

NCSI – CYP

National Test Site Report

1. Your Details

Name	Geraint Hughes
Organisation	Yorkshire Cancer Network
Email	geraint.hughes@ycn.nhs.uk
Contact Number	01423 555759
Month	August 2010

2. The Project

The Yorkshire Cancer Network (YCN) supports two integrated national test site projects that aim to develop and test a supported self-care approach to the management of long term survivors of childhood and adolescent cancer.

The vision is one that mirrors and supports the “5 Key shifts” at the core of the National Cancer Survivor Initiative’s vision and the clear direction of travel outlined within the Cancer Reform Strategy. The aim is to move away from the traditional tertiary management of patients (currently based at Leeds Teaching Hospitals NHS Trust) to one that allows appropriate patients to take control of their care and be increasingly managed within their own community with primary care support.

As well as allowing care and clinical monitoring to be delivered close to the patient’s home, the aim – again, in line with national policy direction - is to ensure the patient is sufficiently empowered to ensure they experience greater control, ownership, understanding and peer support throughout their follow-up.

The YCN initiative comprises two integrated components namely the development of a clear, sustainable and safe shared-care pathway and also the development of a Community Cancer Portal (CCP).

The CCP is an e-platform that will not only allow seamless communication and information exchange between the tertiary centre and any future primary-care based partners in follow-up but also between patients themselves and the tertiary team. Finally it will facilitate peer support for patients via on-line chat fora.

3. How you have implemented your project

The wider project was overseen by a broad and inclusive Steering Group. Sub-groups were also established to direct discreet pieces of work around the development of both the pathway and CCP.

The project was implemented via the following key steps:

Ownership

The first task for the project was to ensure ownership of the work at the highest level and across all stakeholders. The project aims, and anticipated outcomes, were discussed with the Yorkshire Cancer Network (YCN) Board in May 2008. The project was given the Board's full support.

Leadership

A decision was made at the outset to ensure that there was sufficient clinical leadership in place in order to ensure wide engagement, the positioning of the project at a high level as well as a 'hands-on' clinical drive. Dr Glaser was seconded as Clinical Lead for the project as well as being appointed as Clinical Lead for Survivorship for the YCN to undertake these roles.

Engagement

a) GPs

The success of the project would rely heavily on GP support for the concept of shared care between GPs and the Cancer Centre. In order to better understand GPs views of both the concept and proposed mechanics of the pathway, Dr Glaser made several presentations at Leeds PCT post-graduate training sessions – securing both invaluable feedback but also agreement by some GPs to play a more active role in the project via a proposed GP focus group.

A facilitated GP focus group was arranged in September 2009. This was externally facilitated by Dr Peter Rose from the Department of Primary Health Care, University of Oxford. The half-day focus group produced interesting, and generally supportive, views regarding the proposals. Some of the headline feedback was:

- There needs to be prior agreement that GPs can directly request relevant tests eg echo. GPs won't want to negotiate this for each and every patient when the alert comes through.
- It is important that the right (named?) GP (and perhaps not a locum/trainee) sees the patient otherwise some of the benefits of community follow up may be lost.
- The mobility of patients is a concern. If they choose community F/U in one practice but move then they may be lost to follow up or have to resort back to tertiary F/U

- Mobility of GPs could be of concern. If a GP involved with community monitoring moves practices the remaining GPs may not wish to continue with community F/U.
- The community model will appeal to patients as often the healthy patients won't want to be sitting in clinics with clearly poorly patients.
- The small numbers involved will mean the process will take a long time to bed-in/become systematic.
- Difficult to imagine patients younger than 18 being empowered enough to utilise the pathway.
- Patients need to be offered community F/U and not have it imposed – ie negotiate with each patient.
- Are GPs comfortable with the unique psychological issues that pertain to teenagers/young adults? Perhaps the CNS could do outreach to support the GP with such issues?
- There should be a means of electronically alerting GPs of steps that need to be taken (test/consultations). Whilst GPs don't routinely use such prompts at present there is no reason to believe it wouldn't work.
- Patients should also be sent alerts and that they in turn could act as prompts to GPs to initiate action. Good example of patient empowerment.
- GP rapid access to advice from the Cancer Centre is vital. This should be available by 'phone and not just the CCP (technology not always the answer)".
- A means of rewarding GPs for this work and the related tests needs to be established.

b) Commissioners

The radical nature of the proposed shared care pathway would necessitate sophisticated commissioning arrangements to ensure:

- On-going funding support of the Cancer Centre LTFU Team to both continue with Late Effects monitoring of high risk patients but also to advise and support both (low risk) patients and GPs in any shared care arrangement.
- Appropriate incentives for GPs.
- Arrangements to support tests to be undertaken in the Cancer Centre, local hospital or GP practice as necessary/chosen by patient.
- Flexibility to allow patients to move to and from shared care as they choose or becomes necessary.

The approach to secure commissioner engagement and advice entailed:

- YCN Board discussion.
- Commissioner representation on the Steering Group.
- Single-issue meetings with commissioners.
- Seeking ad hoc advice eg from the SHA.
- Consideration of a consultancy arrangement.

Despite clear support for the project it has proved difficult to secure the depth of commissioning support that has been required. Many of the key commissioning

questions remain. It is hoped that through a better understanding of the current and possible future costs there will be a firmer basis for more meaningful discussions with commissioners. To this end the YCN project has participated as part of a NCSI economic evaluation exercise (see below).

c) Patient/Users

Both a user and the YCN User Facilitator are key stakeholders within the Steering and Pathways Sub-groups.

Our patient representative has specifically helped in understanding and improving the current cancer pathway.

User views have been established through questionnaire surveys administered in clinic (concern that we have not captured the views of non-attenders).

d) IT

The YCN supported the employment of an IT developer to progress the CCP - under the professional support and direction of the Leeds Teaching Hospitals NHS Trust (LTHT) IT Department.

The LTHT IT were cognisant of the potential benefit for their patients and services should the CCP prove successful. As such, they contributed invaluable leadership and support – including project management – in ensuring the CCP was delivered.

A key to the success in delivering the IT solution was to build upon the success of a renal web-based system with some significant similarities. The clinician involved in leading the development of the renal system was paid on a sessional basis to help shape and steer the CCP project.

Understanding Processes

A facilitated process mapping session was held with members of the multi-disciplinary LTFU Team in order to:

- Understand and clarify exactly how patients move through the current pathway.
- How the pathway differs between a complex and non-complex patient (Wallace levels 1 and 3 respectively).
- How long key steps took.
- What aspects of the pathway were not working as expected and why?

The views of a parent of a current patient were then canvassed by taking them through the process map in order to identify:

- If the map represented the pathway as they experienced it.
- What issues they felt needed to be addressed in order to improve the patient experience?

A follow-up mapping event was then held on the 12th August 2010 in order to:

- Reflect on how an 'ideal' future-state pathway would look like.
- Understand how the CCP could add value to the pathway.
- Identify ways of maximising added value.
- Identify ways to reduce waste.

Gathering Baseline Data

Considerable baseline evidence has been/is being collected against which the scale and consequences of testing of the CCP and transformed long-term follow-up care pathway will be evaluated.

Evidence to-date includes:

- Questionnaires on current patients' use of IT and their attitude to the use of IT in supporting possible shared care. The survey of 51 adult survivors of young people's cancer attending the Leeds LTFU programme revealed that 90% were comfortable with the use of the internet to help with their healthcare. Furthermore, 88% felt comfortable with follow-up being delivered via the internet for some or all of the time.

However, a challenge to the proposed model of care came from the survey's results that 12% did not find the concept of remote e-follow-up acceptable.

- LTHT is one of six sites helping to evaluate the treatment summary/care plan developed at the Christie and GOSH. The aim is to provide a personalised treatment summary and late effects follow-up care plan including;
 - Diagnosis
 - Stage
 - Treatment (including chemo and XRT doses)
 - Summary of potential Late Effects and the importance of follow up needed post disease specific surveillance
 Questionnaires have recently been circulated to understand patients', carers' and professionals views of the summaries.

- LTHT staff have undertaken an evaluation of clinic satisfaction (funded via CLIC –Sargent). The main conclusions being:
 - Adult survivors of childhood cancer have important problems with psychological functioning and social difficulties, and reduced quality of life although this had wide variation between individuals, implying a need to individualise approaches to care.
 - Quality of life and social problems appeared not to diminish on average with increasing time from diagnosis, implying a need to continue to support these individuals.
 - Patient satisfaction with long term follow-up care was generally very high, and may be measurable in routine settings with a simple three-question approach.

- Economic evaluation work has been undertaken as part of an NCSI initiative. The purpose of this work, which consists of a case note review and a patient questionnaire, is to enable the NCSI to get a retrospective picture of cancer activity and costs for different tumour types in different parts of the country, and to get the patient view on the cost of attending outpatient clinics and whether they have had issues addressed or unaddressed prior to their current appointment.

The outcome of this exercise will be used to inform decisions about the way services are provided in the future.

100 LTHT patient case notes have been reviewed and the relevant details sent to the DoH for analysis.

- Considerable baseline audit has been undertaken to understand the current pathway and whether patients have access to the internet.

Separate audits were undertaken for the initial visit as well as follow-up visits over a 4 month period. The process will be repeated after 12 months.

268 patients were included in baseline evaluation: 65 patients were under 18 years of age (9 new referrals, 56 follow-up) and 203 were aged 18 years and over (13 new and 190 follow-up).

Results will be analysed after collection of repeat evaluation in order to determine whether increased numbers of service users and their GPs have access to details of the relevant key worker, service contact details and treatment summary/care-plan.

Development of the Community Cancer Portal (CCP)

February 2010 witnessed the first live demonstration of the CCP. The demonstration by IT and clinical colleagues from Leeds Teaching Hospitals NHS Trust was a culmination of one year's work by them on behalf of the YCN.

In addition to showing that the technology does indeed work, the demonstration also clearly showed the CCP's future capability to:

- communicate securely between tertiary, secondary and primary care
- communicate securely between tertiary care and the survivor
- automatically generate Survivor Cancer Care Plan/pathways
- automatically generate treatment summaries
- automatically generate alerts regarding planned surveillance tests
- simply sign-post on-line information resources for both patients and shared care partners
- provide a secure chat-room for improved peer support.

From March to August 2010 the team have been testing the basic functionality of the CCP. The main foci has been to ensure:

- the CCP interfaced with LTHT data-sets.
- It automatically generated treatment summaries
- care plans for on-going late effects monitoring can easily be created from CCP based pathways.

The project timelines have slipped during this period, primarily due to 2 reasons:

- The need to undertake external 'penetration' testing to ensure the system was secure against hackers.
- The retirement of the CNS supporting the project.

The system recently received a generally positive penetration report and action is being undertaken to ensure the required levels of security.

A replacement CNS project support post has been advertised in early August.

4. Evidence of QIPP throughout testing and implementation

The project is being formally evaluated against the QIPP framework. Anticipated benefits include:

Quality

- Patient choice over model of follow up
- Possibility of care closer to home for a significant (stratified) patient group
- Patient peer support via CCP
- Follow up tests co-ordinated
- Direct access by GP/other care professionals to care records/treatment plans
- CCP generated Treatment Plans for all patients
- Late Effects team able to focus support on patients most in need
- Collection of comprehensive outcomes data

Innovation

- Transforming the pathway from a traditional tertiary-based one to one that provides care service closer to home
- Providing web-based access for both patient and GP to tertiary centre's care history/plans and appropriate information.
- Providing web-based access for both patient and GP to the Late Effects Team
- Developing a web-based system that allows community-based healthcare staff to access records held at a tertiary level
- Development of a web-based platform that can easily and cheaply be adopted by any trust

Productivity

- Late Effects Team able to support a greater number of patients
- Fewer tests undertaken at Cancer Centre
- Tests undertaken more cheaply in community
- Late Effects team's skills targeted on patients most in need
- By providing care closer to home this should ensure less time off work/education for the patient/carer
- No unnecessary outpatient visits for tests

Prevention

- Cancer survivor care plan available to all patients and GPs/other care providers
- Comprehensive outcomes database – wherever patient followed up

Patients/Users

The CCP and shared care pathway will:

- Lead to patients being fully informed regarding their treatment histories, care plans and follow up test results
- Ensure patients have on-line access to appropriate relevant patient information
- Ensure patients have ownership of their proposed follow-up pathway and make patients integral to the management of the pathway eg ensuring tests are undertaken in accordance with the pathway
- Allow patients to share their treatment histories/care plans with appropriate health care professionals as and when they wish
- Enable on-line peer support
- Allow the patient a degree of choice as regards the nature of follow up and where tests should be undertaken eg GP surgery v hospital

5. Other Sources of Evidence

An economic evaluation has been completed to firstly, capture the salient interventions by the team for 100 patients and secondly, to cost these episodes. An evaluation of the possible future community-based costs can then be made to demonstrate the potential impact of the proposed model of care. This data was sent to the Department of Health at the end of July for economic analysis.

As a test site for the care plans developed via the wider NCSI initiative, the Leeds LTFU Team has issued questionnaires to patients, staff and GPs. This was part of an NCSI process to fully evaluate the impact of the care plans.

The benefits of the CCP, and the proposed community-based pathway, in facilitating a shift from tertiary-based care could potentially be rolled out across other cancer sites or even across non-cancer pathways. The CCP has been specifically designed as a 'plug and play' system requiring minimal resources to set it up in potentially any provider organisation.

6. What are the challenges and positive elements of testing

<p>Are there any potential top tips or potential pitfalls?</p>	<p>Tips</p> <ul style="list-style-type: none"> • Harness, encourage and support clinical leaders. • Get explicit support for the project at the very highest level eg YCN Board at the outset. • Develop IT projects in liaison with experts – don't go it alone. • Constantly reflect to ensure your project is in line with national policy direction. • Never forget the politics. • Don't give up. Even I.T within the NHS can sometimes come good.
<p>Please identify negative elements of the testing and implementation</p>	<p>There was/is considerable difficulty in engaging senior commissioning support in order to assist in both the evaluation and in describing the required commissioning framework that will facilitate this shift in how care is provided.</p> <p>A recent attempt to secure advice on a consultancy basis has had to be abandoned due to the realities of the current economic and political circumstances.</p> <p>As with most IT projects – and despite considerable project management – the development of the CCP has required more resources than initially planned and was delivered slightly behind schedule</p>
<p>Give details of what worked really well throughout the life of the project</p>	<ul style="list-style-type: none"> • Clinical leadership • Delivering a radical IT solution within a tight timeframe and comparatively limited budget
<p>What are the plans for long term gains</p>	<p>The potential wider benefits of the CCP</p>

	are being considered as a potential key component of the YCN's contribution to the QIPP agenda across north and west Yorkshire.
--	---

7. Relevant contacts or resources

<p>Service Improvement Lead, YCN Carol Ferguson</p>	<p>01423 555799 carol.ferguson@ycn.nhs.uk</p>
<p>Lead Clinician, Late Effects, YCN Adam Glaser</p>	<p>0113 2064984 adam.glaser@leedsth.nhs.uk</p>
<p>Service Improvement Facilitator, YCN Geraint Hughes</p>	<p>01423 555759 geraint.hughes@ycn.nhs.uk</p>