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Understanding What Success In Health Information Systems Looks Like: The Patient Pathway Management (PPM) System At Leeds

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THE PATIENT PATHWAY MANAGEMENT (PPM) SYSTEM AT LEEDS

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Abstract

The National Programme for IT in the UK National Health Service has been described as "the biggest IT project in the world". The literature suggests that IT projects don't scale well so it is perhaps no surprise that all has not gone well. This paper looks at a health information system that has been a success. The Patient Pathway Management (PPM) system developed by Leeds Teaching Hospital Trust holds the records of 669,000 patients. In contrast to the National Programme it was a bottom-up, user led development that evolved over an extended period at a fraction of the cost. Our study looked at the characteristics of success from the perspective of 268 users of PPM and links these to the development approach. It is hoped that an understanding of what success looks like will inform the inevitable debate about whether the UK's National Programme has been value for money.

Keywords

Electronic health, software development, user centred design, IS evaluation.

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A CASE STUDY OF THE PATIENT PATHWAY MANAGEMENT (PPM) SYSTEM AT LEEDS

Abstract

The National Programme for IT in the UK National Health Service has been described as "the biggest IT project in the world". The literature suggests that IT projects don't scale well so it is perhaps no surprise that all has not gone well. This paper looks at a health information system that has been a success. The Patient Pathway Management (PPM) system developed by Leeds Teaching Hospital Trust holds the records of 669,000 patients. In contrast to the National Programme it was a bottom-up, user-led development that evolved over an extended period at a fraction of the cost. Our study looked at the characteristics of success from the perspective of 268 users of PPM and links these to the development approach. It is hoped that an understanding of what success looks like will inform the inevitable debate about whether the UK's National Programme has been value for money.

1   INTRODUCTION

What does health information systems (IS) success look like? Since 2002, our discussions in the UK have been pre-occupied with the National Programme for IT in the NHS or NPfIT. The Programme has an estimated total cost of £12.4 billion (National Audit Office, 2006) and encompasses an ambitious 10 year investment in new health information systems and technology being developed and delivered by a complex organisational infrastructure including public sector bureaucracy and private sector service providers centrally controlled by large outsourcing contracts. During its life NPfIT has had major changes in structure, scope and direction and has faced organised resistance, delays in delivery and criticism from health professionals, stakeholder groups, academics and politicians such as Edward Leigh. Leigh, as Chair of the Public Accounts Committee that reviewed NPfIT, said "this is the biggest IT project in the world and it is turning into the biggest disaster" (Telegraph, 2007). Whether NPfIT should be regarded as a health information systems failure is, and will continue to be, the subject of much debate. That is not the subject of this paper.

This paper has a more modest aim. To help develop an understanding of what success in health information systems looks like by investigating a system that we believe can be considered a success. We are interested in what health IS success looks like in real terms, to real users and stakeholders. We hope that by examining a successful health information system that was developed within the context of NPfIT, and to some extent despite NPfIT, this paper will help inform the debate about whether the UK's investment in NPfIT has been value for money.

In the UK, the health sector is dominated by the National Health Service (NHS) which, with 1.3 million employees, provides free healthcare to all citizens (BMA, 2010). When NPfIT started the expectation that health IS in the NHS would therefore be developed and funded centrally had profound implications for local health organisations across the UK. Why spend limited budgets on local IS projects? Especially when local solutions might not fit the national strategy and may soon be replaced. This was precisely the dilemma faced by Leeds Cancer Services in 2002, one of the larger tertiary referral centres for cancer in the UK. The Centre had a disparate range of paper based systems with limited patient data from central systems and a collection of small isolated end user computing applications (Leeds Cancer Services, 2003). Patient care relied too heavily on paper based and verbal processes inappropriate for a large scale operation. The Centre made the difficult and, at the time, bold decision to launch a system development project to build an electronic patient records system for cancer patients rather than wait for an NPfIT solution. The success of this local project and the system that it created is the subject this paper.

Our study examined the Patient Pathway Management (PPM) System that was developed at Leeds Cancer Services by a small team of developers working closely with clinicians. Co-incidentally both PPM and NPfIT started in 2002. While NPfIT has been criticised for being costly, slow, bureaucratic, late and unpopular with clinicians

(Clegg and Sheppard, 2007), the PPM system at Leeds has been praised for how well it meets clinicians needs. From a small start it has grown organically to a level where it now has 2,088 users across six hospitals in the Yorkshire region and holds the electronic records of 669,000 patients. A survey of users (n=241) by members of the original development team in 2008 (Waugh, 2008) found high levels of user satisfaction with the system's ease of use, reliability and impact on working practices. Our research consisted of an examination of project documentation and an analysis of audit logs followed by semi-structured interviews with representatives of each main user category and a questionnaire survey (n=268). We found high levels of user satisfaction in all aspects that we looked at and concluded that here we have an example of a system that can be classified with some confidence as a "success".

This paper is structured conventionally. Rather than a detailed literature survey we review some of the discussion on success and failure relevant to our case study. The case study is presented in terms of the context, motivation and chronology of the system's development. The research method included examining system audit data, interviews and a questionnaire and the results are presented in this order. The paper concludes with some reflection on our understanding of success that developed as a result of this study.

2   SUCCESS AND FAILURE IN HEALTH IS

Information systems project failure seems to be a fact of life. Such failure is easy to spot when projects are cancelled prior to completion or delivered and never used. Since the Standish Group started to track project success and failure in 1994 the percentage of projects in their surveys classified as "failed" by the above criteria has ranged from 31% to 15% in 2002 to 24% in 2009 (Standish Group, 2009). Standish Group note that failure rates are on the increase and that, in 2009, a further 44% were classified as "challenged" (i.e. late, over budget and/or with less than the required features and functions) leaving only 34% classified as "successful". Of relevance to

those involved in large IT projects is the now well established notion that software development does not scale well (see, for example, Brooks, 1995) and that bigger systems have an unavoidably larger risk of project failure as a result (Jones, 2008). In this light, the description of the National Programme for IT as "the biggest IT project in the world" sounds painfully unfortunate given the high risk of failure this implies (Clegg and Sheppard, 2007).

Health Information Systems have had a problematic history with some notable failures (Berg, 1993, Beynon-Davies, 2001). Beynon-Davis and Lloyd-Williams (1999) identify a number of reasons why the UK NHS might be particularly "prone to failure" including the numerous stakeholders involved, the lack of a unitary power structure (the UK NHS could more accurately be seen as a network of semi-autonomous organisations dominated by powerful clinicians and stakeholder groups), a history of piecemeal development, lack of clear IS planning and organizational uncertainty. NPfIT started in 2002 and grew in scope from an initial three year £2.4 billion project to a ten year £12.4billion project of programme of enormous scale and ambition. It aimed to address some of challenges of the past by providing a unitary planning structure. Since 2002 it has some notable successes – the NHS now has a national infrastructure network (called N3), 100% of General Practitioners (GPs) using electronic health record systems and near 100% usage of digital Picture Archiving and Control Systems (PACS) in secondary care organisations. Despite the successes, the organisations that make up the NHS have often been slow to adopt IS, resistance from clinicians and stakeholder groups has been fierce and core parts of the programme, notably the development of fully integrated hospital management systems, have still not been delivered. Clegg and Sheppard (2007) note the additional difficulties that NPfIT faces as a public sector project with high political visibility and driven by the need to meet politically-motivated timescales while under the control of a culturally risk averse civil service.

NPfIT has been regularly been criticised as a "failure". Some of this criticism is perhaps unfair and is probably premature - the programme is still ongoing and will need to cope with a new phase of organisational uncertainty as the NHS commences another major restructure (DH, 2010). The definition of "success" or "failure" is complex, these are emotive words and, as Lyytinen (1988) suggests, failure can be seen as a failure to meet expectations as well as an absolute measure. The canny project manager knows how to manage stakeholders' expectations carefully so that the information systems they deliver "exceed expectations" and are therefore considered a success. By contrast, evaluating a large complex information systems project against promises made by political leaders well removed from the practical nature of IS delivery seems pointless.

Sauer's model of IS as an innovation process (Sauer, 1993) provides a useful framework for judging success or failure. The project organisation depends upon continued support from its supporters, while it has this support it is able to sustain the IS and the IS will continue to deliver benefits to the supporters – a positive feedback loop which drives development and, while it continues, the project can be seen as a success. Following Sauer's thinking both NPfIT and the PPM system can be seen as successful, both have continued support. The model also suggests success is temporal - when an IS fails to deliver benefits, the supporters withdraw resources from the project team and their ability to sustain the IS diminishes leading to reducing benefits.

3   CASE STUDY: THE DEVELOPMENT OF PPM

Cancer is the leading cause of premature death in many countries around the world including the UK. According to Cancer Research UK (CRUK, 2010), one in every three people are likely to develop cancer, while one in four people will die from it. Cancer is a chronic condition which can, with good management, span many years although such long term care is technology dependent, costly and involves a wide range of interdisciplinary clinical skills (IOM, 1999). Timely information and effective

communication about patients' condition are essential for the delivery of high quality care (DH, 2000) and the volume and complexity of information found in the medical record of cancer patients can be significantly greater than for patients who have largely enjoyed good health.

The Leeds Cancer Centre is one of the larger specialist cancer centres in the UK. It is part of Leeds Teaching Hospital NHS Trust and delivers cancer care to a local population of about 715,000 as well as acting as the region centre for the Yorkshire Cancer Network covering a population of about 2.6 million (LCC, 2003). In 2002 the Centre was still essentially a paper based organisation. Cancer information relevant to patient pathways was collated from diverse independent systems and processes within the organisation. An internal document at the time noted that there had been "no effective corporate approach to developing a co-ordinated cancer information system and this is reflected by the fact that some cancer multi-disciplinary teams have established standalone databases, others rely on paper based forms while some have no means of collecting any clinical information" (LCC, 2003). There was recognition that what was required was an electronic patient record (EPR) system to hold and manage a richer and more complex information set than that required for other illnesses. In particular it needed to support the integrated care of patients through complex "pathways" involving a range of specialists often working across departments. It also needed to support local and national cancer research programmes with reliable data to help improve the long term survival rates for the disease.

The PPM project was conceived by a clinician, a Medical Oncologist, keen to improve information collection and use within Medical and Clinical Oncology Services. With the recruitment of an Information Manager for the Centre in 2002 an Output Based Specification (OBS) was produced (LCC, 2003) which linked local plans to the need to provide a solution to the national requirements arising from the recently published Cancer Plan (DH, 2002). While NPfIT offered the eventual prospect of a full EPR solution which might be rich enough to support cancer care the team's assessment was

that such a system would be a long time coming. They were proved right. Following an expensive and extensive international procurement exercise there were very few EPR solutions considered by NPfIT to be good candidates for the UK market. The Programme eventually opted for adapting one US based hospital management system (Cerner Millennium) while also supporting the development of a new hospital system (iSoft Lorenzo) subsequently outsourced to India. Independent of NPfIT, the NHS Information Authority issued a specification in 2003 for the National Cancer Dataset (NHS Data Dictionary, 2010), while not mandatory it includes mandatory components and now specifies 297 data items covering referral, diagnosis, investigations, treatment modalities, follow up and pathological staging of disease. Individual NHS cancer care organisations were expected to deliver all this information centrally as the basis for the National Cancer Audit.

In 2002, cancer centres across the UK were suddenly under pressure to supply large amounts of structured clinical and waiting time information with no obvious information systems available either nationally or commercially. Leeds Cancer Centre opted to continue its in-house development of the Cancer Patient's Pathway Management (PPM) system as the 'system of choice' for addressing the requirements specified in their OBS. They had a number of advantages to help their development plans. Firstly, the systems conception was ambitious, the system was consciously designed to support care pathways with information rather than simply being designed to provide an information repository – the emphasis being on workflow design rather than an EPR data store. Secondly the information requirements needed had already been specified in the National Cancer Dataset and, with fortuitous timing, this provided the data schema for the EPR. Thirdly the project was driven by strong clinical leaders who saw the project as essentially a business change project. The technical development was based on a client server architecture written in Visual Basic with an SQL database but the small development team were co-located within the Cancer Centre and considered very much part of the operational team. Design and development therefore took place in short iterations with extensive collaboration between clinicians, other users and the developers. Such collaboration closed the gap

between developers and users so that discussion about what was possible and what was desirable were able to take place on a daily basis in informal as well as formal settings.

The PPM development was started and went live in 2003 with a small number of users and limited functionality. The system has continued to grow organically with new features being suggested by clinical users and incorporated into the live system in tight iterative cycles. The development team has remained small (2-3 people) throughout the time that the system has been in operational use and this has allowed it to continue to evolve, growing in functionality and responding to the many and various suggestions for improvement that its expanding user base suggest. The PPM system brings together large amounts of clinical data from disparate systems and this presents many opportunities for operational and clinical innovation. Line management of the development team remains with the clinical leads for the Centre while the PPM team maintain collaborative links with the hospital's central IT team who provide the infrastructure and support interfaces to 35 other hospital systems which contain information relevant to cancer care. PPM has since been deployed in the cancer units of six other hospitals so that the organisations and teams caring for the same cancer patients can share their data.

4   RESEARCH METHOD

This study was designed to evaluate the benefits derived from the use of the Patient Pathway Manager (PPM) system at Leeds Cancer Centre. The objectives were to understand the impact of PPM in accomplishing health workers' tasks and work processes; to determine the level of users' satisfaction with PPM, to examine the impact of PPM on patients' care and to identify problems users encounter with PPM. Our starting point was a survey conducted by members of the PPM team in 2008 (Waugh, 2008) which had found high levels of user satisfaction. This survey had consisted of semi-structure interviews with four senior stakeholders and an electronic questionnaire sent to the users of the system via their PPM user-id. We were aware

that the questionnaire had had a good response (n=241) with strong positive feedback for all aspects of the system and were keen to independently verify the results. The interview transcripts, survey results, supporting documentation and subsequent report were made available to our team.

The study applied a multi-method approach that included qualitative and quantitative methods. There were four stages. Our familiarisation stage included training in ethics, reading the earlier work, observation of the system in use to form use case diagrams and activity diagrams for common business processes and interviews with the development team which led to the construction of rich pictures. The aim of the familiarisation phase was to gain a strong enough understanding of the domain context, the socio-political context and the language used by the users and organisation. Sensitivity to the domain was considered an essential pre-requisite to a study which would involve asking busy clinical staff to give up their time to take part; it was also invaluable to our learning about the system. The following three stages were a quantitative analysis of system audit logs, semi-structured interviews with representative stakeholders and an electronic questionnaire sent to users.

Audit logs for the last six months of live use were used to understand patterns and volumes of use. These included transaction details, account details and dates and times but did not include any patient-related data. The audit logs had been anonymised by removing names of individual staff members but job titles were used to identify the categories of users that would form the basis for the interview stage.

For the interviews, the PPM development team were asked to assist in finding willing interviewees from each of main stakeholder groups. It was understood from the outset that there was a potential for bias in this selection method – the interviews represented a significant disruption to the work of busy professionals in a demanding work environment and the interviewee's selection and their willingness to take part may

have be linked to their enthusiasm for the system. Despite this we found that the interviewees were generally candid about their views and willing to reflect on the work they did and discuss negative as well as positive features.

The interview topics were used as the basis for the online questionnaire. We were particularly keen to use this to verify the extent to which our interviewees were representative of their category. The questionnaire used a five point Likert scale asking respondents to rate the strength of their agreement or disagreement with positive statements linked to characteristics of successful systems from the information systems literature. There were 20 questions in total covering the quality of functional and non-functional features of the system and the extent to which the respondent felt the system had improved their work processes and the patient experience. Users selected a job role from a pull down list based on our analysis of the audit logs and were asked how long they had been using the system so that we could examine whether length of use correlated to "satisfaction" levels. Open questions on the use of the system, its performance and benefits were also included and these were transcribed and analysed separately to identify common themes and patterns. As with the 2008 survey a link to the questionnaire was sent with a covering email to all registered users of the system.

5   RESULTS

The results include data from the activity log, semi-structured interviews and survey questionnaire.

5.1 Activity Log Analysis

The analysis of the user database shows that 3,653 users have been created since the inception of PPM although many accounts have subsequently been disabled due to staff turnover. 75% of the users were based in Leeds Teaching Hospital Trust while the remaining 25% were based in the cancer teams at six other hospitals in the region. An analysis of the activity log between 1st January and 4th of August 2010 revealed that

there have been 4,194,304 activity events by 1,537 distinct users giving an average of 19,000 transactions per day (assuming a seven day week). This is a large system, in regular use by a large number of people. The analysis of active users by user category is shown in Figure 1 below.
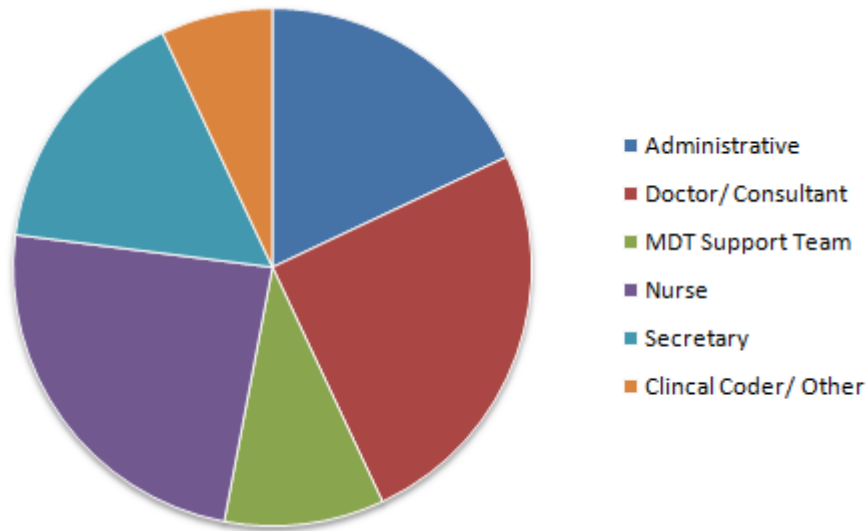

Figure 1 – Analysis of Active Users by Category (n=1537)

5.2 Semi Structured Interviews

Nine participants from five of the six user categories above were interviewed. These were Doctor/ Consultant (2), Multi-Disciplinary (MDT) Support Team (2), Nurse (1), Secretary (2), Clinical Coder (2). Interviews were recorded and transcribed and the transcripts confirmed by email with each participant.

The responses to initial questions were used to construct use case diagrams which were confirmed with the project team and helped structure our analysis and understanding of the key business processes. Some sample responses to questions are given in the tables below:

Q3. Could you share your experience working with paper and PPM?	
Interviewee	*Phrase*
Consultant Oncologist	*".... There is a good chance the [paper] notes are not even there... the notes get missing, the papers get ripped and there is time delay..."*
Specialist Nurse	*"..PPM is much better than paper because of the accessibility. I am cross site... I might not necessary have access to the medical notes because it could be anywhere, in the file or in different hospital but I can switch on the computer, log on to PPM and have all the information...."*
MDT 1	*"...We could not have done our job properly without PPM...."*
Secretary 1	*".....PPM is a lot quicker. You don't have to put in the demographics, diagnosis and result at all... it's all fed in....."*

Table 2 – Comparing PPM with paper-based processes

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Q4 How would you describe the impact of PPM in accomplishing tasks when compared to manual process?	
Interviewee	*Phrase*
Consultant	*"...I use it to retrieve data for national audit. Without PPM I could not have done it on time. I would have needed to retrieve 600 sets of case notes. I'd fill half of this room with notes...."*
Specialist Nurse	*"..Just wherever I am, any ward, I can look up anything about the patient.... With PPM I can quickly and instantly see what is happening with the patient ... The fact that it pulls the scan, pathology is brilliant because we use those functions all the time ..."*
MDT 1	*"...If I didn't have PPM, I would not be able to do my job at all..."*
Secretary 1	*" we get through more work than we used to do....."*
Clinical Coders	*"...PPM is quite a good source for us in oncology coding... We definitely get higher accurate coding if we are using PPM...."*

Table 3 – Views on the impact of PPM on accomplishing tasks.

Other questions gave some deeper insights into the use of PPM within the organisation. The interviewees had varying responses when asked the problems they

faced using PPM, disadvantages included performance concerns by some but not other individuals and the desire to extend the functionality to include access to information not currently available. Other challenges identified include the inability to view laboratory and blood test results on PPM, and the delay in accessing some data caused by overnight batch updates from some other departmental systems. There was a consensus that PPM had led to major improvements in collaborative working and the cancer care that could be provided to patients. There was a clear enthusiasm for PPM by all interviewees.

"At times patients are amazed when we have got access perhaps to a letter written by a doctor they saw some days ago in a different hospital" (Specialist Nurse).

"I know what it is like when around 2.00 am in the morning the patient comes to the hospital very unwell. You can't always get the medical notes at 2.00 am in the morning, they would be somewhere in the medical library and you having to rely on the patient or the family....it's risky... so in that sense the patient care is enhanced." (Consultant Oncologist).

5.3 Questionnaire Survey

Data from the online survey was collated a week after its launch. Of the 1,537 email addresses used, a total of 268 respondents had completed the questionnaire. This response rate could be considered a low return but from the activity logs only around 950 users appeared to be regularly active which might suggest a response rate of around 28% of active users which could be regarded as quite satisfactory (Cook *et al.*, 2000). The categories of users who responded to the survey summarised in Figure 2 (below). According to Cook *et al.* (2000) the response representativeness in a survey research is as important as the response rate and a comparison with Figure 1 show that the survey appears to have been a fair representation across the various categories of users.

Of the 268 respondents 70% had worked in the organisation for over five years, while only 5% had been there less than a year. Most respondents (72%) had used PPM for more than one year but relatively few (10%) had used the system for over five years. 62% made use of PPM more than once a day and could be considered as regular users.
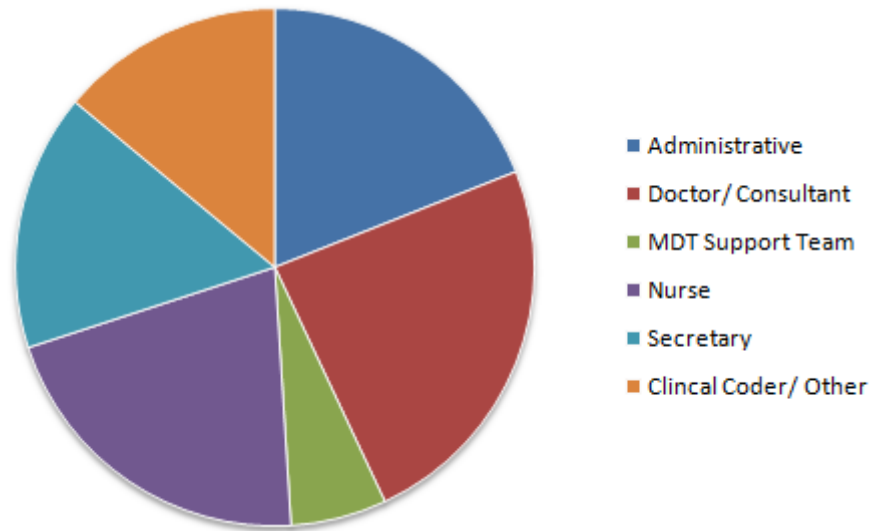

Figure 2 – Analysis of Survey Respondents by Category (n=268)

The Usability of PPM was assessed with three questions. 76% of respondents agreed that the information displayed on PPM made it easy to use, 73% felt their tasks could be performed easily on PPM. 89% agreed that they found the system easy to use while a small number did not and, in a supplementary question, gave varying reasons such as small font size, speed and inadequate training. The reliability of the PPM did not achieve quite such high ratings; only 68% agreed with the statement that "PPM rarely experiences temporary shut-downs or delays".

The accessibility of patient information on PPM was assessed with five questions. 87% were satisfied with the number of computers available. 84% were satisfied with the functionality to access patients' records using PPM while 82% were satisfied with the speed with which patient records could be retrieved. 66% of the respondents found the information was displayed in the way that they wanted. Of particular concern given the clinical nature of the system was the extent to which respondents

felt they could rely on the information on PPM, 64% felt that they could rely on the information but 12% felt that they could not always rely on it and 24% remained neutral. This was reflected in points raised by some of the interviewees who expressed concerns that sometimes data may have been inconsistently input by others and that other parts of the hospital were still recording patient information on paper systems which meant it was not available via PPM.

The impact of the system on work processes was assessed with three questions. 82% of respondents felt they were able to accomplish their tasks much faster with PPM while 81% agreed that monitoring cancer patient progress is better with PPM and 82% agreed that PPM helped communication between professionals and health workers.

The impact on patient care was also assessed with three questions. 84% of the respondents believed that the use of PPM is improving cancer patient care. Rather surprisingly when asked whether PPM decreases waiting time, the majority of 63% remained neutral with 26% agreeing and 11% disagreeing. A patient's waiting time occurs before they visit the hospital which is when the majority of PPM users see them so it may be that the respondents felt unable to judge the impact of the system or it may be that other factors, notably the availability of beds and resources have a bigger impact on waiting times than access to information. Furthermore, while 47% agreed with the statement that "patient information is more confidential with PPM than with paper records", 41% of the respondents remained neutral and 12% disagreed. This may well echo the doubts on the privacy and confidentiality of EPR being expressed in the national debate about NPfIT. The security of paper records is based on their physical location whereas electronic security relies on more complex social and technical arrangements that may be poorly understood or poorly implemented.

6   CONCLUSIONS

The PPM system at Leeds is a successful health information system - this is what a successful health information system looks like. Our research provides evidence of many of the characteristics of success - high levels of user activity by large numbers of diverse users who report that they are getting significant benefits from its use. While the user interviews have scope for bias, the results were echoed by a significantly large and representative survey. Following Sauer's model (Sauer, 1993) any system which enjoys continued support from its stakeholders can be regarded as a "success" but what we found with PPM was much more than that – in the questionnaire survey we were consistently getting positive views from over 80% of the respondents. We believe that what we have found with PPM is an example of a positive feedback loop – for the last eight years the project team have been listening to and responding to user feedback, they have built a good system and have been rewarded with continued high levels of support which has lead to further development and growth. The system looks set to continue to grow in reach, functionality and size.

The most remarkable feature though is how little this development has cost. The project team remains small and continues to work hand-in-hand with clinicians inside the hospital. The comparison to NPfIT is stark. Both projects started in 2002, both have implemented national standards and both have changed the delivery of healthcare away from a paper-centric model towards a modern health service based on electronic patient records. The development methodology is however quite different. The PPM team have iteratively developed software while co-located with the people who use it whereas NPfIT invested in protracted consultation processes designed to build consensus on detailed requirements documents to be used as the basis for procurement of standard solutions to be "rolled out" by deployment teams. As the UK's National Programme draws closer to a conclusion there will inevitably be further discussion on lessons learnt which should be relevant to all countries looking to develop their health information systems. We hope that by presenting a clear example of success this paper makes a contribution to that debate.

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