Patient Experience
National Cancer Information
Pathways Programme

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From Patient Information to the Informed Patient

Cancer Information Prescriptions – our progress so far

Presentation to the Cancer Patient Experience Advisory Group
14th May 2012
Personalised information:
Cancer Information Prescriptions – our progress so far

THE STORY SO FAR…
The starting point for the programme....

- **Building on good work** – aiming to take the best from existing patient information initiatives and develop it further
- **Hugely ambitious** – doing something that had not been done before
- **Many variables** – e.g. quality of information, technology, attitude of providers
- **A genuine partnership** – doing something together that none of the partners could have done on their own
The story so far…

- **Some good progress** has been made with some inspiring examples of how providers are using information to support better outcomes:
The story so far....

• There have also been **significant challenges**
  – Technology issues (IPS, Local IT, Information Governance)
  – Content problems (National Cancer Patient Information Pathways)
  – Relationships (clarity of expectations, accountabilities, roles and responsibilities)
  – Access to senior-level trust managers and CEOs

• And, in a **changing world** too:
  - Structural and system change in the NHS (delivery environment)
  - Efficiency challenge (pressure on resources)
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ACUTE TRUST IMPLEMENTATION....
# Beacon and Wave Timetable

(December 2010-December 2012)

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### Beacon period

#### Wave One

#### Wave Two

#### Wave Three

**EVALUATION**

**TRANSITION**

**TRANSITION**

**TRANSITION**
Number of acute Trusts supported during the programme (December 2010-December 2012)

- 70% of acute Trusts in England by end of year
- Re-modelled from 6 to 3 waves; longer in each
- Broad brush to targeted approach
- Working with willing Trusts
- Embed and sustain

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<td>28</td>
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Information Prescriptions: A targeted approach

1. Cancer Patient Experience Survey Results
2. Development of a Trust Diagnostic Profile from the CPES
3. Layering on local Trust Patient Experience Data, Peer Review Patient Surveys, CQuINs
4. Identify locally which MDTs and Cancer Services to target IP rollout on
5. Targeted implementation of Information Prescriptions
Models of IP delivery – key messages for success

• Implementation is not prescriptive - the IPS and the National Cancer Information Pathways are tools and resources to be used

• Local engagement and ownership is key - determine how IPs will be used locally and sustainability success

• “One size does not fit all” - Flexible models of delivery have emerged

• Integration not ‘in isolation’ – align with other initiatives (e.g. HNA, Survivorship, Shared decision making)

• Service development not just implementation
# Beacons and Wave One Statistics

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<td>Acute Trusts</td>
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<td>62</td>
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<td>MDTs/Clinical Services</td>
<td>203</td>
<td>396</td>
<td>599</td>
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<tr>
<td>MDTs/Services routinely issuing IPs - overall</td>
<td>54.6% (n=111)</td>
<td>36.3% (n=144)</td>
<td>45.5% (average)</td>
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<td>MDTS/Services routinely issuing IPs – targeted approach</td>
<td>N/A</td>
<td>56.2% (n=95)</td>
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<td>Cancer Networks involved</td>
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<td>Information Prescriptions Facilitators</td>
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MDTs issuing IPS in Beacons and Wave 1
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SUCCESSES AND CHALLENGES
Impact so far…. Some key points

What has gone well….

• Trusts are clear that they have freedom to implement what is appropriate locally
• Integration with other initiatives is happening
• Strong Trust Leadership (Lead Cancer Nurses)
• The planned, targeted approach
• Less problems with technology but more with issues with information Governance

Ongoing challenges….

• Resource intensive for Trusts, patchy implementation
• Majority of staff involved are still CNSs
• Limited measurement locally to record IPs issued
• Limited implementation across whole patient pathway
• Lack of computer/printers in or near clinics for real time dispensing
• Integration with Information and Support Centres

Source: Quality Health, April 2012
Examples of success – Nursing leadership

• **Modes of delivery** – very much Clinical Nurse Specialist (CNS) led and success where strong leadership of CNS staff and cohesive group (share office and learn system together); well organised work routines and administrative support. Invested in project management and roll-out.

• Several tumour areas implementing IPs via **nurse led clinics**.

• **CNS objectives** are set for IP implementation and delivery contained within their job plans.

Source: Quality Health, April 2012
Examples of success - Integration

- Integration with **Holistic Needs Assessment** (especially putting the IP within the electronic HNA tool), book adequate time with patients.
- **Peer review** catalyses staff to use IPs, they can demonstrate ‘the opportunity for the patient to be given written information’.
- Opportunity with **service development** to use IPs to better co-ordinate patient care.
- **Wider organisation awareness** – e.g. long term conditions, maternity services

Source: Quality Health, April 2012
Benefits to patients and carers

- Clearer flow of information
- Better communication
- Available to both patients and carers
- Access information at own pace
- Reduced information ‘overload’
- Greater clarity about what happens next

- Images/Pictures are helpful
- Follow-up email after conversation with healthcare professional very useful
- Access to local services information

Source: Quality Health research funded by Cancer Research UK, 2011
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THE WAY FORWARD…..
The journey from Patient Information to the ‘informed patient’
(Based on reflections from Information Prescriptions implementation)

**Patient Information**
- Passive information received
- Information overload
- Clinician driven
- Confusion with data
- Low profile and low priority

**Information for patients**
- More active process
- Based on assessed need
- Tailored to point of need
- Personalised

**The informed patient**
- Proactive process with outcomes
- Informed
- Supported
- Empowered
- Shared decision making
- Self-management
Moving forward we need to focus on…

**National Level**
- Securing a clear mandate to ensure sustainability  
  (A programme which is not mandated and has no “required element”, or targets, is unlikely to be sustained, Quality Health, April 2012).
- Maintain leadership, expertise, skills and experience developed at national and local levels
- Robust evidence collection and sharing
- Supporting the implementation of the Information Strategy and Outcomes Framework

**Local Level**
- Increasing levels of engagement at Trust level
- Building on implementation successes to deepen commitment to informing patients
- Supporting Trusts which have strong local leadership and have integrated IPs with other initiatives
- Support development and integration of services (information and support services)
Moving forward......

The past

• To date, the focus of the information prescriptions programme has been on getting right the process of developing, prescribing and dispensing information.

The future

• The emphasis will be on improving outcomes (not process)
• Provides a practical way to make real the ‘no decision about me, without me’ commitment
• Supports implementation of other policies and encourages signposting to a wide range of available support