My Cancer Portal – Local Evaluation

Executive summary

My Cancer Portal is a phase II TCAT project delivered over 2 years (April 2015-17). It is a digital health system comprising a patient ‘app’ and a patient management system, the ‘dashboard’. Together the ‘app’ and the ‘dashboard’ create the portal and are linked across the NHS e-health firewall. MCP allows patients to fill out Holistic Needs Assessments (HNA), symptom dairies and exchange messages with the healthcare team. In addition, the portal signposts patients to valuable sources of information.

The healthcare team can access the ‘dashboard’ on any NHS Highland computer. The latest HNA and symptom tracker information is clearly displayed with new concerns highlighted. Unread messages are also clearly visible. Treatment Summaries (Tsum) are pre-populated with essential information from the Multi-disciplinary Team (MDT) form. Both the MDT and Tsum documents, once validated, are sent immediately to the primary and secondary care electronic patient records (EPRs).

My Cancer Portal has been co-designed with a wide range of stakeholders and is currently being utilised by patients with colorectal cancer in NHS Highland. Our plans over the next 18 months encompass the following.

- Apply for phase III TCAT funding
- Incorporate patient and staff feedback into portal design
- Build an electronic Care Plan
- Further test MCP on all patients with colorectal cancer in NHS Highland
- Incorporate another cancer group into MCP and test usability
- Test and measure feasibility of implementing MCP into another NHS Board’s digital infrastructure
- Explore the export of anonymous data sets for academic research

Project description

My Cancer Portal (MCP) is a digital health project that is designed to improve the care we give to patients with cancer. It consists of two elements; a clinical dashboard and a patient app. Both are connected across the NHS e-health firewall. MCP brings together the following elements that are utilised in a patient’s care pathway: the Multi-disciplinary Team (MDT) record, Treatment Summary and the Holistic Needs Assessment (HNA). In addition, MCP also allows direct messaging between patients and the health care team. Other adjuncts have been designed specifically for the MCP patient app. ‘My Information’ allows patients to be sign-posted towards information resources already available on the internet. ‘My Story’ is a safe (only patients have access) digital space for patients to record personal feelings and thoughts; these cannot be seen by the healthcare team but can be shared with friends, if a patient wishes. Together with the University of Aberdeen we have also incorporated the colorectal cancer ‘Symptom Tracker’ in both the ‘app’ and the ‘clinical dashboard’. This allows patients to answer some straightforward questions on well being and physical symptoms. The data is displayed graphically for the healthcare team to see.
The Treatment Summary (Tsum) was adopted from work performed by the Forth Valley TCAT work. We have incorporated Tsum into MCP and have also improved its potential utility by pre-populating many of the Tsum data fields with information from the MDT form. Once completed, the Treatment Summary is sent directly to the primary and secondary care EPRs. It can be printed off for a patient or sent to them by mail.

The MDT form has been used in NHS Highland for colorectal cancer, upper gastrointestinal and hepatobiliary cancer patients for over 2 years. The form (Formstream) was co-created by Voice Technologies and NHS Highland e-health team and is compiled real-time by clinicians during the MDT meeting. The form and its information, is validated during the meeting and is sent directly to the primary and secondary care electronic patient records (EPRs).

MCP was principally developed by Professor Angus Watson [AJMW] (NHS Highland) and David Sim [DS] (Open Brolly). The design was informed by a monthly Project Management Team (PMG) and a quarterly Steering Group (PSG). Most importantly, however, was the input received from two patient panels. The Symptom Tracker was developed by Dr Peter Murchie and his team at Aberdeen University. It was adapted for use on MCP by AJMW and DS.

**Patient and staff involvement**

MCP, in its first phase, has been designed to be used for all patients with cancer on the rationale that all patients should have an MDT discussion, a Treatment Summary and a Holistic Needs Assessment. For this phase of the project, however, we engaged patients with colorectal cancer. Patients were approached and consented to take part in co-design panels and/or to test the MCP. Two co-design panels were completed with 6 participants. Thirty-three patients are currently enrolled to test MCP in this first phase.

Patients were approached in clinic by clinical nurse specialists or by invitation letter. Participants in the test group were sent a short training presentation and a login and pin number to access the ‘app’.

The colorectal nurses were given face to face training session on how to use MCP by AJMW in addition to a training handout.

The PMG consisted of AJMW, DS (Open Brolly), Dr Gill Clarke (General Practitioner and colorectal cancer patient) and the Director of NHS Highland e-health or his representative. In addition, a Macmillan member of staff was present at the PMG. This ensured that both the primary and secondary care sector needs were considered in the MCP design and that the portal would interface with all existing NHS Scotland e-health systems. (PMG staff list in Appendix)

The PSG encompassed a range of colleagues from diverse sectors. This included a cancer nurse consultant, healthcare managers, a lay representative, a general practitioner, a hospice medical consultant and specialist nurses. The PSG was chaired by an academic, active in cancer research. The PSG met quarterly through the lifetime of the project. (PSG staff list in Appendix)

Taken together, the patient panels, the PMG and the PSG gave the project access to a diversity of opinions and advice which has been reflected in the design of the portal.
Why is My Cancer Portal needed?

Staff and patients are becoming increasingly familiar with digital health applications. This familiarity is set to expand and there is an expectation that care will be delivered in the future using digital platforms. In parallel to this, we needed to introduce Treatment Summaries and Holistic Needs Assessments, as these were not being used routinely anywhere within the North of Scotland Cancer Network. We therefore wanted to explore how digital health could be used to deliver these adjuncts to care, efficiently. As a local group, we were also not using risk adjusted follow up regimens as often as we should have been, possibly related to a lack of confidence in referral routes back to care. An aspiration for MCP, was to provide a virtual ‘safety net’ for patients to be able to contact the cancer team if they needed help or advice. In addition, we also identified potential ‘traps’ within cancer pathways, when a patient was being transferred from one service to the next. We wished to explore how MCP could address the safety of a patient’s journey using an ‘every patient, every time’ approach.

Aims

The aims of the MCP project were:

- Build an exemplar digital health portal for staff and patients
- Use a co-design approach to create the portal
- Link together the essential elements used for caring for patients with cancer: MDT, treatment summary, holistic needs assessment with a messaging system
- Embed the portal in core NHS Scotland e-health systems
- Train staff and patients to use MCP

Evaluation methods

The MCP project differs from other TCAT phase I&II projects as the evaluation concerns measuring the ability to create and build a digital health product that can be used by staff and patients alike. Evaluation of MCP was performed by the project management and steering committees and was judged against pre-determined milestones for the MCP project. These milestones were:

- Incorporate an electronic MDT form into primary and secondary care Electronic Patient Records (EPRs)
- Utilise a digital Treatment Summary (TSum) form and pre-fill data fields from the MDT form
- Integrate TSum into the EPRs
- Embed the electronic Holistic Needs Assessment (e-HNA) into the Clinical Dashboard
- Display current needs concerns on Clinical Dashboard
- Create easy access to archived MDT, Tsum and eHNA forms
- Create a graphical display for the Symptom Tracker
- Develop and test links between MCP-Clinical Dashboard and SC1store and Electronic Document Transfer (EDT)
• Create an intranet domain on NHS Highland’s clinical applications page on the intranet
• Acquire and build an internet domain for My Cancer Portal
• Develop secure login and password identification steps for patient access to MCP
• Design and execute messaging system for patient to contact secondary care
• Create the eHNA page
• Adapt and incorporate the University of Aberdeen Symptom Tracker into the ‘app’
• Design the My Information page and validate contents and hyperlinks to external web pages
• Create and design the My Story page and content
• Develop sharing options for My Story content
• Design and create secure data flows between MCP ‘app’ and the NHS Highland e-health
• Conduct and analyse patient panels
• Conduct and analyse staff panel
• Train patients and staff to use MCP
• Conduct patient testing for 6 months
<table>
<thead>
<tr>
<th>MCP Milestone</th>
<th>Outcome</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incorporate an electronic MDT form into primary and secondary care Electronic Patient Records (EPRs)</td>
<td>Done</td>
<td>Validated in real time and sent immediately to SCIstore and Docman (GP records) via EDT system</td>
</tr>
<tr>
<td>Utilise a digital Treatment Summary (TSum) form and pre-fill data fields from the MDT form</td>
<td>Done</td>
<td>Tsum adopted from Forth Valley TCAT project</td>
</tr>
<tr>
<td>Integrate TSum into the EPRs</td>
<td>Done</td>
<td>Using a specific interface developed between Voice Technologies and NHSH e-health/Open Brolly</td>
</tr>
<tr>
<td>Embed the electronic Holistic Needs Assessment (e-HNA) into the Clinical Dashboard</td>
<td>Done</td>
<td>Version controlled and archived</td>
</tr>
<tr>
<td>Display current needs concerns on Clinical Dashboard</td>
<td>Done</td>
<td>Displayed in red – but no method of recording if concerns addressed</td>
</tr>
<tr>
<td>Create easy access to archived MDT, Tsum and eHNA forms</td>
<td>Done</td>
<td>Searchable in a drop down menu</td>
</tr>
<tr>
<td>Create a graphical display for the Symptom Tracker</td>
<td>Done</td>
<td>Traffic light system to easily identify problem areas</td>
</tr>
<tr>
<td>Develop and test links between MCP-Clinical Dashboard and SCIstore and Electronic Document Transfer (EDT)</td>
<td>Done</td>
<td>Integration is key to ensure primary care team are sighted on patient journey</td>
</tr>
<tr>
<td>Create an intranet domain on NHS Highland’s clinical applications page on the intranet</td>
<td>Done</td>
<td>Under the heading Remote Outpatient Care</td>
</tr>
<tr>
<td>Acquire and build an internet domain for My Cancer Portal</td>
<td>Done</td>
<td>Data housed by Microsoft Azure</td>
</tr>
<tr>
<td>Develop secure login and PIN identification steps for patient access to MCP</td>
<td>Done</td>
<td>Login and PIN created using the Clinical Dashboard- manage users function</td>
</tr>
<tr>
<td>Design and execute messaging system for patient to contact secondary care</td>
<td>Done</td>
<td>In addition, text messaging alerts put in place to notify patients have a message awaiting them in the portal</td>
</tr>
<tr>
<td>Create the eHNA page in patient ‘app’</td>
<td>Done</td>
<td></td>
</tr>
<tr>
<td>Adapt and incorporate the University of Aberdeen Symptom Tracker into the ‘app’</td>
<td>Done</td>
<td>Some overlap with eHNA and will need validating at a later stage</td>
</tr>
<tr>
<td>Design the My Information page and validate contents and hyperlinks to external web pages</td>
<td>Done</td>
<td>Icons created to a range or resources. Icon ‘clicked’ and page opens in new window</td>
</tr>
<tr>
<td>Create and design the My Story page and content</td>
<td>Done</td>
<td></td>
</tr>
<tr>
<td>Develop sharing options for My Story content</td>
<td>Done</td>
<td>Patients can share with specified ‘friends’ using email</td>
</tr>
<tr>
<td>Design and create secure data flows between MCP ‘app’ and the NHS Highland e-health</td>
<td>Done</td>
<td>All data anonymised until it gets across NHS firewall</td>
</tr>
<tr>
<td>Conduct and analyse patient panels</td>
<td>Done</td>
<td>Transcribed</td>
</tr>
<tr>
<td>Conduct and analyse staff panel</td>
<td>Not complete</td>
<td>Planned for August 17</td>
</tr>
<tr>
<td>Train patients and staff to use MCP</td>
<td>Done</td>
<td></td>
</tr>
<tr>
<td>Test group to utilise MCP for 6 months</td>
<td>Not complete</td>
<td>Testing not complete till September</td>
</tr>
<tr>
<td>Component</td>
<td>Questions</td>
<td></td>
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<td>--------------------------------------------------</td>
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<td></td>
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<tr>
<td>Implementing Holistic Needs Assessment</td>
<td>The eHNA was created in the patient ‘app’ and can be filled in on a personal computer, tablet and smart phone. The eHNA can also be filled out, in the presence of a health professional, in clinic using the form on the intranet. Patients continue to fill out the HNA, currently. We have set the interval at which they can complete the form at monthly. New needs concerns appear in red on the Clinical Dashboard.</td>
<td></td>
</tr>
<tr>
<td>Increasing Personalised Care Planning after treatment</td>
<td>The MCP project currently does not have enough data to establish whether the messaging system which connects patients to the health care team has had any impact on care planning after treatment. Whilst elements of the needs concern assessment can be recorded in the Treatment Summary, the form is not specifically designed to acknowledge concerns or create care plans associated with the assessment. In phase II of MCP, we will incorporate the Macmillan Care Plan into the portal, to explicitly deal with needs concerns and to ensure documented resolution where possible.</td>
<td></td>
</tr>
<tr>
<td>Enabling and supporting patient self-management</td>
<td>MCP has created the digital infrastructure to support self management. We have yet to adopt routine risk-adjusted follow up, however, NOSCAN have agreed to implement it in their workstreams in the next period. MCP allows the explicit identification of patients who will benefit and can be offered risk-adjusted follow up and gives patients easy access to information on self-support utilising the My Information page. In addition, we have created the ability to send media content to a patient’s smart device. MCP utilises a searchable library for content (videos, documents, audio files) which can be ‘prescribed’ and sent to patients. This may include information on diet, exercise, rehabilitation, relationships etc. Patients also have the ability to message the secondary care health team for advice if needed.</td>
<td></td>
</tr>
<tr>
<td>Implementing End of Treatment Summaries</td>
<td>We have adopted the work from NHS Forth Valley. They created End of Treatment Summaries (TSum), which can be filled in electronically and then emailed or posted to primary care colleagues. In MCP the TSum is pre-filled with relevant data from the MDT form. Data fields are completed by the specialist nursing teams. The summaries, once saved and validated, are sent immediately to SCIstore and to Docman (main document manager used by GPs). One learning point for the next phase of MCP is that we chose patients who had already received treatment for their colorectal cancer and as such very few patients in the test group needed TSums. If funded for Phase III, we</td>
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<tr>
<td>Area</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Enhancing Cancer Care Reviews in primary care</td>
<td>This has not been implemented in this TCAT project.</td>
<td></td>
</tr>
</tbody>
</table>
| Developing approaches to risk stratified follow up (e.g. reduced medical follow-up) | As discussed above, MCP created the digital infrastructure to implement **safe** risk adjusted follow up. It does this in three ways:  
  1. A secure messaging service between patient and specialist nurses  
  2. Providing patients with links to useful resources in the community and on-line using the My Information function of MCP  
  3. Filling out regular eHNA and Symptom Tracker information that may alert patient and staff to concerns that need assessment. |
| Enhance service integration and coordination for care after treatment | MCP improves safety and efficiency by amalgamating the core elements of cancer care into a single portal. Data from the MDT, TSum and eHNA are visible in one place. Furthermore, all elements are visible to the entire care team through primary and secondary care EPRs. In particular, this allows primary care teams to have ready access to where patients are in their cancer journey.  
In the next iteration of MCP we will build a searchable registry of all patients, based on the large volumes of data already collated through MCP. This will facilitate cancer specific outcome measures, patient reported outcome measures and patient experience (PROMs & PREMs) |
| Improving outcomes and experiences of after care for people affected by cancer | We have not performed a cost benefit analysis at this phase of the MCP TCAT project. We plan to evaluate this with phase III funding (if granted). We anticipate offering patients greater opportunity to have virtual follow up using an expanded telephone, video-conferencing and home conferencing facility (Attend Anywhere). We expect that the adoption of MCP, risk adjusted follow-up, improved sign-posting to self help and virtual follow up will both improve the patient experience and also be cost effective. |
| **Increasing skills and knowledge** | The colorectal nurse specialists are involved in this study. They have been trained with both face-to-face sessions and handouts. The system is intuitive. There are areas that need further assessment: How do we incorporate MCP into CNS job planning? Can we utilise lower banded staff to deliver elements of MCP care (triaging & answering received messages, addressing straightforward needs concerns etc)? Does MCP use impact on the telephone help line use? Will other CNSs from other areas adopt MCP for their patient’s use? |
| **Increased awareness/acceptance of the importance of care after treatment, leading to attitude and practice change** | This was not formally assessed in this phase. Although we have disseminated the concept of MCP widely (Cancer leads, surgical colleagues, Senior Managers, Macmillan, Academic colleagues, Innovation centres) to raise awareness, the project is still in its infancy with regards to leading to a wholesale change in practice. |
| **Increasing the patient voice** | Patients are key to MCP. Patients were represented on the project steering group and in the patient panels. The panels directly influence portal design. Our ambition is to create MCP as a patient-owned resource so that its design can be influenced directly by them. We have created a ‘My Feedback’ resource so we can incorporate changes directly into MCP, in an agile way. |
**Discussion, including conclusions and recommendations**

This ambitious project has successfully designed and built a digital health application for patients with cancer and for the healthcare staff who look after them. It pulls together key activities and documents into one area which is also linked to the patient’s electronic patient record in primary and secondary care. Whilst the co-design process, which involved a wide range of stakeholders, is complete, patient testing of the portal is ongoing and is behind the anticipated schedule.

The MCP team was highly aware of the risks involved in implementing a new digital health application and the major slippage in the project was due to integrating data from the portal into the EPRs. Interoperability is key to the modern day working of digital health applications within the NHS and the success of getting data to flow from patients into all core e-health systems is a major achievement and strength of this project. Our strategy of having local e-health team engagement from the beginning has been vindicated. In addition, we have been updating Scottish Government e-health colleagues on progress.

Wider adoption of MCP within Scotland will depend on a number of factors:

- Integration with e-health systems within territorial NHS boards
- Healthcare team engagement
- Patient engagement
- Successful design

From the outset we designed MCP to operate within all core e-health systems; Trakcare, SCIstore and Docman. Currently MCP interfaces with SCIstore and Docman and integration with Trak is planned for the next phase. We have already designed a link straight into a patient’s SCIstore record from their portal page, negating the need to separately log in to that EPR. The ability to send the MDT and Treatment Summary forms straight into the GP EPR (Docman) is a huge strength of the application and takes the Forth Valley Tsum work, one stage further.

Patient engagement has been excellent. Three months into the test phase all but 2 of 33 patients are using the portal. Google Analytics reveal that 185 online sessions have been completed. The average session time is 7 minutes and 8 pages are viewed during this session. 68% are returning visitors. One third uses the portal through iPads, a further 45% use PCs and 25% use phones. The messaging function is the most popular page visited followed by the eHNA page. The messaging function has been used to ask about symptoms, appointments and results.

The colorectal nurse specialists have been key to engagement; however there is still work to do to estimate how MCP will impact on their job plans. MCP will not function as a system without specialist nursing resource. In particular we need to learn from the other TCAT projects that have been using the needs assessment tools to see how we can ‘close the loop’ once a need has been identified. After discussion with cancer nursing and Macmillan colleagues, we plan to introduce the Macmillan Care Plan into MCP to specifically address needs concerns.

MCP is positioned well to take advantage of the training currently being given to nurse specialists across NOSCAN. Allowing patients to fill out the HNA at home, in their own time, is advantageous. Concerns can be discussed in virtual consultations and then summarised in a Care Plan, which can then be shared with the patient and stored in the EPRs. Self help support is being developed within the portal to facilitate patients identifying community assets/on line resources to meet their needs.
Next steps and lessons for the TCAT program

- Apply for phase III funding
- Test with all NHS Highland colorectal cancer patients
- Implement in NHS Western Isles for colorectal cancer patients
- Build Care Plan function and searchable registry
- Design for other cancer types (Breast/Prostate)

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Appendices

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Acknowledgements and thanks

Thank you to Laura Mcilhatton who has provided admin support for the project. Ran the budget, organised and minuted the PMG and PSGs and co-ordinated a whole host of other meetings in this project.

Peter Murchie and his team at the University of Aberdeen for inviting us to utilise the Aberdeen Colorectal Cancer Symptom Tracker.

My CNS colleagues for embracing MCP and advising on its design.

Joanne, Sian and Gordon from Macmillan. I have really enjoyed my working relationship with you all.

Jackie Rodgers for her support and encouragement and my particular thanks go to all the patient panellists for giving up their time and experiences.

The statistics in this report are the results of a self-evaluation carried out by the project team. The views expressed in this report do not necessarily Edinburgh Napier University or Macmillan Cancer Support.