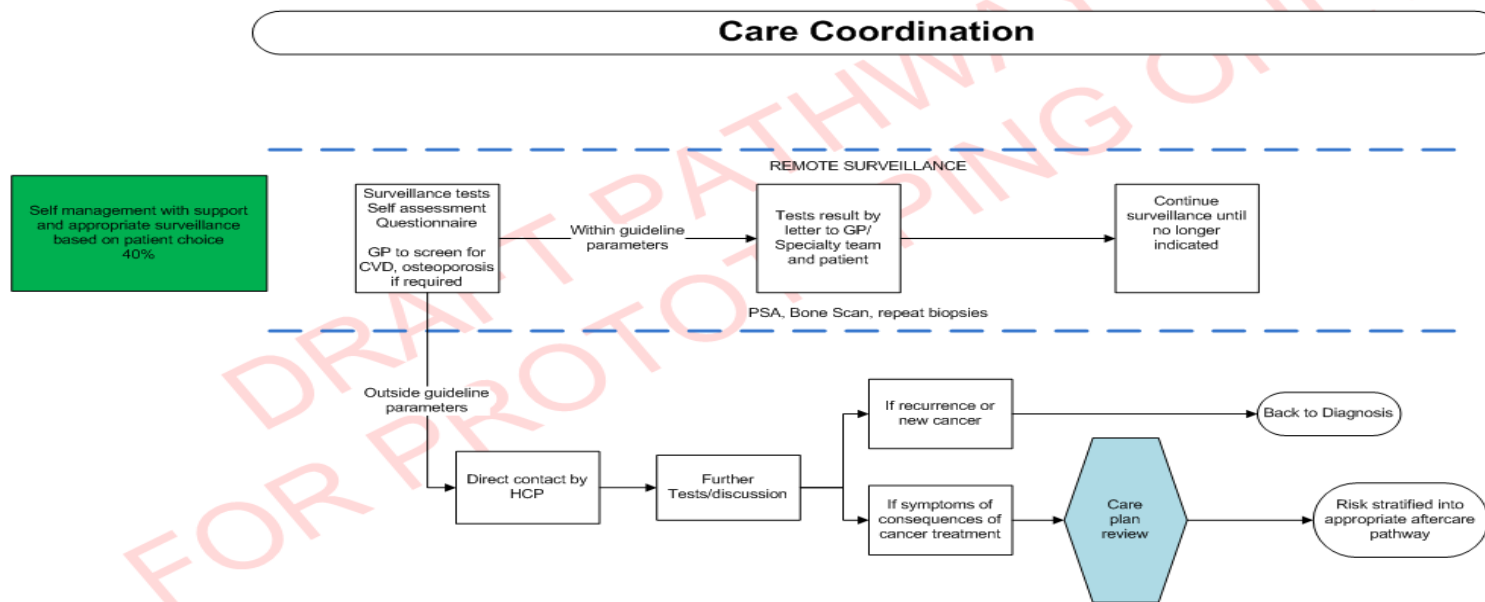
Risk Stratified Model of Care

Generic Prostate Cancer Care Pathway for Prototype Testing

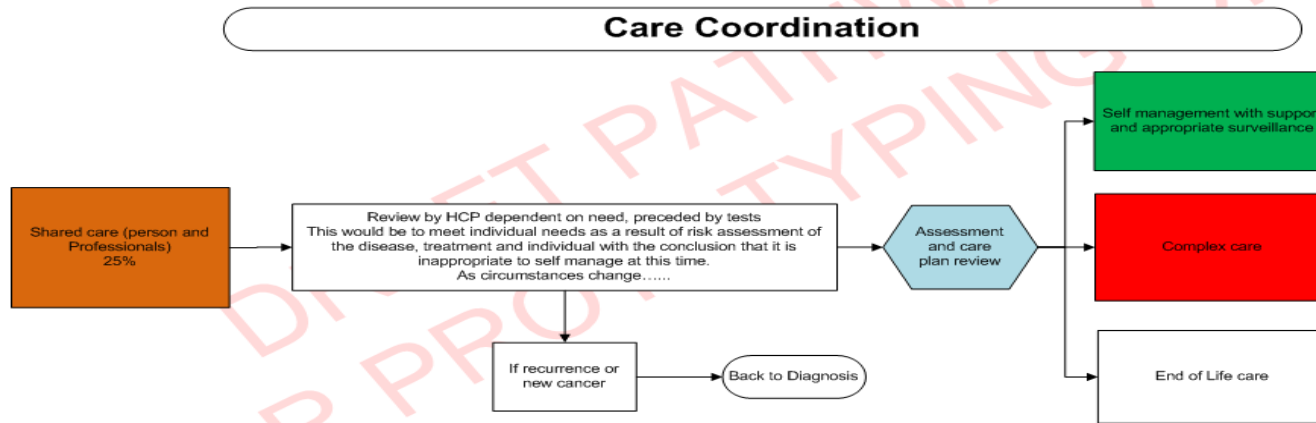
Care Coordination



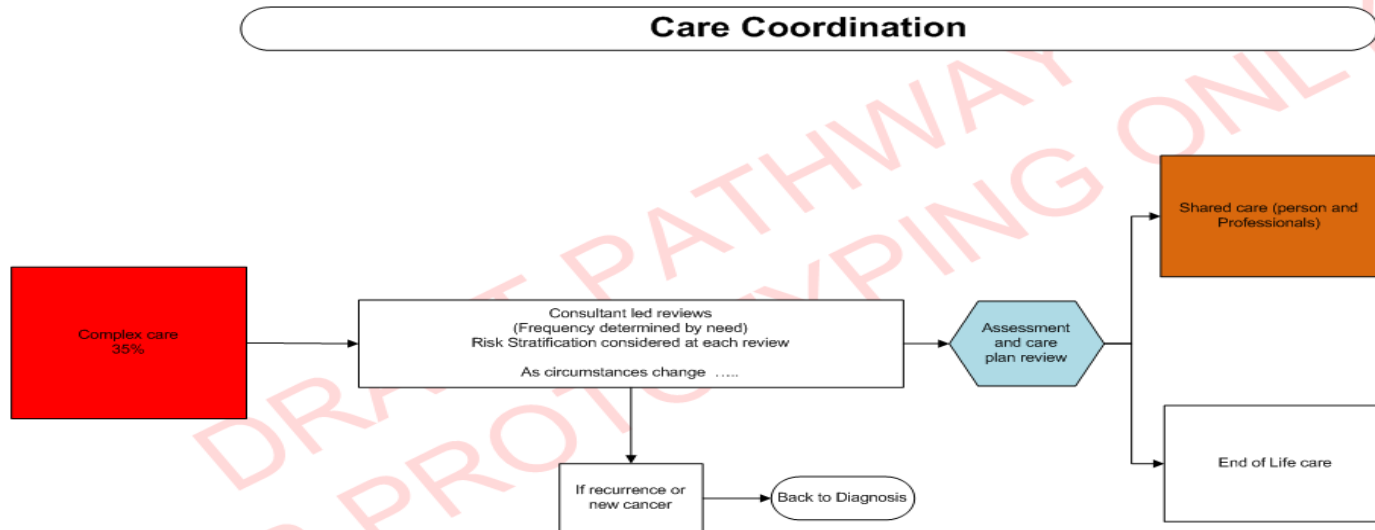
Self-Management Prostate Cancer Pathway for Prototype Testing



Shared Care Prostate Cancer Pathway for Prototype Testing



Complex Care Prostate Cancer Pathway for Prototype Testing



Potential Enablers

- IT solutions for coordinated remote surveillance systems for blood tests and imaging, with appropriate quality assurance
- Effective care coordination service
- Professional education packages (hospital to community)
- Commissioning bundles of care; rather than activity based care, with incentives for best practice

Alignment to QIPP

Quality:

- New pathways of care will address current issues through ensuring the prototype testing of quality pathways are safe, effective and address the needs of patients and the service.

Innovation:

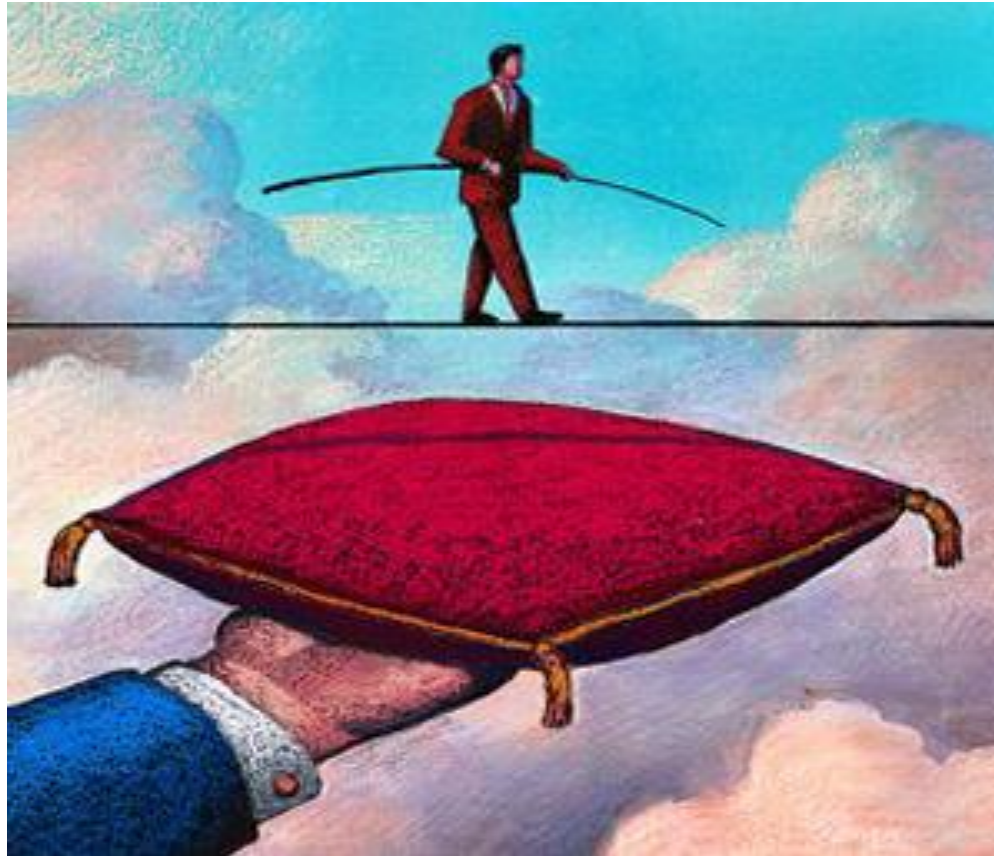
- The pathways and their constituent parts are innovative in that, as far as we are aware, there are no clinical teams nationally or internationally who have pulled together elements of care into a 'total' package driven by stratified pathways of care

Productivity:

- Through delivering quality pathways there would be a reduction in routine follow up which adds no value, and also a reduction in emergency A&E attendances and avoidable admissions through better managed and informed care

Prevention:

- The emphasis will be on secondary prevention through having an effective pathway that is personalised to the individual and encourages a healthy lifestyle through exercise and healthy eating



THANK YOU FOR LISTENING