

1.0 Introduction

The Winston Churchill Fellowship Grant supported my attendance at three international hospitals; Memorial Sloan Kettering Cancer Centre of New York, USA, University College London Hospital, London, UK and the St James Hospital, Leeds, UK. The focus of this fellowship was to observe cancer services that have incorporated a Patient Reported Outcome (PRO) model as standard of care to determine success factors and challenges. I met with a range of staff from each hospital; Registered Nurses, Nurse Practitioners, Colorectal Surgeons, Senior Managers, Medical Oncologists, Researchers, Software Developers and Information Specialists and patients. The focus of this report is to document the learnings from this observership and subsequently assist the effective adoption of PRO firstly in the Colorectal Service at Wellington Hospital and secondly guide the implementation in other departments and finally across New Zealand.

The identification of hospitals visited was based on their early adoption of PRO methods with a mix of public and private to observe similarities in service operation and funding mechanisms and also a healthcare system underpinned by market competitiveness motivating patient centred care and experience.

Patient Reported Outcome (PRO) is the impact on quality of life (QoL) and/or functional status resulting from a condition or treatment reported by the patient without interpretation from a clinician. A PRO tool is a set of questions pertaining to a condition or treatment that measures the health status by its impact on function, symptom burden and quality of life. PRO's can be used for service strategy or as consult tool. This is in contrast to existing methods that use indicators such as length of stay, re-admission to hospital, surgical complications and mortality at 30 or 90 days to indicate quality of care and service.

2.0 Overview

2.1 PRO in Practice at MSKCC

Memorial Sloan Kettering, a private cancer centre (MSKCC) situated in New York commits itself to providing patients with optimal care and service. One contributing method to achieving this incorporates patient reported outcome tools; currently totalling twenty as at 2019 (excluding numerous tools currently in pilot phase). Each of these tools has been developed with a focus on a particular cancer type, for example Breast, Colorectal, Head & Neck each measuring health outcomes relevant to the condition and its associated treatment. The success underpinning the integration of these tools to everyday practice is multi-faceted; clinicians to champion the utility, software development and support, information specialists, and systems that measure the impact on hospital resource.

In order to ascertain the utility and motives underpinning the use of PRO's I met with clinicians using PRO tools in practice and managers involved with the implementation and subsequent use of the collated data. The motivations were widely ranged; clinician-patient relationship building, quality of life improvement, efficient use of clinical time, data collation to inform impact of surgical procedure by type, reducing impact on resources, and data analysis to inform market strategy.

Two PRO software tools are currently in use at MSKCC. The first tool implemented is utilised in minimal risk surgical procedures to support patient self-management at home. The Recovery Tracker tool requires patients to complete the tool daily, and any concerning symptom prompts an email alerting the Clinical Nurse Specialist to respond with appropriate advice. The second tool developed on the back of the success of the Recovery Tracker tool is named 'Insight'. Insight, currently in its ninth month of pilot is a PRO tool for patients currently on chemotherapy treatment. Patients are requested to complete the tool daily and any deviation or trending negative symptom prompts an alert. Both software packages are sophisticated triaging tools, hinged on real time patient reporting outcomes underpinned by algorithms built on common symptom clusters.

The intention for developing both these tools was to support patients to self-manage symptoms at home by remote clinical feedback indicated by an alert system, in order to reduce presentation to emergency departments, reduce length of stay in hospital and enable engaging geographical areas further from MSKCC centres. Discussions with the Manager of Ambulant Cancer Services involved in the implementation of the 'Insight' software, utilised the data to inform the placement of resources. Currently the alert system was clinically managed by a Nurse Practitioner, two Registered Nurses and one Fellow (Medical) 24 hours 6 days per week. The system acts as a triaging service, with clinicians providing advice to patients at home and thereby minimising the attendance at the Emergency Department.

'Insight' has demonstrated reduction in mortality by increasing adherence to chemotherapy regimens. By treating symptoms earlier than the next scheduled clinician review circumvents omission or discontinuation of treatment resulting from toxicities caused by treatment such as chemotherapy. The 'Recovery Tracker' tool used to support patients having minimal risk surgical procedures has had its greatest impact on the inpatient setting, freeing up beds for patients with complex care requirements. Nurses responsible for monitoring patients had mixed feelings regarding its use. Nursing staff identified the algorithms assigned to the tool often triggered false positives and resulted in unnecessary interventions. Management at MSKCC are aware of this feedback and facilitate regular meetings between clinical staff and Informatics Specialists. These meetings serve to refine responses that trigger alerts to provide greater specificity. This work is ongoing.

Both tools have proven to be an effective way of managing patients with a wide geographical spread without access to community nursing resource. The software allows for effective triaging of patients ensuring those seen in the emergency department are appropriate referrals. Patient focus groups have reported feeling well supported and secure knowing a medical professional equipped with expertise in oncological treatments and surgical procedures are available punctually.

The Colorectal Survivorship Nurse Practitioner applied a Colorectal Survivorship PRO tool to all patients in the clinic at defined intervals. The tool, sent via email, allowed for completion prior to the consult. Additionally, to ensure consistency, administrative staff request patients to complete the tool when they present to clinic (if not completed prior). The tool offered is in both electronic and paper form dependant on patient preference and recorded on the Electronic Medical Record for review by the Nurse Practitioner (NP) and other clinicians involved in the patient's care. The recorded information is in a format that enables anonymization for large-scale data analysis.

In discussion with the NP and patients in the clinic, both indicated the tool's greatest benefit was the ability to prepare for the consult focussing on the area of greatest concern for the patient. Patients identified that the tool was useful in articulating their symptoms, and consequently addressed concerns appropriately. Further, the consult felt meaningful and fostered a sense of confidence in the intentions of the clinician. The NP recognized simply referencing the tool highlighted to the

patient the significance of the information and elevated the participatory relationship between the clinician and patient. Consequently, this increase in willingness to complete the tool led to consistency of information, and provided a depth to the patient's symptom representation. An additional highlighted point was the increase in dialogue to gain greater understanding of patient concerns. The NP identified that without a PRO prompt culturally or emotionally difficult symptoms were often not revealed until the end of a time constrained consult or potentially not raised at all. The tool prompted patients and facilitated a safe means of communicating difficult issues such as sexual dysfunction, body image, social roles or financial difficulties in a timeframe that allows appropriate discussion and management.

Colorectal Surgical Consultants utilised PRO tools alongside established scorecards to measure symptoms and impact. The Low Anterior Resection Syndrome Scorecard determines the level of impact that the surgical procedure; low anterior resection, has had on the patient by measuring frequency of bowel function. A PRO tool to measure the impact the procedure has on patient quality of life (QoL) is applied concurrently to assess the level of intervention required. This method enhances an individualised approach where intervention occurs as indicated. Urology and Breast Surgeons were utilising PRO tools for low risk surgical procedures.

With the multitude of PRO tools in clinical use, collecting data prompted the creation of an Informatics Specialist Team (developed 12 months ago at the time of visit). This team comprises a mix of skills from, Medical, Nursing and Data Informatics. The team is tasked with interpreting the collected data to provide management and clinicians with trends, information solutions for educational use, improvement to existing PRO tools and future direction of PRO development and service improvements. The informatics department has a focus on the best use of the vast data to effect a clinical and/or economic benefit.

MSKCC are not encumbered by limited resource to the same level that Public Services are exposed to. MSKCC has resource to implement large scale pilots that include software development, integration solutions to existing software and ongoing financial support for software maintenance and development. A further enabling factor is the ongoing budget allowing for staffing and training of clinicians, IT development and software maintenance personnel. A driving force enabling these projects was the requirement to identify populations MSKCC had not attracted to their services and how best they could attract and maintain the custom of these identified groups.

2.2 University College of London Hospital

The University College Hospital of London (UCLH) is a large central London hospital with 1,161 beds and includes a dedicated cancer centre, MacMillan Cancer Centre. The centre provides facilities for diagnosis and treatment as well as a drop in support and information centre for all those affected by cancer. Additionally, UCLH have created a Centre for Cancer Outcomes, with focus on key areas to decrease variation, optimise resource and develop outcome measures that better reflect patient's concerns.

A number of pivotal United Kingdom reviews together with the endorsement and funded research by an influential Non-Government Organisation; MacMillan Cancer Organisation, led to the development of a three pronged process to support cancer patients through diagnosis to survivorship. The 'Recovery Package' includes a PRO; the Health Needs Assessment (HNA) at two time points, along with the provision of a Treatment Summary to both patient and GP and thirdly, facilitation of patients to attend a Health & Wellbeing Event. This is a government-mandated

program with an attached target; 70% of cancer patients must have all three factors applied to effect readiness for discharge to self-management.

Driving the development of this program was a resource capped National Health Service that required a method to support patients through treatment and subsequently prepare patients to self-manage in order to free up services after standard of care 5 year surveillance. Research undertaken indicated by addressing patient concerns early, assessing quality of life following treatment, and assessing alterations to function and symptom burden at pivotal time points prevented patients rebounding to hospital services and the subsequent increase in resource utility. As a result, Care Plans were implemented with content based on the assessment of patient concerns, symptom burden and QoL impact. Further, care plans coupled with communication to primary care (GP's) and the provision of the same information to patients, resulted in less loss to follow up and provided primary care with a relevant clinical guide for ongoing surveillance and late effect symptom support. Finally, the attendance at a Health & Wellbeing event prepared patients with what to expect following treatment and beyond. This education provided support for late treatment effects and alleviated anxiety around discharge. These measures have been successful in circumventing delayed discharges and patient rebounding to hospital services. Both measures have had a positive impact on resource use. A full time administrator is responsible for reporting the hospital's attainment of the target and provides feedback and project direction to increase adherence and achievement.

Other examples of successful use of PRO in practice observed at UCLH was the Palliative Care Outcome Scale (POS). This tool is being used in conjunction with a Patient Reported Experience Measurement tool (PREM). As the name suggests the PREM measures patient satisfaction with care received. Correlations exist between a higher scoring PREM where the POS had been utilised at pivotal sign posts in the patients care. The Sarcoma Assessment Measurement PRO tool was recently created to measure Quality of Life for Adolescent and Young Adults (AYA) with Sarcoma. This tool adopted by Sarcoma Trials as an endpoint measure for quality of life for patients within the AYA demographic exemplifies changing methodology. The focus of trials is expanding from demonstrating effectiveness or otherwise to give weight to the impact the trial drug has on the patient's quality of life and health status. This change provides a holistic measurement for clinicians to consider and discuss when risk vs benefit is the focus of the consult. In addition, but still under construction, is the Patient Concerns Inventory. This forms part of a greater project 'Exemplar Ward', which aims to increase the efficiency and effectiveness of inpatient wards at UCLH. The inventory utilises the PRO model to build care focussed on the concerns of patients and will include 70 data points.

2.3 St James University Hospital - Leeds University

The Patient Centred Outcome Research Group (PCORG) at the University of Leeds employs 25 researchers developing and translating PRO data and software development. This group resides within Europe's largest teaching hospital, St James University Hospital. The PCORG have multiple studies underway and have implemented the use of PRO in clinical practice in two cancer tumour streams; testicular and anal, with plans to include other tumour streams in the near future.

Of particular note is the Bowel Cancer Improvement Program (BCIP). This program aims to understand the variation in services and provide feedback to participant hospitals in order to standardise care to best practice across the northern region of the UK. To achieve this the BCIP utilises existing cancer data sets and enriches the data with Patient Reported Outcome measures.

Their inclusion provides a voice to the quality of life experienced following treatment and is included as a prognostic outcome indicator to clinicians.

The e-Rapid study recruited 500 patients over two years having radiation and chemotherapy treatment. They asked participants to report symptoms over a six year period. They based questions on internationally standardised classification of adverse effects from cancer therapy, the Common Terminology Criteria for Adverse Effects (CTCAE). This classification allows for grading of symptoms as observed by clinicians. The development of a PRO CTCAE incorporates these same indicators but allows for the reporting to be graded by the patient without interpretation from a clinician. This is important, as we understand that clinicians downgrade symptom reporting, the reasons for which are multifactorial and include; the diluting effect of exposure to extreme degrees in symptoms and consult time pressures.

The clinician endorsed e-rapid trial is supported by IT software. Patients complete questions graded for severity according to the CTCAE. The alerts are graded, and actioned according to their severity. A low severity alert prompts the patient with self-management suggestions and conversely symptoms of high severity prompts the nursing team to take immediate action. The software is enhanced with additional information for patients on common themes covering psychosocial concerns, diet and exercise and other commonly occurring physical symptoms.

The results of this trial are currently being analysed, but initial findings indicate that patients find the tool acceptable and supportive. Clinician findings suggest the tool is useful in supporting patients to adhere to treatment by reporting symptoms early enabling support and thereby avoiding deferment or cessation of treatment. Indications of its acceptability and clinician use-ability was signalled early leading to the development of further studies; e-Prime and Optimal, these are both supported by software and clinicians and take a focus on particular tumour groups and the impact of Radiation and/or Chemotherapy. Analysis has not commenced on these studies.

3.0 Conclusions

Variation in the number of tools in clinical practice and in development between the centres visited varied greatly. Supporting the great number of tools in practice at MSKCC was the drive for market share and the ability to support patients remotely with smaller centres in a spoke and wheel service model. Clinicians at MSKCC utilised the tools to assist a focus at consults, documentation and data collection. Commitment, successful use and development of PRO tools was evident by the implementation of an informatics specialist department to clean data, report on the collection and gather feedback from clinicians on tool usability and future development. Further, the support and acceptance of these tools was widespread covering multiple disciplines and management levels. This provided consistency in their application and the ability to support their implementation and ongoing use with an appropriate level of clinical and IT support.

The UK recognises and demonstrates the importance of the patient voice by implementing a nationally mandated PRO tool. The application of the tool at two pre-determined time points serves as a listening post for the patient to communicate what health needs are most important to them. Subsequently this enables identification of existing deficits and provides opportunity to address these deficits. From the service perspective the HNA tool is used to inform resource allocation, redirect patients from tertiary to primary care by better informing the patient early in the pathway. Clinician support for this tool was mixed; a number of staff members canvassed suggested the

application of a target detracts from its intent. Nursing staff charged with completing the forms felt this tool covered a basic nursing assessment, and added to increasing paperwork requirements.

Leeds University have a research group dedicated to providing meaningful and measurable means to inform practice and service design through the patient voice. They have recruited large numbers of participants into multiple studies and have successfully implemented PRO tools in two tumour streams. Translating research to practice remains challenging, although the inclusion of PRO at a national level in both the HNA tool and the BCIP project are examples of success driven by a top down approach. Clinicians involved with both the PCORG group and clinical practice faced challenges with implementation to everyday practice. These challenges included colleague views on whether PRO tools should influence their decisions on treatment, software development and ongoing support and of course ongoing funding.

The greatest commonality between each of the centres in both countries was resource utilisation. Increasing pressure on hospital resources has driven changes to multiple models of care in order to optimise resource allocation. PRO tools designed to inform service requirements has led the building of specialist teams and services that exist to respond to the PRO information. Manifested in clinical teams allocated to respond to alerts created by the completion of online PRO tools by patients with clinical advice as indicated. Symptom focus or procedure specific PRO tools developed to gather feedback whilst on treatment or following surgical procedure has allowed patients to remain at home with the reassurance that medical advice is close to hand. The financial and social impacts associated with presentations to hospitals is minimised for the patient and their family and reduces hospital attendance costs.

Increasing numbers of patients progressing through treatment to survivorship is one part of the pressure on resources. Patients supported through treatment and at the end of treatment with an intent on self-management enables transition away from hospital delivered care to online support where appropriate. It is understood that the greater percentage of patients can be stratified to this level of care allowing for closer surveillance at a hospital level for the percentage that requires this.

Each centre was cognisant of creating patient and clinician survey fatigue. They acknowledged that too many tools in circulation runs the risk of not gaining quality data, and losing effectiveness.

UCLH and Leeds funding streams created the greatest hurdle in the implementation of PRO tools. The creation of software posed a number of issues for funding; development and ownership, maintenance and improvement and Medical Classification of software (debate around whether the software is a medical device). Further hurdles around implementation and attitude to their incorporation into practice existed. Clinical champions are driving leeway, prominence is gaining with the inclusion QoL as an end point in clinical trials and further credibility is gained by the inclusion of PRO in government targets.

4.0 Recommendations

The fundamental challenges of effecting change to existing care models remain the same across all the centres visited including Wellington hospital. Where a top down approach is not present, then the application of change management principles is required. Firstly, in applying lessons learnt to the local context, successful demonstration of PRO tools in the clinical setting is an effective means to change practice. Effecting wider clinical change requires champions of the PRO model in order to

create multi-disciplinary consistency in their use. In achieving this I make the following recommendations;

- Ascertain the acceptability of a PRO tool in the NZ population by constructing a patient focus group and test validated PRO tools in the Colorectal Cancer population at Wellington hospital.
- Investigate the potential for cultural bias and/or sensitivities which would need to be factored into the design of any PRO tool in the New Zealand context.
- Early inclusion of Whanau and Pacific Services to ensure tool is representative of cultural specifics.
- Create a patient focus group to identify survivorship needs.
- Canvass clinicians New Zealand wide to ascertain current understanding of PRO tools and their application. Investigate willingness of clinicians to incorporate PRO tools as a pilot in the first instance.
- Demonstrate utility of PRO tools in practice by publication of data in high subscription journals and presentation at national meetings.
- Investigate existing data collection infrastructure to determine whether future PRO tools can be incorporated into existing IT architecture.
- Analyse data at frequent intervals in order to provide insight on benefits to management.
- Posit the development of a PRO working group with the Ministry of Health.

Footnote:

In September 2019 the draft National Cancer Plan 2019-2029 was released by the Ministry of Health for consultation post my Winston Churchill travels. The Principles of the plan are; equity-led, knowledge driven and outcome focussed. These principles supported by 'key outcomes' are broken down further into 'key focus areas'. Patient experience is highlighted as a priority under the principle 'outcome focussed' with the key goal to improve cancer diagnosis and treatment outcomes. The cancer plan undertakes to develop a national set of patient reported outcome measures. This is encouraging in that a top down approach led to the initiation of the HNA in the UK. It will be important to make clear the difference between Patient reported outcomes and Patient reported experience and that they should exist together to leverage greater satisfaction in patient perception of service and patient quality of life.

Further detailed in the plan is a commitment to support patients through 'living well with and beyond cancer'. This strategy includes the creation of survivorship care plans that meet the holistic needs of the patients and families. These plans encompass treatment summary, potential late and long-term effects arising from treatment, follow-up recommendations, surveillance guidelines and other strategies to ensure the person remains well. This key area acknowledges Survivorship Care Plans are a pivotal strategy to improve communication between people affected by cancer and their primary and secondary health care teams.

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