

**Health informatics and the delivery of pharmaceutical care to
patients with cancer**

Thesis submitted by
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Signed:

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Date: 8th April 2018

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Glossary

Abbreviation	Text in full
APC	Area Pharmaceutical Committee
BCC	Better Cancer Care
CAV	Cyclophosphamide, doxorubicin, vincristine
CHI	Community Health Index
CMG	Clinical Management Guideline
CMS	Chronic medication service
CNS	Central nervous system
CoW	Computer-on-wheels
CPS	Community Pharmacy Scotland
CRAG	Clinical Resource and Audit Group
DH	Docetaxel / Herceptin (trastuzumab)
DVT	Deep vein thrombosis
eGFR	estimated glomerular filtration rate
e-PCP	Electronic pharmaceutical cancer care plan
EPR	Electronic patient record
FEC	5-fluorouracil / epirubicin / cyclophosphamide
FVHB	Forth Valley Health Board
GRI	Glasgow Royal Infirmary
Haem	Haematological toxicity
HEAT	Health Improvement, Efficiency, Access to Services and Treatment
HIT	Health information technology

HNA	Holistic needs assessment
ICJ	Improving the Cancer Journey
ICT	Information and communication technology
IDL	Immediate Discharge Letter
LCPs	Lead Clinical Pharmacists
LFTs	Liver function tests
LOS	Length of stay
MAS	Minor Ailments Service
MCN	Managed Clinical Network
MDT	Multidisciplinary team
NES	NHS Education Scotland
NHS	National Health Service
NHSGGC	NHS Greater Glasgow and Clyde
NoSCAN	Northern Cancer Network
NSCLC	Non-small cell lung cancer
NTCO	National Transitions of Care Coalition
NVH	New Victoria Hospital
PCIs	Pharmaceutical care issues
PCP	Pharmaceutical Care Plan
PCs	Personal computers
PDA	Personal digital assistant
PMR	Patient medication record
PPI	Proton pump inhibitors
PPSU	Pharmacy Prescribing and Support Unit

PS	Performance status
QEUH	Queen Elizabeth University Hospital
R-CHOP	Rituximab / cyclophosphamide / doxorubicin / vincristine / prednisolone
RPS	Royal Pharmaceutical Society
SACT	Systemic anticancer therapy
SCAN	South East of Scotland Cancer Network
SCLC	Small cell lung cancer
SOB	Shortness of breath
TC	Docetaxel / cyclophosphamide
TCT	Teenage Cancer Trust
UKONS	United Kingdom Oncology Nursing Society
US	United States
WHO	The World Health Organisation
WIG	Western Infirmary
WoSCAN	West of Scotland Cancer Network

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Abstract

This research was conducted to investigate how e-health technologies can contribute to the delivery of pharmaceutical care throughout the patient's journey and across traditional care boundaries. The hypothesis was that e-health technologies are enablers of efficient seamless delivery of pharmaceutical care. Qualitative and quantitative methods were used to examine how hospital clinical pharmacists work; to find out which toxicities were experienced by patients prescribed systemic anticancer therapy (SACT) and what their pharmaceutical care issues were; and to investigate the views of both cancer patients and community pharmacists relating to delivery of pharmaceutical care.

The main findings were: access to mobile technology improved the efficiency of hospital clinical pharmacists; patients receiving SACT experienced a range of toxicity, some of which could be managed in primary care; patients would be happy to receive more from their community pharmacist; and community pharmacists should have access to electronic patient records (EPR) to safely deliver pharmaceutical care.

Most patients who receive SACT experience toxicity in the community. Community pharmacists are ideally placed to support these patients but pharmacists require training and access to EPR to improve their confidence in managing SACT toxicity. Cancer care specialist pharmacists can contribute to the education and training of community pharmacists and initiatives to do so were implemented in NHS Greater Glasgow & Clyde (NHSGGC).

Health and wellbeing Smartphone Apps can support patients and the *Wellness Tracker*, designed in this study, aimed to be an innovative technological aid for patients with cancer. Feedback from teenage patients was positive.

Post-study initiatives implemented in NHSGGC included electronic referral from hospital to GP-based pharmacists as step one. Two-way sharing of the electronic cancer pharmaceutical care plan; electronic referral to community pharmacists (step two) once access to EPR is granted; and clinical vignettes to support community pharmacists in providing advice to patients who have SACT toxicity will follow. Scottish cancer care pharmacists, in collaboration with the Scottish Directors of Pharmacy, have started development of nationally agreed pharmaceutical care bundles for community pharmacists to enable local delivery of pharmaceutical care to patients prescribed SACT.

Chapter 1

The evolution of pharmaceutical care (1960-2016), cancer and health informatics

1.1 The evolution of pharmaceutical care, 1960-2016

The role of the hospital pharmacist in Scotland's National Health Service (NHS) has evolved over many decades, from what was primarily a technical function of medicines supply and dispensing, into a clinical and prescribing role working side by side with medical and nursing colleagues to deliver pharmaceutical care. Clinical pharmacy began in the 1960s when pharmacists transitioned from dispensaries to the bedside (Hepler and Strand, 1990). The first definition of pharmaceutical care was “*the care that a given patient requires and receives which assures safe and rational drug use*” (Mikeal *et al.* 1975). The essential components of medicines therapy are the right medicine, to the right patient, at the right time and this is at the very heart of NHS clinical pharmacy services.

NHS hospital pharmaceutical services continued to evolve throughout the 1970s and 1980s with a far greater focus on the patient in addition to drug or drug delivery. The Noel Hall Report and the Nuffield Report made it clear that pharmacists should be more involved in individual patient care (Department of Health, 1970; Nuffield Foundation, 1986). NHS hospital pharmacists became specialists in therapeutic areas such as cancer care, general medicine and surgery and, by aligning themselves to clinical teams, contributed to individual patient care at the bedside.

Drug therapy is not without risk and drug-related morbidity and mortality remains as problematic today as in the past years (Hepler and Strand, 1990; Barnett and Blagburn, 2016). Adverse drug events are costly in terms of hospital admission and readmission, increased length of stay, additional interventions and possible legal action. In recognition of this, pharmaceutical care was redefined in 1990 by Hepler and Strand as “*the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life*” (Hepler and Strand, 1990). Pharmaceutical care aims to identify, resolve and prevent actual and potential drug-related

problems. The hospital pharmacist monitors patient care and the outcomes of drug therapy and many hospital pharmacists now are autonomous prescribers.

The World Health Organisation (WHO) recognised the importance of pharmacists in healthcare in their 1994 report *The Role of the Pharmacist in the Health Care System* (WHO, 1994). The WHO recommends that where healthcare involves medicines, a pharmacist must be part of the multi-professional team. The report stated that there is a requirement to communicate with other pharmacists to ensure the continuity of pharmaceutical care beyond traditional boundaries for patients with complex care needs and that design and implementation of a pharmaceutical care plan makes a positive contribution to the effective and safe use of medicines which will improve health (WHO, 1994).

In NHS Scotland in 1996, a steering group and working group set up by the Clinical Resource and Audit Group (CRAG) published *Clinical Pharmacy in the Hospital Pharmaceutical Service: A Framework for Practice* (CRAG, 1996). At that time CRAG was the lead body within the Scottish Executive Health Department promoting clinical effectiveness in NHS Scotland. It provided advice on the development of policies on clinical effectiveness issues. The *Framework for Practice* gives detailed guidance on the implementation of a clinical pharmacy service. Statements of good practice were developed to improve the pharmaceutical contribution to patient care by developing a structured and systematic approach to clinical pharmacy practice (CRAG, 1996). Pharmaceutical care planning was a key recommendation and by the end of the 1990s, many NHS hospital pharmacists were documenting their care in purpose designed pharmaceutical care plans. These were generally uni-professional records and few were shared with community pharmacists.

In 2002 the Scottish Executive Health Department published *The Right Medicine, A Strategy for Pharmaceutical Care in Scotland*. *The Right Medicine* was a reshaping of NHS Scotland's pharmaceutical services (Scottish Executive Health Department, 2002). By 2002, many NHS hospital pharmacists had specialist roles for example, cancer care, and there were opportunities for new ways of working to optimise clinical pharmacist time at the bedside. To implement *The Right Medicine*, some hospital pharmacy services across NHS Scotland redesigned services to become more patient focussed. For example, core technical functions such as aseptic dispensing were centralised or clinical pharmacy technicians were enabled to take on patient-facing roles which released pharmacist time and capacity. Also contained within the strategy was a commitment to remove the barriers to pharmacist prescribing. This was realised in 2003 when the first cohort of UK pharmacists completed the supplementary prescribing training programme (Scottish Executive Health Department, 2002).

The Right Medicine made a commitment to review skill mix at national policy level. This was to release pharmacist time spent on non-clinical duties to enable more time for direct patient care. The Scottish Executive Health Department consultation paper, *Making the Best Use of the Pharmacy Workforce* published in 2005 (Scottish Executive Health Department, 2005a) recognised the extensive training that pharmacists have in science, pharmacology and the use of medicines. Many of NHS Scotland's hospital pharmacy departments became managed by pharmacy technicians. Specialist clinical pharmacists relocated to pharmacy workstations located in wards and day-case units to enable full integration within the clinical medical and nursing teams.

In 2012 the Scottish Government published *A Route Map to the 2020 Vision for Health and Social Care* (Scottish Government, 2012a). The major challenges faced by NHS Scotland over the next ten years were an aging population with higher health and care needs, health inequalities and patients

with multiple co-morbidities. Central to the *2020 Vision* for NHS Scotland is that the majority of patients will be out-patients or day-case patients. By utilising preventative strategies and implementing anticipatory care packages it is expected that fewer patients will require an in-patient admission. The preferred model of care is an ambulatory one delivered as close to the patient's home as possible (Scottish Government, 2012b). There will be a particular focus on increasing the role of primary care pharmacists.

In response to the changing health needs of NHS Scotland, *Prescription for Excellence, A Vision and Action Plan for the right pharmaceutical care through integrated partnerships and innovation* was published in 2013. The *Vision and Action Plan* complements the *2020 Vision Route Map* and recognises that the integrated delivery of care as set out in the *2020 Vision Route Map* would be achieved through new and innovative models of pharmaceutical care (Scottish Government, 2013). The models of care would be collaborative working practices with services arranged around patients enabling a personalised approach to care with community based services. Patients should be supported for self-management of their medicines and of the multiple diseases they might have. This will be backed by better use of pharmacy technicians, technology and automation. Patient information systems that allow sharing of data electronically across primary and secondary care and electronic prescribing systems are required. *Prescription for Excellence* makes reference to telehealth and mobile apps as tools to drive improvement and improve the effectiveness of delivery of pharmaceutical care. Mobile apps should be promoted to enable patients to self-manage their medical conditions and improve medicines concordance (European Innovation Partnership on Active and Health Ageing, 2015).

1.2 Pharmaceutical care planning

A key activity for the delivery of pharmaceutical care is the design, implementation and monitoring of the patient's pharmacotherapeutic plan known as the pharmaceutical care plan (PCP). The clinical pharmacist will gather and interpret the patient's clinical information and then apply what is relevant to the design and implementation of the PCP (Figure 1.1) (Hepler and Strand, 1990).

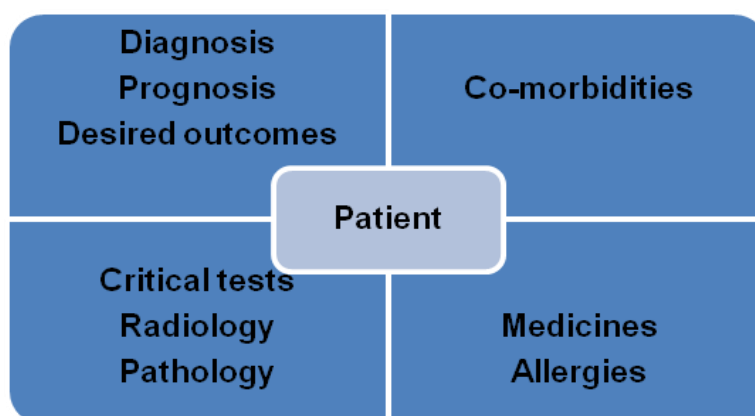


Figure 1.1 Data capture for design and implementation of a pharmaceutical care plan

The patient's clinical information is contained in paper case notes or an electronic patient record. Access to relevant patient clinical information is vital to the successful delivery of pharmaceutical care. Hospital pharmacists and general practice-based primary care pharmacists have had access to patient's case records for many years and are expected to check and confirm the suitability of a therapeutic plan against the relevant patient information. In contrast, community pharmacists do not have access to patient clinical data, a gap which should be addressed.

Our understanding of diseases coupled with an ever increasing number of complex therapeutic options, demands more from pharmacists in all care settings including community pharmacy. Patients are more engaged with disease management and prescribing of medicines. It is commonplace for patients to be given choices with respect to their medicines. A pharmacist cannot deliver comprehensive pharmaceutical care unless they have access to the entire relevant patient's clinical information and document their contribution to patient care. Measurement of patient's outcomes and evaluation of the pharmacist's contribution to patient care can only be realised through documenting what the pharmacist has done (Strand *et al.* 1992). In practice, this is done in multiple ways using paper or an electronic system. Historically within NHS Scotland, paper-based systems are used which can be inefficient and incomplete. They tend to be uni-disciplinary, are often not shared with the wider clinical team and generally do not follow the patient's journey through healthcare systems. This leads to duplication of effort and often little or limited communication with primary care. Electronic data capture and sharing of information addresses some of the limitations of paper systems. Regardless of the method, a standardised approach to documentation with agreed data sets will provide a structured base to the delivery of pharmaceutical care (Strand *et al.* 1992).

1.3 Cancer in Scotland

Cancer, stroke and coronary heart disease are the top three killers of the Scottish population (National Records of Scotland, <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/births-deaths-and-other-vital-events-preliminary-annual-figures/2016>, accessed 19.6.17). Cancer is a health priority in Scotland and the UK. In Scotland, the number of people diagnosed with cancer is likely to rise to nearly 35,000 per annum between 2016 and 2020 (<http://www.gov.scot/Topics/Health/Services/Cancer>, accessed

23.11.16). Between 2006 and 2010 this was 30,000 patients annually. The reason for this increase is twofold: the ageing population in Scotland and the success of improved diagnostics.

UK cancer death rates are predicted to fall 17% by 2030 according to Cancer Research UK (Wise, 2012). In Scotland, between 1995 and 2009 the rate of premature death from cancer (under 75 years) reduced by 22% (The Scottish Government, 2011). This can be explained by earlier detection of cancer, faster access to effective treatments and a more cohesive and integrated approach to the management of cancer services in Scotland. Some cancers are now considered a long term condition whereby patients live for many years after their diagnosis and treatment (Williamson, 2011).

Lung cancer still remains the main cause of cancer death in Scotland. In 2010 over 15,200 people died of cancer in Scotland. More than a quarter of these deaths were from lung cancer: 27% of males and 26% of females (The Scottish Government, 2011). Reducing deaths from lung cancer is a priority for the Scottish Government. One strategy employed to address this is the Scottish Government's HEAT (Health Improvement, Efficiency, Access to Services and Treatment) target for lung, breast and colorectal cancer (The Scottish Government, 2012a). It is a performance management system and targets are designed to support national outcomes for health. NHS Boards are accountable to the Scottish Government for achieving HEAT targets. The target for lung cancer is to increase the proportion of people diagnosed and treated in the first stage of lung cancer by 25% by 2014/15. The aim of this target is to improve cancer survival as it is recognised that late diagnosis is related to overall poorer survival. Complementary to this are HEAT targets for smoking cessation and waiting time targets for treatment and referral.

Scotland has three cancer networks: West of Scotland Cancer Network (WoSCAN), South East of Scotland Cancer Network (SCAN) and the Northern Cancer Network (NoSCAN). The networks collaborate in the

planning of cancer services. The Networks have designated five Cancer Centres and many associated cancer units which operate in a hub (the Centre) and spoke (the unit) design (FRMC Decision Support, 2002). The Cancer Centres deliver radiotherapy and treat the less common tumours. Cancer units are typically district general hospitals with local expertise in systemic anticancer therapy (SACT) for the four most common solid tumours (breast, lung, colorectal and urological cancers). The delivery of cancer services in Scotland for specific tumour groups is organised through a system of Managed Clinical Networks (MCNs) (The Scottish Government, 2008). There are MCNs for most of the common tumour types. The MCN is a structured network of specialised healthcare professionals who work jointly to improve the quality of cancer treatments. The Networks allow sharing of best practice and develop treatment protocols assuring equity of care across geographical divides (The Scottish Government, 2008). Their core objective is delivery of timely, safe, efficient, equitable, effective and patient-centred care, to improve outcomes and the patient experience.

1.4 Lung cancer

Lung cancer is the most common cause of all cancer deaths worldwide resulting in 1.69 million deaths in 2015 (World Health Organisation, 2017). In the United Kingdom in 2014, lung cancer was the third most common cancer and the most common cause of cancer death with 35,895 deaths attributed to lung cancer (Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer>; accessed October 2017). In women, lung cancer is the leading cause of cancer death having overtaken breast cancer (Cancer Research UK, <http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/lung-cancer>; accessed October 2017). The risk of developing lung cancer increases with age, with a median age at diagnosis of 70 years. About 90% of lung cancers are caused by smoking (National Institute for Health and Clinical Excellence, 2011). Most patients have incurable

advanced disease at diagnosis and treatment options are palliative. Early detection and intervention is key to improving the 5-year survival, which in Scotland is 7 – 9% (Information Statistics Division Scotland, 2012). Approximately 80% of patients diagnosed with lung cancer have non-small cell lung cancer (NSCLC); the remainder have small cell lung cancer (SCLC) (Socinski *et al.* 2003).

Early stage (stages I, II and IIIa) NSCLC is considered to be operable and resection of the tumour offers the only cure. Most patients however present with locally advanced (stage IIIb) or metastatic disease (stage IV) neither of which is operable. Patients with stage IV disease who are considered fit enough (Performance Status 0 to 2) are offered SACT or palliative radiotherapy. Any therapeutic intervention should be used to improve symptoms and increase overall survival but must not be at the expense of quality of life (Socinski *et al.* 2003).

When a patient receives SACT, it is essential to assess toxicity and tolerability after each cycle and before the next planned treatment and to ensure that patients know who to contact for specialist advice if they become unwell at home. The lung cancer population is a group of mostly elderly patients with multiple co-morbidities and so toxicity assessment is vital. The mainstay of SACT in lung cancer is cisplatin or carboplatin and therefore the toxicity from SACT can be significant and includes myelosuppression, neutropenic sepsis, reduced renal function, nausea and vomiting and neurotoxicity.

Toxicity might result in a hospital admission. A retrospective evaluation of hospital admissions in oncology resulting from drug interactions or an adverse drug event showed that nearly one in 10 unplanned admissions in the cancer population were associated with an adverse drug event, significantly higher than the rate of 5% reported for adults who do not have cancer (Miranda *et al.* 2010). Factors that may have contributed to

hospitalisation in cancer patients were concomitant SACT, increasing numbers of prescribed medicines and altered pharmacokinetics caused by cancer. Undoubtedly SACT improves overall survival in patients with advanced lung cancer however, toxicity should not be underestimated and further research on toxicity and adverse effects is needed (Burdett *et al.* 2008).

A patient might seek advice from their GP or community pharmacist who may not have the most up to date information about the patient readily to hand. There is a need to ensure appropriate and relevant information on patients undergoing SACT is widely available to healthcare professionals who are able to make use of it in all care settings.

1.5 Cancer services in NHS Greater Glasgow and Clyde

NHS Greater Glasgow and Clyde (NHSGGC) is the largest Health Board in Scotland and serves a population of approximately 1.2 million people. The Health Board also provides specialist cancer services to the whole of the West of Scotland (NHS Greater Glasgow and Clyde Cancer Services Steering Group 2010).

Adult chemotherapy services are delivered both locally in cancer units and centrally at the Beatson West of Scotland Cancer Centre (WoSCC) where specialist services are situated (Strategic Review of Chemotherapy Steering Group 2007). The four main tumour types treated in local cancer units are lung, breast, colorectal and urological cancers and haemato-oncology cancers. This is achieved by having visiting oncology consultant teams who provide specialist sessions at the local hospitals and who are fully integrated into the local multidisciplinary team (MDT). Delivery of care as close as possible to patient's homes is the model for the West of Scotland Cancer

Network (Scottish Executive Health Department, 2005b; Strategic Review of Chemotherapy Steering Group, 2007).

The referral of a patient with cancer to oncology services involves discussion by the tumour-specific MDT. Decisions about the appropriate treatment for each patient are made following an MDT meeting and discussion with patients and carers. Cancer treatment pathways in NHS Scotland are defined in what is known as a Clinical Management Guideline (CMG) where all therapeutic options are described. The CMG includes surgery, SACT and radiotherapy.

Each of the main tumour groups has a named pharmacist whose role is to support the safe and effective use of cancer medicines within that patient group. These pharmacists are key members of the tumour-specific MCNs. The cancer care pharmacist and lead consultant co-author SACT treatment protocols which are used to support prescribers in making decisions about treatment options. The SACT protocols define the choice and dose of anticancer drug. SACT is prescribed electronically using the Chemocare® system and prepared by pharmacy aseptic services. The Health Board has robust governance systems in place to ensure the safe delivery of SACT and equitable access to treatment across NHS hospital sites.

1.6 Cancer services to patients with lung cancer

Local teams, led by a respiratory physician, have overall responsibility for their patients. Specialist oncology input is provided by the lung cancer consultants, based at the Beatson WoSCC. Lung cancer SACT is available in five sites across NHSGGC, with all radiotherapy delivered in the Beatson WoSCC. Each of the sites has a named specialist pharmacist, however, Board-wide strategy and planning within the MCN is the responsibility of the lung cancer MCN lead pharmacist.

Effective treatment of lung cancer is challenging as the population of NHSGGC has a shorter life expectancy than the rest of Scotland, and areas of higher levels of deprivation with its associated impact on health (NHS Greater Glasgow and Clyde Cancer Services Steering Group, 2010). Smoking remains a significant public health challenge for NHSGGC, which has the highest smoking rate in Scotland. Pharmacy public health and community pharmacy all have an active role in lung cancer prevention and treatment, be it smoking cessation initiatives or awareness and early detection of lung cancer. It is recognised that patients with lung cancer in NHSGGC frequently have multiple co-morbidities such as cardiac or respiratory diseases partly due to the smoking rates. Multiple co-morbidities are reflected in performance status and the lung cancer clinicians are aware that patients in the real-world are generally less tolerant of SACT regimens than the patients who participated in cancer clinical trials. Informal discussions with South Glasgow patients have indicated that some patients struggle with SACT and that the decision to continue beyond two cycles is not easily made.

The lung cancer patient pathway for SACT in NHSGGC is complex and many healthcare professionals are involved in the care of a patient undergoing treatment for lung cancer (Appendix 1). Patients receive care in hospital, the community and in hospices. There are multiple handovers and transitions of care. This results in many opportunities for drug-induced toxicity and/or drug errors to occur and up to 60% of drug errors occur during care transitions (Kirwin *et al.* 2012). Patients' requirements for medicines change throughout the cancer journey and a significant number of these medicines will be complex requiring specialist input.

A USA based retrospective review of cancer outpatients investigated the rate and types of medication errors. Of 1,262 adult patient episodes involving 10,995 medicines, 7.1% were associated with a medication error. Eleven errors resulted in injury to the patient. Most errors occurred in administration

and several resulted from duplicate drug orders/prescriptions (Walsh *et al.* 2008). Few administration errors occurred in sites with an electronic prescribing and/or administration system. The errors were independently reviewed by doctors. Improved communication was the intervention most often cited as preventing the error (Walsh *et al.* 2008). Electronic prescribing, which is one solution proposed to reduce SACT errors, was implemented across the West of Scotland and all cancer prescribers use the Chemocare® system.

As the biology of cancer is unravelled, therapies are now more receptor-driven, targeting for example, protein over-expression or genetic mutations with the aim being to "switch off" uncontrolled cellular proliferation. There has been a significant change in SACT over recent years, whereby there is a move away from traditional parenteral SACT to targeted small molecules, many formulated as oral therapies for daily administration. This presents new challenges for pharmacy, for example identifying drug interactions and patient education and concordance. Pharmacists have an important role in patient education, not only how and when to take medicines, but to ensure early recognition of toxicity and where and when to seek specialist advice especially out of hours and in the intervals between SACT treatments. Patients undergoing SACT are very likely to experience side effects (Williamson, 2011). Patients with lung cancer are perceived as being a higher risk population due to multiple co-morbidities and frequent admissions to hospital. Their care switches between oncology, respiratory, primary care and palliative care with multiple care transfers. Implementing e-health solutions to communicate the care already delivered and the requirements for follow up, monitoring and referral back to specialist services will provide an integrated model of care for lung cancer. This would be transferable to other patient groups and provide a framework for other cancers and diseases.

1.7 Pharmaceutical care planning for patients with cancer

Cancer care clinical pharmacists within NHS Scotland are essential for the delivery of SACT and have been at the centre of care for patients with cancer for many years. National guidance for the delivery of SACT issued in NHS Scotland in 2001 (updated in 2005 & 2012) recognised that cancer care clinical pharmacists were central to safety and quality of delivery of SACT services to patients with cancer in Scotland (Scottish Executive Health Department, 2001; Scottish Executive Health Department, 2005c; Scottish Government, 2012c).

The Scottish Oncology Pharmacy Practice Group developed and implemented a standardised paper-based generic cancer pharmaceutical care plan (PCP) in 2001 to facilitate pharmaceutical care planning for cancer patients receiving SACT (Macintyre *et al.* 2003). This was the first step to harmonise the delivery and documentation of pharmaceutical care across the Scottish Cancer Networks. Successful pharmaceutical care planning requires that the pharmacist is integrated within the multidisciplinary team and this is true of the cancer care clinical pharmacy team in NHSGGC (Macintyre *et al.* 2003).

The sharing of appropriate information across all health care sectors is key to the provision of high quality care and the generic PCP was considered the first step in a series of processes to switch data capture from paper to electronic means using portable technology. Development of an electronic PCP was explored in 2001/2002 but was unable to be progressed due to the lack of a suitable information technology framework within the NHS. This changed in 2009/10 with the introduction of the Clinical Portal in NHSGGC. The Health Board had a paper-light vision and invested in systems to facilitate this. The Clinical Portal is a web-based system for viewing patient-specific clinical information such as test results, scans, the immediate discharge letter and clinic letters in one single location. It is accessed on a desktop PC or wireless enabled laptop/tablet PC using a unique user log in.

Over 14,000 NHS GGC staff have Clinical Portal access. Real-time data is entered using structured electronic forms (e-forms) which then become a permanent part of the patient's record. In 2010 an electronic pharmaceutical cancer care plan (e-PCP) was designed and implemented in the South Glasgow cancer pharmacy service.

1.8 Transfer of pharmaceutical care between hospital and community care settings

Healthcare is the largest industry in the world. Its diversity in terms of activity and delivery make it extremely challenging to ensure patient safety is always at the forefront of care (Vincent C, 2010). Polypharmacy, drug interactions and incomplete medicines reconciliation can result in hospitalisation or death (Frydenberg *et al.* 2012). Medication errors can arise due to poor communication across care sectors. A systematic review showed that 5 – 6% of all patients present with an adverse drug event as a contributing factor to hospital admission (Kongkaew *et al.* 2008). The error rate in oncology out-patients has been shown to be even higher with a greater potential to harm patients (Walsh *et al.* 2009). Kliethermes (2003) cites examples of adverse drug events where poor communication and lack of coordination of care resulted in unintended or adverse outcomes for patients.

As depicted in the NHS GGC lung cancer pathway (Appendix 1), patients receive care from multiple healthcare professionals who work across many treatment locations and so fragmentation is likely to occur. Patients might move between wards within the same hospital, move hospitals for example to a tertiary care centre and move between secondary and primary care. A literature search offered many definitions of continuity of care (Kliethermes, 2003). The preferred definition is “*a relationship between present and past care requiring a flow of information and a care plan*” (Kliethermes, 2003). This remains aligned with Hepler and Strand’s definition of pharmaceutical

care (Helper and Strand, 1990). Lung cancer is just one example of where care is provided by multiple healthcare professionals but this group of patients is particularly suited to investigate and model e-health initiatives. The poorer baseline level of overall general health in this population and the use of therapeutic interventions of short duration with known toxicity profiles puts this patient population at a high risk of drug misadventure, and, therefore suitable for closer examination in terms of toxicity and pharmaceutical care issues.

Medicines are increasingly complex and patients might be prescribed multiple medicines from several different sources, for example, discharge medicines from the hospital pharmacy, repeat prescriptions from the GP, over the counter purchases from a community pharmacy and specialist services such as cancer, mental health and community addiction teams. Patients with lung cancer are frequently prescribed cardiovascular and respiratory medicines. The NHS in Scotland does not have a single electronic prescribing system and so rapid access to all the systems where information on medicines is located is necessary to improve medicines safety.

Information technology and improved communication are means to reduce errors (Walsh *et al.* 2009). Using health information technology (HIT) to improve communication and make information readily accessible can reduce medication errors (Vincent, 2010). The National Transitions of Care Coalition (NTCO) released a position paper in 2010 on the use of HIT for care transitions (NTOC, 2010). NTOC recognised that the role of the pharmacist should be expanded in medicines reconciliation in transitions of care (NTOC, 2010). Expertise in medicines optimisation and medicines safety is the value that pharmacists bring to an interaction with a patient, for example medicines reconciliation, dose recommendations and patient education (Jenkins *et al.* 2012). Medication histories taken by pharmacists are more accurate and complete than those taken by doctors (Strunk *et al.* 2008). Pharmacists

should actively manage the medicines aspects of continuity of care and careful thought and planning as to how that is done is required from pharmacy leaders.

In 2012, the European Association of Hospital Pharmacists investigated the extent to which pharmacists are in contact with each other and at what point in the patient's journey the communication is most important (Preece *et al.* 2014). The results indicated that communication between hospital and community pharmacists is infrequent yet both groups of pharmacists believed it is important, especially at transitions of care. The three core barriers to communication were that it is not considered a core part of practice, there is a lack of an electronic system to share information and a lack of time.

The Royal Pharmaceutical Society (RPS) launched a campaign in 2011 which led to the 2012 publication *Keeping patients safe when they transfer between care providers – getting the medicines right* (Picton and Wright, 2012). The publication aims to raise awareness of the need for consistent transfer of information about medicines when patients move between care locations. The RPS also called for a structured clinical record to a nationally agreed format. The guidance is a framework for good practice and offers practical examples for implementation. The technology required to electronically transfer patient clinical information exists. However, the wider NHS does not have an integrated patient information single system and often relies on individual communications between healthcare professionals. Patient's health records are contained in "sector silos" and are currently not widely shared.

It is therefore necessary to identify opportunities within existing technology frameworks for health information transfer. Whilst HIT is a valuable tool for improving quality of care, it will not address every medicines safety issue and solve every miscommunication problem. Standardised electronic forms with defined data sets that add value and quality to patient care should be

developed in conjunction with the appropriate medical and pharmacy stakeholders (NTOC 2010). This ensures that pharmacists, regardless of the care setting, are working to a shared goal during care transitions. NHSGGC clinical pharmacy services delivered part of this goal in 2010 with the introduction of the electronic pharmaceutical care plan (e-PCP). Fully integrated HIT systems across care boundaries and access to the relevant clinical information are all still required to enable the delivery of pharmaceutical care across all care locations. Pharmacists in all care environments recognise the need to transfer care. Legal and professional frameworks for data protection, information governance, data security, patient confidentiality and consent must be adhered to at all times. Further discussion of this is out with the scope of this thesis but the following provide a useful precis.

1.9 Drivers for electronic systems

An electronic health record integrated with e-prescribing and pharmacy drug distribution systems is the ideal model. This allows for capture of real time patient data and facilitates working across and within healthcare organisational boundaries (Siska and Tribble 2011). A barrier to integrated systems in the United States hospital pharmacy service is the lack of overall vision and leadership resulting in a fragmented approach (Siska and Tribble 2011). In contrast, NHS Scotland has the national e-health strategy and the leaders in healthcare have been tasked with its implementation. Thus Scotland has a focussed approach with one common, shared vision. It is incumbent on pharmacy leaders to encourage cultural changes and to foster an environment of innovation whereby technology is embraced. A cultural change was needed to move forward with the informatics systems NHSGGC had available as many pharmacists were reliant on paper systems. Accepting that small incremental steps are the best way forward was needed as waiting for the "perfect" system will merely delay any advances (Siska and

Tribble 2011). Acceptance of this is an important point and has probably held back technological developments.

Pharmacists have an increasingly important role in supporting medicines reconciliation and identifying medicines-related care issues to be followed up by the next care provider. Patient pathways are now far more complex and rely on excellent channels of communication to ensure the prescriber's intention is met. Use of technology to support care transitions and improve medicines safety must be explored.

Sharing of pharmaceutical care plans supports the delivery of treatments in the community, including SACT, and is consistent with *Shifting the Balance of Care* and the *Better Cancer Care (BCC)* national implementation plan (<http://www.shiftingthebalance.scot.nhs.uk/>, accessed 23.11.16, <http://www.gov.scot/Publications/2008/10/24140351/0> accessed 23.11.16). There are eight improvement areas in the *Shifting the Balance of Care Improvement Framework*, and the three of particular relevance to delivery of pharmaceutical care to patients with lung cancer are: (i) shared information and electronic health records to improve communication across traditional professional and organisational boundaries; (ii) improve joint use of resources; (iii) improve palliative and end of life care (Scottish Government 2009). Cancer patients generally have good access to palliative care services but there can still be gaps with respect to shared information about medicines and access to specialist end of life medications.

Better Cancer Care (BCC) asks healthcare professionals to focus on the quality of care. This requires looking at clinical outcomes and ensuring the NHS resources are utilised to their best. It was noted in *BCC* that during cancer treatment, communication between care providers should be improved and the use of electronic communication should be explored (<http://www.gov.scot/Publications/2008/10/24140351/0>, accessed 23.11.16).

Interventions to improve continuity of care in the follow-up of patients with cancer were reviewed (Aubin *et al.* 2012). The interventions used were a patient-held record, telephone follow-up, communication and case discussion between distant healthcare professionals, changes in medical record systems, care protocols / directive / guidelines and co-ordination of assessments and treatment. Use of a shared electronic record was not included. There were no significant differences in health-related outcomes between patients assigned to interventions and those assigned to standard care. Further research was recommended to evaluate interventions aimed at improving continuity. Of note, continuity measures should be validated in cancer patients whose cancer journey has involved many care providers, for example, patients with lung cancer.

NHSGGC Pharmacy Prescribing and Support Unit identified the enhanced use of technology as a means of improving efficiency of services and as a research priority. Also identified for further research and evaluation are models of care for transferring pharmaceutical care between primary and secondary care sectors. This study builds on systems already established in cancer care whereby an electronic pharmaceutical care plan is maintained on the NHS Clinical Portal and readily accessible by the wider multidisciplinary team.

1.10 Technologies, barriers and enablers to support electronic data transfer

The hospital clinical pharmacist is expected to provide pharmaceutical care to all in-patients. To enable this, clinical pharmacists must work in the most efficient and effective way appropriate to their skill set. The use of information technology to increase communication and improve efficiency is a realistic vision. Lessons learned from the United States (US) Fleetwood pharmaceutical care planning system are worthy of comment (Lapane *et al.*

2006). The Fleetwood pharmaceutical care planning software was designed as a bespoke web-based system for nursing homes. The Fleetwood model included pharmacist assessment of the patient; direct communication with the prescriber and formalised pharmaceutical care planning for elderly patients at highest risk of medication-related problems. The study showed inconsistent documentation and offered some reasons for this. A major barrier to extended use of the software was the dependency on single commercial software which proved unsustainable. In addition, interventions were made but not recorded electronically. Unlike many US IT systems, the NHS does not have individual Health Board interdependency on commercial software and one of the aims of the Scottish national e-Health Strategy is to reduce variation in and duplication of clinical activities.

Worldwide, several healthcare organisations have explored many systems for electronic documentation and tested various mobile devices such as personal digital assistant (PDA); tablet personal computers (PCs); Smartphones; and laptops. Despite this, no mobile device has truly shown a clear advantage over any other (Krogh *et al.* 2008). Two studies, both in orthopaedic patients, were included in a systematic review of the evidence to evaluate the effects on clinical care of hand-held electronic medical records, (Wu and Straus 2006). Changes in documentation with handheld records were compared to paper charts. In both studies the hand-held device was a PDA. The PDA significantly improved documentation but led to inaccuracy in coding diagnoses (Wu and Straus, 2006). It took longer to complete the documentation using the PDA compared with a paper chart. No firm conclusions can be made from this small number of studies and further research with a focus on assessment of clinical outcomes is warranted (Wu and Straus, 2006).

Using a laptop/tablet personal computer at the bedside is preferable to a PDA. The PC has several advantages over the PDA including the screen size, ability to open and work with multiple screens and/or programmes and

encryption security (Cockerham, 2009). Although the PDA is lighter and the battery life may be longer, the PC offers clear advantages. A tablet PC to support clinical documentation is preferable to a computer-on-wheels (CoW) for pharmacist's use on in-patient ward rounds (Krogh *et al.* 2008). The CoW has restricted mobility and remains on the ward. One limitation in switching from paper to mobile technology is the pace of the ward round and so it is essential that the device can move quickly between screens and programmes (Krogh *et al.* 2008).

Using wireless Smartphones has been shown to improve efficiency of communications between hospital staff (Wilson *et al.* 2012). Information retrieval was fast and did not disrupt daily work flow. Use of a Smartphone did not reduce the time to resolution of a pharmacist's intervention compared with traditional communications (Wilson *et al.* 2012). Whilst a Smartphone may not be the preferred IT device in NHSGGC, the principles of electronic communication are applicable. This system would lend itself to triaging communication and, within NHSGGC, could be used to signpost clinicians to updated patient information. In 2016 an NHSGGC Twitter account was set up to communicate information about medicines.

The pros and cons of portable PC technology are mirrored in experiences in NHSGGC. Two tablet PCs (Lenovo ThinkPad) were purchased in 2010 as a trial for use by NHSGGC cancer care clinical pharmacists based in South Glasgow to implement e-care planning. The portability and immediate access to data cannot be overstated and at the time, were used at the South Glasgow lung cancer oncology clinic every week to capture real time clinical data, verify SACT, and access treatment protocols. However, some NHSGGC hospitals did not have wireless networks and there were occasions where the wireless connection was lost.

The NHSGGC e-PCP can be converted to a PDF file to enable electronic transfer by email, for example to community pharmacy, to allow follow up of

unresolved or pending pharmaceutical care issues. Previous research by Davenport *et al* (2007) reported that a significant number of transferred care issues are not actioned, reasons cited as readmission or not having received a prescription from the patient. It is vital that the patient/carer attends the named pharmacy otherwise the outstanding care issues will remain unresolved. The community pharmacists in the Davenport study acknowledged that they may not have time to read and action all the transferred care issues. The community pharmacists were asked how they would like to receive patient information. By facsimile was the preferred method (72%, n=25) and only 9% (n=3) opted for electronic transmission.

Davenport's study however pre-dates the implementation of the chronic medication service (CMS) in community pharmacy in Scotland. Under the CMS, patients with long term conditions can register with a community pharmacy. The community pharmacist assesses patients to identify and prioritise unmet pharmaceutical care needs. The pharmaceutical care needs, care issues and actions/outcomes are documented in an electronic pharmacy care record (NHS Scotland 2013). Work is underway in NHS GGC to investigate a two-way sharing of electronic care plans with community pharmacy. This builds on work completed by Forth Valley Health Board (FVHB) which evaluated the benefits of both providing the community pharmacy record to secondary care and hospital discharge information to community pharmacy (NHS Forth Valley 2012). The benefits confirmed the success of the FVHB project which was given Scottish Government support to be extended to two further health boards, one being NHS GGC.

Changing behaviour to adopt new ways of working can prove a challenge. A systematic review of the effectiveness of interventions to promote the adoption of ICT by healthcare professionals was inconclusive. The ICTs were defined as digital and analogue technologies that facilitate capture, processing, storage and exchange of information via electronic communication, such as electronic health records. The review recognised

that some healthcare professionals do not use ICTs despite their availability. The review concluded that there is uncertainty around effective strategies to promote the use of ICTs (Gagnon *et al.* 2009).

These findings match a peer group discussion with NHSGGC cancer care pharmacists in 2010 which focused on the cancer e-PCP. Some cancer care pharmacists did not want to adopt the technology available for direct data entry into the e-PCP. The main barrier cited was time. This is an important consideration when designing and implementing new systems of working practices which are expected to be adopted by all staff and where staff engagement in system design is essential (Siska and Tribble 2011). The American College of Clinical Pharmacy white paper on improving care transitions is a reminder of the importance of engagement with the patient too (Hume *et al.* 2012). Whilst there is no doubt that transfer of clinical data between healthcare professionals is essential, it must not be forgotten that the patient is central in this and should be involved in discussions. NHSGGC's clinical practice does not include giving the patient a copy of their PCP. This is worthy of being explored further, even if only an abbreviated care plan with an up to date list of medicines is supplied. Patients who are actively involved in their care experience fewer adverse drug events, readmissions and medication errors (Brennan *et al.* 2011). Pre-discharge patient education by a pharmacist reduces adverse drug events compared with patients who did not receive pharmacist counselling (Brennan *et al.* 2011).

1.11 Scotland's e-health strategy

NHSScotland's eHealth Strategy (2011 – 2017) focuses on benefits and outcomes delivered by technology. All NHS Boards have developed an e-health plan. Two of the strategic ehealth aims are:

- (1) to improve the availability of appropriate information for healthcare workers and the tools to use and communicate that information effectively to improve quality and*
- (2) to improve the safety of people taking medicines and their effective use.*

The e-Health strategy is quite clear in that the focus is not on the technology as a product or service, rather the focus is on outcomes and benefits. The systems are in place – the NHS Clinical Portal and the SACT electronic prescribing system (Chemocare®) for example. It is essential that the technology and patient's clinical information held within the systems can be used to improve medicines safety and contribute to patient care through a co-ordinated and efficient sharing of information. The NHS will become paper-light and pharmacists must be ready to embrace new ways of working. Traditional boundaries or interfaces should become completely seamless and especially those which have prevented the move of information between primary and secondary care. The pharmaceutical care plan is a dynamic document and to facilitate real time updates it needs to be transferable between care providers or, preferably, it should be hosted within an electronic patient record which is available to all relevant NHS Scotland staff delivering clinical services. The use of electronic documentation in 2016 is now embedded into daily clinical practice in most sectors of NHSGGC.

This study will use qualitative research methods to explore opinions and experiences of both patients and pharmacists. The South Glasgow cancer population is the focus of the patient-directed aspects of the research. The patient is central to designing and improving healthcare services.

Prescription for Excellence supports the use of practice research and electronic sharing of information to develop and evaluate pharmaceutical care (Scottish Government, 2013). Pharmacists, regardless of their practice base, must deliver patient-centred care and the conclusions from the research described in this thesis may inform an enhanced technology-driven approach to integrated pharmaceutical care.

1.12 Hypothesis, aim and objectives

The hypothesis was that e-health technologies are enablers of efficient seamless delivery of pharmaceutical care and will support pharmacists in all healthcare settings.

The aim of this thesis is to investigate how health informatics supports the delivery of pharmaceutical care to patients with cancer.

This was broken down into five objectives to mirror the patient pathway and the flow of patient's clinical information between healthcare providers. Each objective is described in Chapters 2 - 6. .

Objective one (Chapter 2)

Describe the current clinical pharmacy service in NHSGG&C Acute Service in selected cancer clinics and non-cancer wards using process mapping and make the case for mobile technology.

Objective two (Chapter 3)

Identify toxicities, common pharmaceutical care issues and episodes of unscheduled care associated with SACT given for lung cancer in a cohort of patients treated in South Glasgow.

Objective three (Chapter 4)

Identify toxicity experienced between SACT cycles, where advice was sought and possible use of a Smartphone App in a cohort of patients receiving SACT.

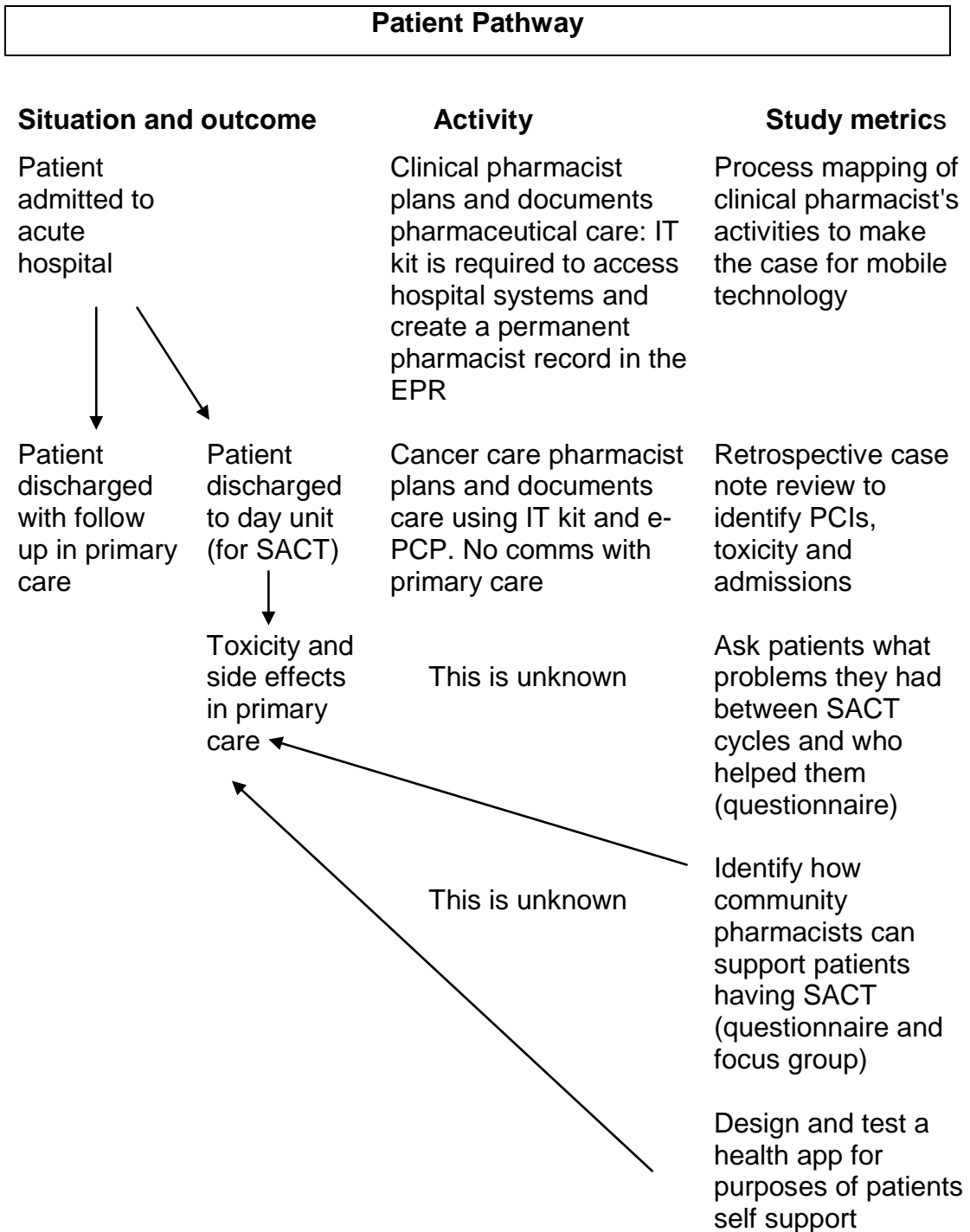
Objective four (Chapter 5)

Determine the information needs of community pharmacists to support patients receiving SACT.

Objective Five (Chapter 6)

Design and test a Smartphone App to support patients who are receiving SACT for cancer.

1.13 Study roadmap



Chapter 2

Making the case for mobile technology

2.1 Electronic patient management systems and mobile technology

NHS Scotland's ehealth vision is expected to bring many benefits to patients. These include opportunities for innovative medicines management, for example home health monitoring with stepped management plans, online ordering of repeat prescriptions and online appointment booking. The vision aims to deliver workforce efficiencies as NHS Boards across Scotland move from paper to electronic-based information. Technology systems such as Patient Management Systems have been the focus of NHSGGC's ehealth vision over the period 2010 – 15.

As described in *Chapter One*, NHSGGC implemented Clinical Portal in 2010 as an electronic platform to view patient's clinical data such as critical tests and clinic letters. This was followed in 2011 by the introduction of InterSystems *TrakCare*, an electronic patient management system for recording real time results, booking tests such as radiology and creating an electronic immediate discharge letter for dispensing and communication to primary care. Some paper systems, such as internal referral forms to, for example, physiotherapy and radiology, laboratory test results and discharge letters were completely switched off in a move to support the NHS Board's vision of paper-light working.

A system to manage patient flow through NHSGGC acute hospitals and to support pharmacy triage and referral was developed in 2013. The system – *WardView* – interfaced with *TrakCare*. *WardView* visually presented real time patient information such as location and discharge status of all in-patients on an electronic patient whiteboard. Whiteboards were installed in all acute hospital wards in NHSGGC. Embedded within *WardView* was an application called *PharmacyView*. Implementation of the *PharmacyView* product was key to managing the flow of patients by clinical pharmacists. It was evident to the NHSGGC Lead Clinical Pharmacists (LCPs) that lack of

access to computers impeded the workflow of their teams performing clinical duties on wards.

For healthcare professionals, fast and direct access to clinical information is essential to provide safe services and avoid duplication of activities. Literature supports mobile technology as a means to deliver patient care effectively (Cockerham 2009; Wilson et al. 2012). Cockerham (2009) describes the advantages of immediate access to real time clinical information on a ward round when using a tablet PC. Wilson *et al* (2012) conducted an observational study to investigate use of a Smartphone by clinical pharmacists. Use of the devices was perceived as increasing efficiency. Unimpeded access to hardware is therefore important to ensure ready access to e-health IT systems.

A position paper outlining requirements for mobile technology was prepared by senior pharmacists (F MacLean, P Mulholland) for the NHSGGC Board Pharmacy Executive in November 2013 (Appendix 2). It was initially rejected due to lack of supporting evidence. A bulk purchase of laptops or tablet PCs would only be made when there was evidence of need with defined deliverables which supported pharmaceutical care. A baseline investigation of clinical pharmacy processes across different NHSGGC sites and clinical specialities was required before further developmental work on e-health initiatives and solutions to change practice could take place.

2.2 Process mapping of clinical pharmacy services in NHS Greater Glasgow and Clyde

In any service improvement project it is helpful to understand all the activities (or processes) undertaken by the team before considering implementation of changes to practice. This provides the platform to redesign services or plan improved services (NHSS Guide to Service Improvement 2005). Process

mapping is a recognised tool for quality and service improvement projects and can help map the entire patient journey (NHS Institute for Innovation and Improvement 2013). It is a simple diagnostic technique which is patient focussed and requires limited resources (NHSS Guide to Service Improvement 2005). Process mapping was identified as the ideal technique to build the case for mobile technology and the purchase of IT kit for use by clinical pharmacists.

Two published reports describe the use of process mapping by pharmacists or within pharmacies. Fitzpatrick (2004) describes a case study whereby efficiencies in dispensing processes were made by using process mapping and automation in a UK hospital pharmacy. This was undertaken in the Royal Wolverhampton Hospital in England in response to the Department of Health's NHS plan for pharmacy. Dispensing pre- and post-automation was examined which identified the rate limiting step (checking technician step) and they reorganised staff to address this. Biczak and McDonald (2014) used process mapping as part of lean process improvement techniques to reduce non-value added work at St Vincent's Hospital in Worcester, Massachusetts. Their group applied three principles to their improvement work which are relevant to any NHS quality and health services improvement projects, namely: (1) patient safety must not be compromised; (2) time to perform a task must not be increased and (3) eliminate waste. Pharmacy technicians were observed replenishing medicines in an emergency trolley. Inefficiencies such as multiple trips to and from the medicines store could be eliminated by taking the trolley to the medicines store which was one of the author's recommendations.

Process mapping is used also by industry and non-health organisations as its value in leading to improvements is widely accepted (Klotz and Horman, 2008; Rother 1999; Crown Prosecution Service 2012). It is used to identify all steps in a pathway and to identify unnecessary tasks, duplication of work and bottlenecks or constraints. (NHSS Guide to Service Improvement 2005).

To ensure maximum effectiveness, process mapping should be used in conjunction with team discussion and feedback to come to a shared understanding of the pathway being studied. (Johnson *et al.* 2012; Hong 2013) This ensures collective ownership of the process map. Klotz and Horman (2008) describe how process mapping can increase transparency for some applications using building projects as their research focus. The visual nature of a process map is one of its strengths (Hong 2013).

Fifteen to twenty percent of time can be lost through duplication of work and incomplete work by colleagues (Crown Prosecution Service 2012). It may not be apparent that this is happening and time should be spent in advance of starting process mapping to understand and agree what the ideal or optimum service looks like. This should take into account any key performance indicators or key quality indicators for the service.

Cancer services in the West of Scotland were redesigned in 2006 and process mapping was used to identify the current service and compare it to an ideal model. The final elements of the redesign of cancer clinical pharmacy in South Glasgow took place in 2010 in advance of moving to the purpose built New Victoria Hospital (NVH) which was to house the South Glasgow cancer unit. Oncology patients from the south of Glasgow who had been treated in the Beatson West of Scotland Cancer Centre were repatriated to the NVH. The NVH was designed to be paper-light and electronic systems were deployed into routine clinical practice. An electronic SACT prescribing system (Chemocare[®]) and the Clinical Portal were introduced into routine clinical practice. The cancer care pharmacists were allocated two Lenovo ThinkPad laptops from an external funding stream to allow them to mirror the ambulatory nature of the new cancer unit. Cancer clinical pharmacy services were included in the process mapping in this study to allow direct comparisons to be made between the redesigned cancer pharmacy service, which used mobile technology, and clinical pharmacists who did not have access to dedicated IT kit.

There is a defined convention for process mapping using flow charts or swim lane charts with symbols representing activities such as decision points. It is desirable to define the start and end limits of a process map. This enables the investigator to maintain a focus on where there are gaps, perhaps in knowledge, evidence or understanding. The level of detail in a process map should be commensurate with identified problem and perceived solutions (NHS Institute for Innovation and Improvement 2013). Once the process map is completed, a comprehensive critical examination is required asking the questions: what?; how?; when?; where?; and who? to identify duplication and variances (Crown Prosecution Service 2012). Process mapping has been used successfully in the NHS to redesign services. Gilchrist *et al* (2008) used process mapping to assist planning of an outpatient parenteral antibiotic therapy service. Process mapping provided a full understanding of the system and enabled the team to identify potential system failures and areas where harm might have occurred thus minimising risk. Ben-Tovim *et al* (2007) used NHS process mapping methodology to redesign patient services across the Flinders Medical Centre in Adelaide, Australia. The Emergency Department was changed first with an immediate beneficial impact. With support from the UK NHS Modernisation Agency, further redesign took place across the entire Medical Centre.

2.3 Aims and objectives

The hypothesis was that unrestricted access to personal mobile technology would increase the efficiency of hospital clinical pharmacists and be an enabler of pharmaceutical care.

The aim of this process mapping was to investigate, on different sites and in different specialties, how clinical pharmacists in Acute Services in NHSGGC delivered pharmaceutical care.

The objectives were to:

- describe where mobile technology was used in the delivery of pharmaceutical care
- identify access points to electronic clinical information in the daily workflow of the clinical pharmacists
- compare the processes in both cancer and non-cancer areas
- highlight improvements in care of patients and workflow
- provide recommendations for service improvement and service development
- provide supporting data as evidence for the need for mobile technology for clinical pharmacists

2.4 Methods

1. The LCPs were asked to identify the clinical areas to be visited for process mapping. Three distinct areas were identified as being representative of high activity in-patient and day case clinics. The areas chosen to visit were: Medical Acute Receiving Unit in Glasgow Royal Infirmary (GRI), Surgical Acute Receiving Unit in Western Infirmary (WIG) and the day case cancer clinics (Clinic B, an out-patient clinic; and Clinic P, the SACT day bed unit) in New Victoria Hospital (NVH). This allowed a comparison of clinical practice with and without ready access to mobile technology as the cancer clinical pharmacists had uninterrupted access to PCs. One day was allocated for each external site visit (GRI and WIG) and a sample of approximately 10 – 15 patients including new admissions was chosen. There was open communication about the visits to reassure staff and secure their co-operation. The LCP was the point of contact for the visits and provided direct access to their staff.
2. All of the observations in the non-cancer wards were undertaken by F MacLean. A task-based data collection form was designed to collect data for a high-level process map involving up to 10 steps per patient (Table 2.1). The data collection form was based on the workflow practices in South Glasgow cancer services. It was assumed that clinical pharmacists worked in similar ways across NHSGHC following a mostly linear workflow pattern, completing a task before starting a different task.

Table 2.1 Task based-data collection form for process mapping

	Task 1	Task 2	Task 3	Task 4	Task 5 to 10
Patient 1					
Patient 2					
Patient 3					
Patient 4					
Patient 5					
etc					

3. High level process mapping was undertaken using a flowchart. Flowcharts provide clear visual representation of processes and are used to document decision making activities. The process maps were written in longhand on the visits then converted to task based process maps using Microsoft Visio®.
4. A series of questions was prepared to ask the clinical pharmacists during the observation period (Table 2.2). The questions asked about activities, resources, access to technology, multi-professional interactions and documentation.

Table 2.2 Questions for clinical pharmacists

Question
How is your work generated?
What documentation do you use?
How much rework do you do?
What is the approximate time taken for each task?
Do you think this is being done by the appropriate person?
Can similar work be pooled?
Can you share staff & resources?
What do you do with your documentation?
What are the care transitions?
What are the current processes for transfer of information on medicines between treatment locations?
What IT resource is available - number of clinical applications used, access to PCs, wifi availability?

5. The study site clinical pharmacists (GRI and WIG) were shadowed and observed in December 2013. Observations were conducted on two weekdays between 9.30am and 1pm. Clinical pharmacy processes, workflow and identification of the actual activities performed by clinical pharmacists were undertaken in real time.
6. The process map for the New Victoria Hospital cancer service was written in December 2013. This is the investigator's clinical base and

was self reported. The cancer process map was validated by two senior/lead cancer care pharmacists working in different hospital sites.

7. A debrief took place at the end of the day after the external visits were completed. Adequate time was factored in for questions and discussions of the next steps. The debrief and feedback took place for two reasons: it gave the investigator a final opportunity to clarify roles, responsibilities and interactions between clinical pharmacists; and allowed input from several external site clinical pharmacists who were not directly observed on the visits and who deliver direct patient care in wards which were downstream from the receiving units.
8. The process maps were compared to identify:
 - variations in clinical practice
 - unnecessary steps
 - duplication of effort
 - constraints
 - steps that contribute to patient care
 - steps that do not contribute to patient care
 - opportunities for improvement
 - new skills needed
 - handoffs
 - bottlenecks in process (what takes the longest to complete)
 - any parallel processes
 - how clinical pharmacists use care plans/create patient-centred documentation

2.5 Results

From the observed patient flow through the external sites (GRI and WIG) the in-patient pathway can be broken into five broad sections from admission to discharge/death (Figure 2.1). The clinical pharmacist's input is variable at each of the sections and is at its maximum between *Prescribe* and *Transfer/discharge/death*.

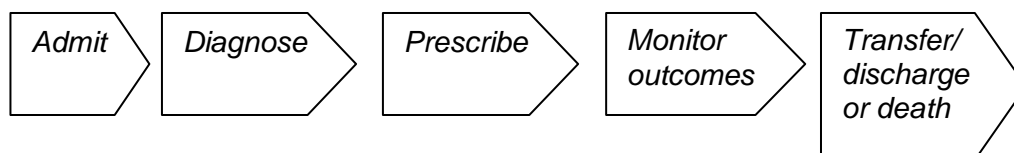


Figure 2.1 In-patient pathway for hospitalised patients

The three study sites had varying demographics (Table 2.3).

Table 2.3 Study site summary data

Site	Grade of pharmacist	Pre-visit preparation	Number of patients observed	Paper or e-systems	Access to mobile technology
GRI	7 & 8a	N	10	P	N
WIG	6	N	5	P	N
NVH	8b	Y	5	Both	Y

After observation of the first patient in GRI, it was apparent that the task-based data collection form was not suitable for the workflow in an acute receiving ward. Lack of access to computers and the disparate nature of the location of patient documentation involved jumping backwards and forwards between tasks in a haphazard and chaotic manner. Processes were not linear and it was challenging for the pharmacists to complete one task before moving on to another task. Workflow was regularly interrupted by other members of the healthcare team with questions and the continued need to log on/log off of shared ward computers. Instead of using the data collection form, processes and tasks were captured in long hand.

2.5.1 Medical Acute Receiving Unit, Glasgow Royal Infirmary (GRI)

Glasgow Royal Infirmary was visited on 6th December 2013. There were four pharmacists allocated to this unit (1x Band 8a team lead, 2x Band 7, 1x Band 6). The pharmacists observed were a Band 7 pharmacist and an 8a pharmacist, both experienced pharmacists. There were 68 beds and six high dependency beds. Medical care in the Acute Receiving Unit is delivered by discrete medical teams according to their speciality. The Medical High Dependency Unit and the Medicine for the Elderly area were treated as two separate units during the visit. Medical, nursing and medicines documentation were in constant use by multiple healthcare professionals and stored in various locations, often in a different area from the patient.

The pharmacists arrived on the ward without having completed any preparatory work such checking the ward in-patient list for new admissions or checking results of critical tests. A daily paper pharmacy screening plan is used by the pharmacists to indicate which patients have been seen. New admissions were identified by checking write-on/wipe-off bed boards located at the nurses work stations. The pharmacists prioritised new admissions to the unit but every patient was seen. The pharmacists did not have laptops or access to their own PCs. Patients in this unit did not have a pharmaceutical care plan written and the pharmacists did not use any pharmacy records which are separated from the in-patient documentation. Care issues were written directly into paper medical case notes. There was no formal handover to the downstream wards for patients who were transferred out of the receiving unit.

The pharmacists were observed in all their tasks for up to five patients each. There was commonality among the tasks and variation in the time taken to complete a task, mostly depending on the access to a computer. There was a mix of doing medicines reconciliation and verifying medicines reconciliation. The time taken with each patient ranged from less than 10 minutes to greater than 30 minutes depending on the reasons for admission and the individual

patient care issues. The shared ward PC was used by the pharmacists to access patient's records and there was a need to walk back and forth many times between patient's rooms and the nurse's station. Some patients had to be seen twice when the ward round was in progress as patient's documentation was in use by medical staff. For every patient the pharmacists confirmed the reason for admission, their list of medicines, any high risk medicines requiring for example therapeutic drug monitoring and checked relevant critical tests such as biochemistry and haematology tests. The pharmacists produced a list of tasks for the junior doctors e.g. change a drug dose, withhold a drug, and discussed any medicines discrepancies with the medical team. Missed doses or other medicines supply problems were discussed with the ward nurses. Tracking patients was very time consuming. The visit pre-dated implementation of *TrakCare* and *PharmacyView* and this was addressed after implementation of the patient management systems.

Each task was documented by the investigator without times being attributed. The reason for this was due to the interruptions and requirement for the pharmacists to switch between patients. The aim of this study was to assist with making the case for mobile technology and so calculation of the precise time taken per task was of less importance than the process mapping.

A team debrief was conducted in GRI which was attended by clinical pharmacists from Bands 6 to 8a. At the debrief there was a frank and open discussion of the investigator's observations and the site clinical teams were encouraged to challenge current workflow practices and suggest ideas for improvement based on the observation of the pharmacists at the study sites (Table 2.4).

The completed process maps captured the activities carried out. The actual time taken to complete each activity was not included in the maps (Figures 2.2 and 2.3). The activities were presented in the maps as linear due to the limitations of the software.

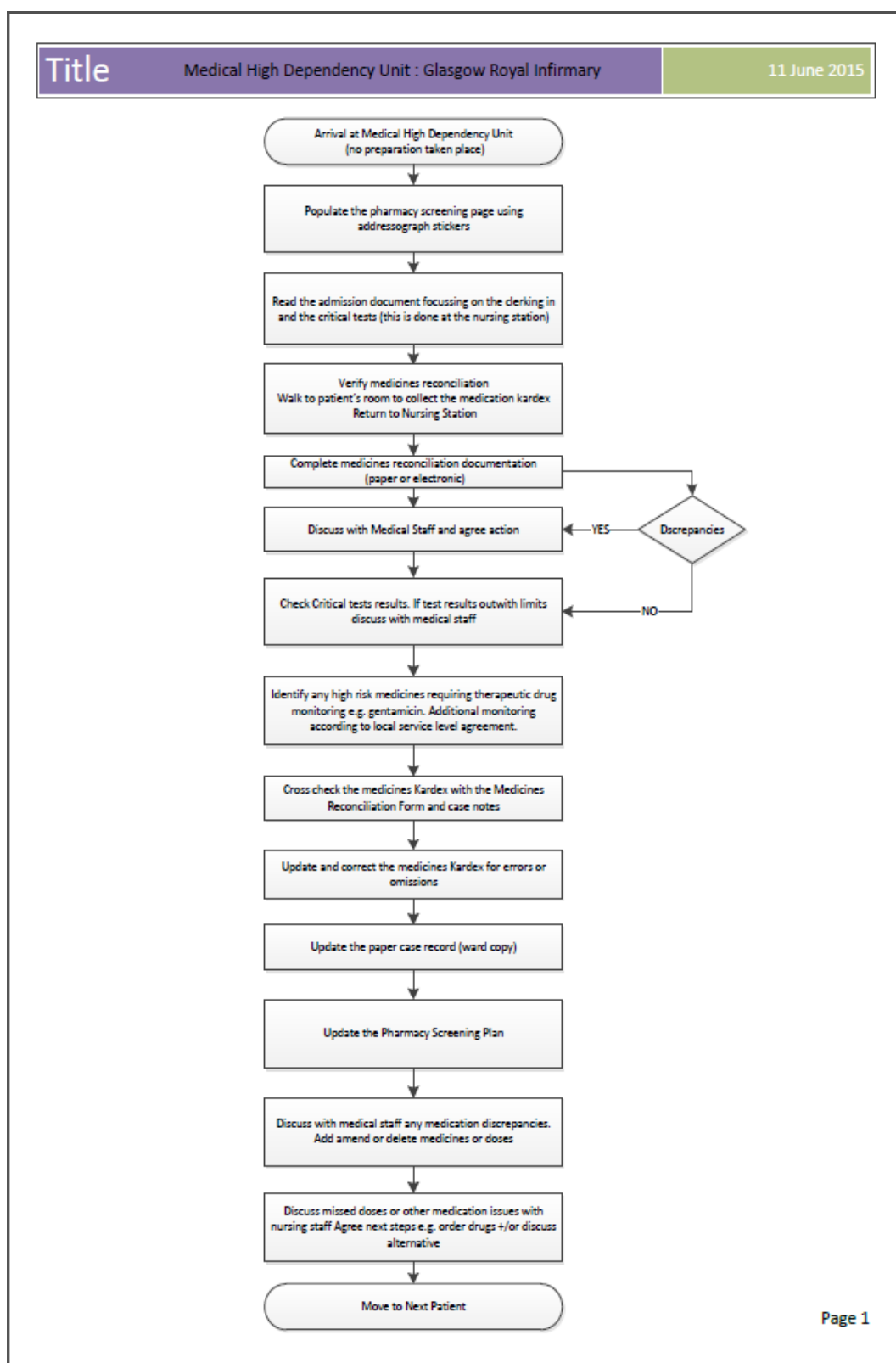


Figure 2.2 Medical high dependency unit process map, GRI

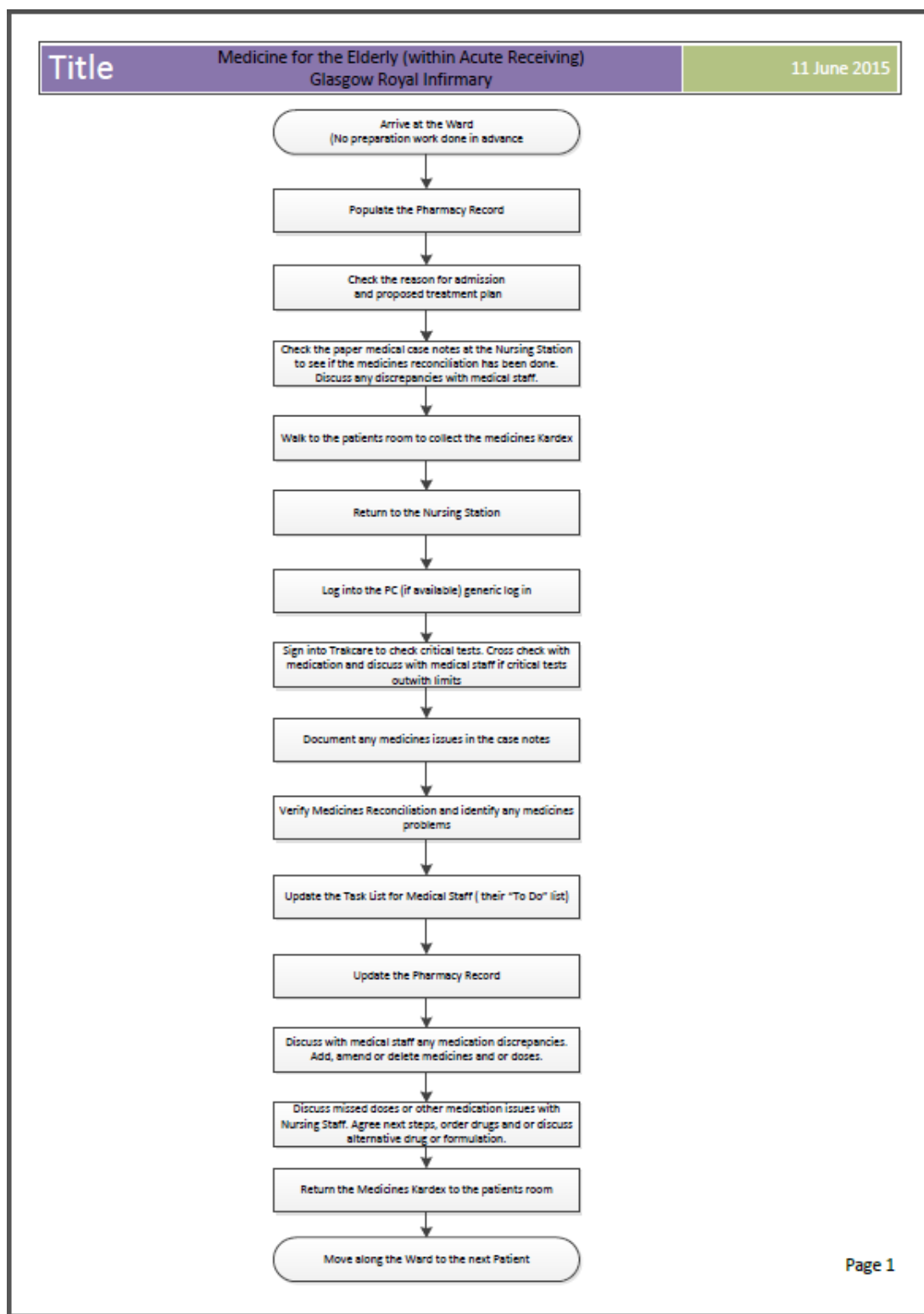


Figure 2.3 Medicine for the elderly (acute receiving) process map, GRI

2.5.2 Surgical Acute Receiving Unit, Western Infirmary Glasgow

The Western Infirmary was visited on 9th December 2013. There were five pharmacists allocated to this unit and they were a mix of Bands 6, 7, and 8a all working to different whole time equivalents on the unit. The unit was a mix of elective and emergency surgery with approximately 20 admissions per day. The bed configuration was 32 beds for emergency trauma and orthopaedics; 46 elective and emergency vascular beds and 62 general surgery beds. Elective patients were seen at surgical pre-assessment clinics. Some patients were transferred to Gartnavel General Hospital two out of every three weeks. The clinical pharmacy handover for these patients was a faxed patient list.

Surgical care was delivered by medical teams linked to consultant and speciality. Medical, nursing and medicines paper documentation were in frequent use by multiple healthcare professionals and stored in various locations, often in a different area from the patient. This was similar to processes observed in acute medicine at GRI. If a patient was in theatre, the documentation accompanied the patient and was not available for the clinical pharmacist. There was variation in each ward with respect to use of the medical notes, kardex and recording charts.

The pharmacists arrived on the ward without having completed any preparatory work such as checking the ward in-patient list for new admissions or checking results of critical tests. There was no mobile IT kit for use by the surgical pharmacists and there was no wifi in the surgical tower block. A daily paper pharmacy patient log was started every day to record which patients were seen. New admissions were identified by checking write-on/wipe-off bed boards located at the nurse's stations. Patients in this unit did not have a pharmaceutical care plan written. Care issues were written directly into paper medical case notes. The units had two trolleys containing medical notes and three trolleys containing nursing notes. The

clinical pharmacy handover for the downstream wards was the handwritten patient log. The length of stay was 24 – 48 hours with 1 – 20 discharges per day.

The pharmacist who was observed was a Band 6 pharmacist recently appointed to the team and who was very inexperienced. The pharmacist was observed in all the tasks for three patients. Processes were not linear and rarely did the pharmacist complete one task before moving to another. Part of this was due to the pharmacist being less experienced than those observed in GRI and becoming distracted. This pharmacist also had to frequently log-on/log-off shared ward computers. Each task was documented by the investigator and time taken was attributed to some tasks. The average time taken with each patient was approximately 30 minutes but the total time taken to complete each patient could not be calculated accurately due to interruptions and the requirement for the pharmacist to switch between patients. The shared ward PC was used by this pharmacist who, on the day of this study, did not have access to the Clinical Portal. This was a major barrier to completing tasks and led to an IT lock-out of greater than 30 minutes. There was a requirement to walk back and forth many times between patient's rooms and the nurse's station. As in GRI, the pharmacist confirmed the reason for admission, the patient's list of medicines, identified any high risk medicines and checked relevant critical tests. Any medicines discrepancies were discussed with the doctors and missed doses or other medicines supply problems were discussed with the ward nurses.

As observed in GRI, tracking patients was very time consuming which was addressed with the implementation of *TrakCare* and *PharmacyView*. The team lead (Band 8a) was debriefed after the observation was concluded.

The completed process map captured the activities carried out. The actual time taken to complete each activity was not included in the map (Figure 2.4).

The activities were presented in the maps as linear due to the limitations of the software.

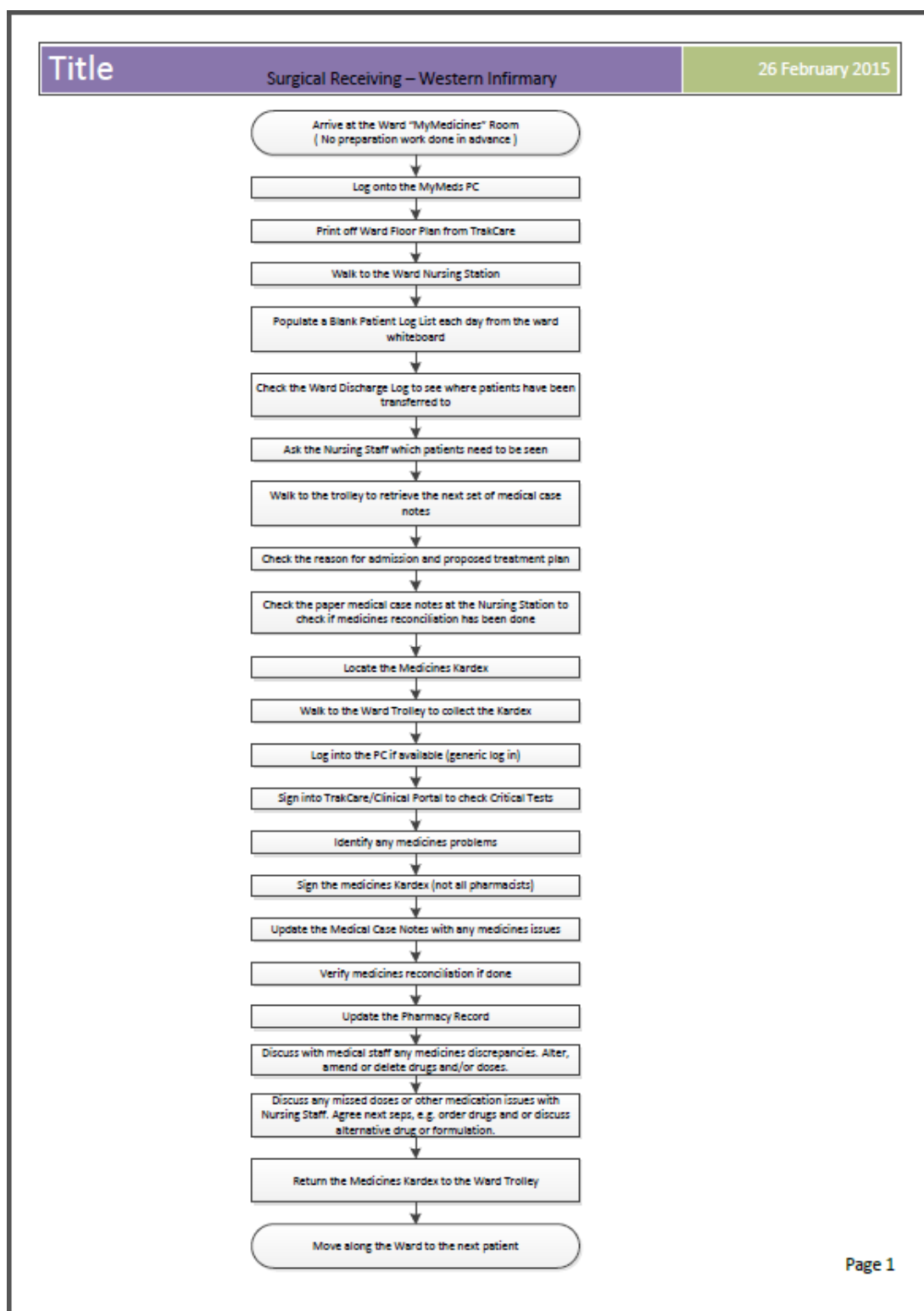


Figure 2.4 Surgical acute receiving unit process map, WIG

2.5.3 Cancer day case clinics (Clinics B, I, P), New Victoria Hospital

Patients who received day case and out-patient systemic anticancer therapy (SACT) attended Clinics B, I and P in the new Victoria Hospital. Clinic P was the day ward and patients' length of stay varied from less than 30 minutes to 6 – 7 hours depending on the nature of the prescribed SACT. Patients were appointed to attend the clinics at set times and so this workload was planned and scheduled. The cancer care pharmacists printed the clinic lists 1 – 2 days in advance and identified which SACT the patient was currently prescribed. New patients were identified from the clinic lists. The trigger to open/start a pharmaceutical care plan was receipt of a SACT prescription. The cancer care pharmacist verified all SACT prescriptions prior to dispensing in accordance with national standards for SACT safety and quality. There is a NHSGGC standard operating procedure for verification of SACT prescriptions and this reduced variation in the tasks performed by the cancer care pharmacists. Approximately 95% of all the South Glasgow cancer patients being treated with SACT had a pharmaceutical care plan. The exceptions were patients prescribed simple oral therapies such as tyrosine kinase inhibitors and hydroxycarbamide.

All pharmaceutical care plans were electronic and some were started in advance of the patient appointment. This permitted advance identification of potential pharmaceutical care issues by checking critical tests and the Electronic Care Summary where medicines prescribed by the GP are listed. Work activities were undertaken in a linear manner with limited need to move around the clinical area to source documentation. Prescriptions and case notes were paper based but the chemotherapy prescribing system was electronic, using the Chemocare® system.

The NVH process map was critically examined by very experienced senior cancer care pharmacists from NHSGGC who concurred with the activities and processes. The completed process map captured the activities carried

out. The actual time taken to complete each activity was not included in the map (Figure 2.5).

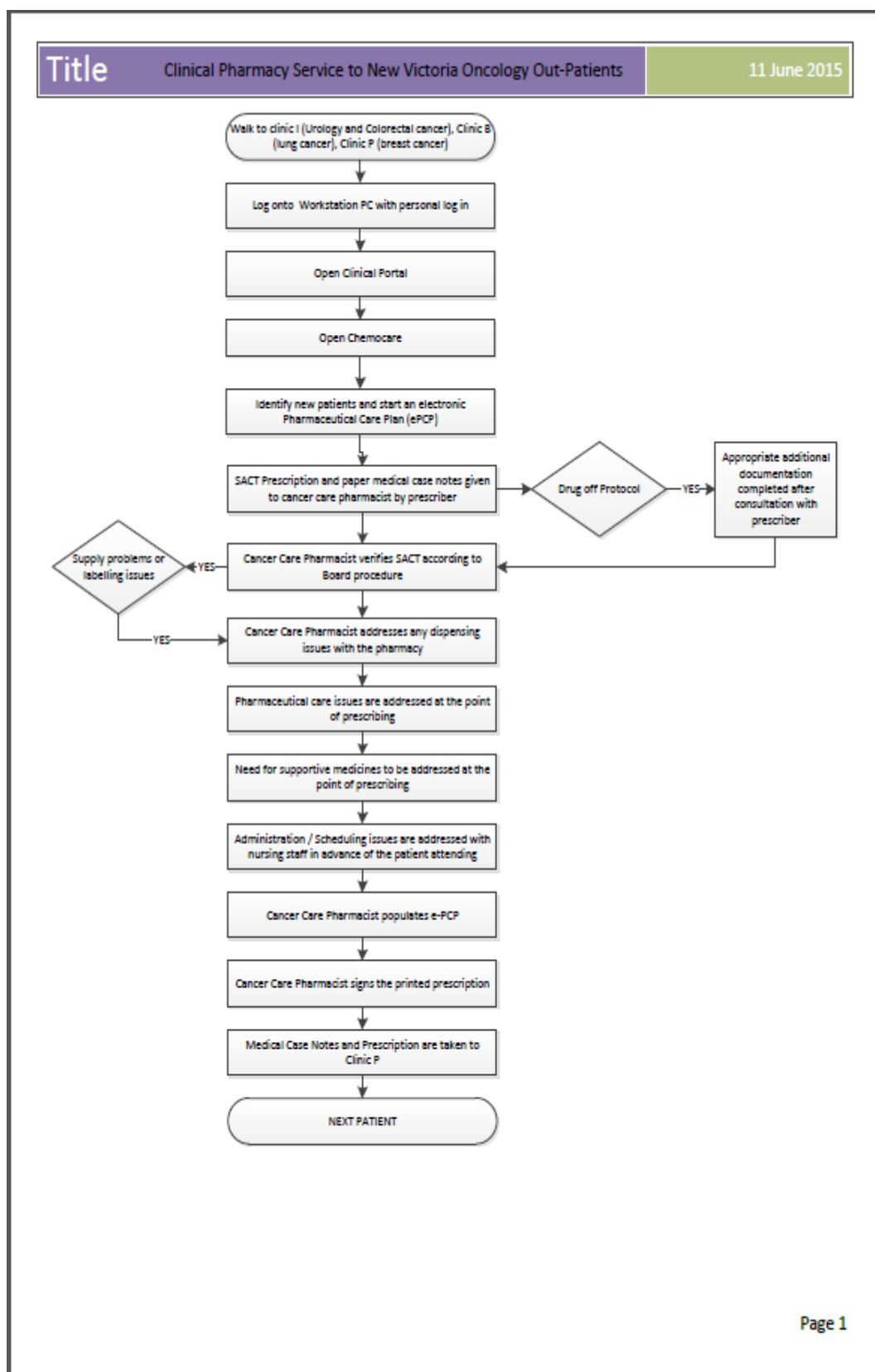


Figure 2.5 Cancer day case clinics process map, NVH

2.5.4 Analysis and comparison of the process maps

The process maps from GRI and WIG were compared to the NVH process map to identify commonalities and deficiencies and to reflect on where e-health solutions could change clinical practice and improve patient care and workflow. Clinical activities in the acute receiving units were broadly similar and were focussed on the admission and discharge or transfer of the patient. The pharmacists identified the patients who had been admitted and the reason for the admission since the last pharmacist visit to the ward. The next tasks undertaken by the receiving unit pharmacists were medicines reconciliation and cross checking medicines with laboratory tests. In contrast, day case SACT activity in NVH was focussed on verification of SACT in accordance with national standards. The day case patients in NVH had appointed time slots and the reason for their attendance was to receive SACT. Regardless of the actual activity performed, each clinical pharmacist required unimpeded access to electronic clinical systems to gather information about their patients to enable them to deliver pharmaceutical care efficiently and this was a key challenge for the teams working in GRI and WIG.

Clinical pharmacists in the receiving units did not use pharmaceutical care plans or indeed any standard pharmacy documentation whereas the cancer care pharmacists used an electronic pharmaceutical care plan to document their input and care for all the cancer day case patients. Cancer care pharmacists in Scotland have used a generic standard pharmaceutical care plan for a number of years and care planning is embedded into cancer clinical practice. At the time of this study NHSGGC clinical pharmacy was working with NHS IT to design a generic electronic care plan for inpatient use. Standardisation of documentation was underway and it was recommended that the receiving unit teams started to use e-forms to record their interventions. The cancer team had switched to e-forms in 2010 and the benefits of recording once in a single accessible record were evident when examining time to complete a single patient interaction.

There was significant variation observed in the time taken to complete patient tasks. This was related to work place factors (access to IT, space, inability to work in a linear manner), personnel (newly appointed band 6 vs. experienced band 7/8a), interruptions, complex medication issues/multiple co-morbidities and uptake and use of available IT systems. One of the pharmacists was very inexperienced and would have benefited from a more structured approach to planning workload. e-Health could have supported this by way of electronic patient worklists which focus the team on defined tasks. The time taken by the cancer team to care plan a patient has less variability. The cancer team created an electronic patient care plan at the first cycle of SACT which is used throughout the cancer journey, often many years. The initial work took between 10 – 20 minutes. Some subsequent patient interactions took less than 5 minutes due to the fact that the information required to verify SACT was already collated and presented in one single electronic document.

The process mapping helped identify variation in documentation, time taken to do tasks and uptake of existing e-health solutions. NHSGGC clinical pharmacy services had standards and operating procedures for the delivery of pharmaceutical care and significant variation in practice would be an unexpected finding. The LCPs did not support variation in the way clinical pharmacists work as any deviation from the standards is not desirable. Natural variation is acceptable and often cannot be eliminated e.g. differences in presenting complaint, patient demographics. Artificial variation, however, is created by e.g. the systems used and factors such as working patterns, and affects workflow much more than natural variation.

2.5.5 Recommendations for service improvements

The results from analysis of the process maps were collated into a series of recommendations (Table 2.4). The site LCP was given a verbal report after each visit for individual consideration of changes to practice.

Table 2.4 Recommendations for service improvements

Recommendation	Rationale	Status
Prepare for the ward prior to leaving pharmacy and pre-populate pharmacy patient logs.	Will identify new and current patients and allow access to own PC in department.	Some initial preparatory work was started after implementation of <i>TrakCare</i> .
Batch tasks for one pharmacist to do e.g. checking critical tests.	This mirrors the junior doctor model which serves the ward round well and would require access to one PC.	Not implemented.
Agree which medicines reconciliation duties are performed by clinical pharmacists. This will reduce variation and create capacity. Verification of medicines reconciliation contributes to patient care.	Some pharmacists performed the full medicines reconciliation process whereas other pharmacists verified the medicines after reconciliation was completed by a doctor.	LCP instruction to their team is to verify medicines reconciliation only.
Use Clinical Portal e-forms to document specialist medicines prescribed by other teams. This will help with avoiding duplication.	There are multiple gaps in access to information on medicines that patients might be prescribed by specialist services such as mental health, cancer, Homecare, infectious diseases, renal and addictions services. Documentation of this once in an e-record will provide this information for other clinical teams.	Ongoing
Consider electronic documentation of care issues for downstream ward clinical pharmacists.	Pharmacy continuation electronic forms are available for use via Clinical Portal.	Uptake is ongoing
Consider use of Clinical Portal to create shared work lists of patients with ongoing care needs. This will assist with tracking patients.	A work list can be created on Clinical Portal. Up to six different lists can be created by one individual. Each list is permitted to contain up to 20 patients.	Not implemented. <i>PharmacyView</i> was created to manage patient flow and track patients.

2.6 Discussion

Principal findings

The key results from this study were lack of IT access, limited engagement with Clinical Portal and limited or no uptake of e-forms to document clinical pharmacy activity. It was strikingly apparent during the observation of the Acute Receiving Unit's clinical pharmacists that their lack of access to a dedicated PC/laptop increased the time taken to complete tasks and hindered them being able to complete a patient interaction before moving onto the next patient. The pharmacists were frustrated with the lack of IT kit and the competition for PC access with other members of the healthcare team. The length of time to log-in was raised and it was noted that there was limited tolerability of the pharmacists using the ward PCs by the nurses and the ward clerk.

The clinical pharmacists agreed that if they had their own laptops they would utilise the Clinical Portal functionality and become more proactive in seeking e-health solutions for service improvement. As discussed in *Chapter One*, the cornerstone to delivery of pharmaceutical care is the care plan or therapeutic plan. It is vital to have all the relevant clinical patient information readily available to construct a plan and, in this era of electronic systems, all healthcare professionals delivering care must have access to clinical information.

There was limited variation observed between the receiving units. In contrast, the variation observed between the receiving units and the NVH services was marked. This can be explained in two ways. Firstly, the NVH workload is planned and scheduled work with allocated treatment slots. Patients are expected to attend at their allocated time and there is advance notice of their appointments thereby allowing advance planning of care. In contrast, the receiving units are all unscheduled care environments where there is no ability for anticipatory planning. Secondly, the variation can be explained by the access to PCs in the NVH by the cancer care pharmacists

versus the limited access to PCs by the acute receiving pharmacy teams. The cancer care pharmacists can choose to take their work to a quiet area where there are fewer interruptions and competing interests. The ability to plan work resulted in the cancer care pharmacists, on the whole, completing a patient interaction before moving to the next patient.

During the debrief, some pharmacists indicated that they were not familiar with the full functionality of the Clinical Portal. If the case for mobile technology was successful, it was clear that directed training was needed by a number of clinical pharmacists to raise awareness of Clinical Portal functions and to create capability in using the system to its full potential.

Comparison with other studies

Cummings *et al* (2008) conducted a comparative workflow study of mobile technology in the paediatric intensive care unit at Children's Hospital in Omaha, Nebraska. The pharmacists had access to a fixed desktop PC and for this study, were given a mobile Motion C5 tablet device. Use of the mobile device resulted in fewer absences from the ward round and increased time dedicated to direct patient care. Multiple log-ins were not required and pharmacist satisfaction with the mobile device was reported as "satisfied to extremely satisfied". Cockerham (2009) reports similar enhanced patient care, efficiencies and satisfaction from a pilot project using a tablet computer in the bone marrow transplant unit of the Louisiana State University Health Sciences Centre. These studies demonstrated the value of dedicated pharmacist's mobile IT kit and this was echoed during the process mapping visits. The frustration and time spent in locating a PC and logging in/logging out multiple times was articulated by the study site pharmacists. In contrast, the NVH site clinical pharmacists has access to both desk top PCs and a laptop and the increased level of efficiency which that afforded was evident.

Implications for pharmacy practice

A take home message received from the clinical teams observed in the process mapping study was that any change to practice should not increase the time taken for them to perform their duties. Or, at the very least, if more time is required, there must be tangible benefits for both the pharmacists and patients. This was a challenge as the cancer care pharmacists recognised that creation of an electronic care plan took more time than a paper one but the e-version was a dynamic document and was available to the wider NHS team which brought added value to the delivery of pharmaceutical care to patients and the multidisciplinary team.

2.7 Limitations

There were limitations with the process mapping exercise. Only 3 sites were included and it cannot be assumed that this is representative of clinical pharmacy practice in the totality of NHSGGC Acute Services. However, the commonality seen in the receiving units suggests that variation in the approach to clinical pharmacy tasks might be less than expected.

The process maps were high level maps and did not include relationships between the clinical pharmacists and other healthcare professionals. The number of years qualified/level of pharmacists' hospital experience and staffing levels on the days of the study were not factored in. The precise time taken per task was not measured as it became clear that this would have been too challenging to measure with any degree of accuracy. A pre-visit pilot of process mapping in an Acute Receiving Unit would have been useful and was not done due to logistical reasons.

The observations and process mapping was conducted by a pharmacist external to the in-patient sites and not by the team themselves. Acceptability of areas for improvement might be enhanced by an internal study.

This study did not set out to determine which device to use and the choice of equipment will be determined by the institution's IT department, cost and the ability of a device to support the multiple NHS IT platforms required to deliver direct patient care. Regardless of whether a laptop or tablet device is used, engagement with the user is essential to provide assurances of system capability and ease of use.

2.8 Conclusion

Direct observation and process mapping resulted in a visual representation of some NHSGGC clinical pharmacy services and was used as a starting point for service improvement utilising e-health. The hypothesis that unrestricted access to personal mobile technology increased the efficiency of hospital clinical pharmacists and is an enabler of pharmaceutical care was correct. Also at this time, a system of clinical pharmacy triage and referral using paper to track patients through acute hospitals was piloted in the Victoria Infirmary. The additional time required by pharmacists to follow-up patients using paper was the final catalyst for the purchase of IT kit. A detailed paper was submitted to NHSGGC Pharmacy Executive in 2014 outlining a strong case for mobile technology (Appendix 2). In 2014/15 NHSGGC purchased over 100 laptops for use by the clinical pharmacists. Work is ongoing with NHS IT to ensure that all clinical areas maintain wifi connectivity and the Board paper-light strategy has enabled development opportunities for further electronic pharmacy documentation.

2.9 Future work

NHSGGC underwent significant changes in 2015 with the closure of the Western Infirmary, the Victoria Infirmary, the Southern General Hospital and relocation of sections of inpatient activity at Gartnavel General Hospital. Most west and south Glasgow adult inpatient activity was relocated to the

Queen Elizabeth University Hospital (QEUH) campus. Mobile IT kit was deployed to the clinical pharmacy teams who relocated to the QEUH and a repeat of this investigation would be valuable to conduct a benefits analysis to understand if the e-health solutions changed what pharmacists did and improved the delivery of pharmaceutical care. There are confounding variables to conducting a reproducible study, most notably the electronic patient management and tracking systems (*TrakCare, WardView and PharmacyView*) which were embedded into clinical practice after 2013 when this study was conducted and have changed the way in which clinical pharmacists work for the better.

Socio-technical qualitative research would be of interest to explore attitudes of pharmacists to e-health opportunities and to understand reasons behind uptake and acceptability of IT in general. A robust exploration of how we interact with technology in real time would be valuable and could contribute to functionality requirement gathering for future IT systems ensuring systems meet the requirements of the end users.

Chapter 3

Lung cancer

3.1 Lung cancer

Lung cancer is the most common cause of cancer deaths worldwide resulting in 1.59 million deaths in 2012 (Ferlay *et al.* 2012). The risk of developing lung cancer increases with age with the median age at diagnosis is 70 years old. Thus the population is a group of mostly elderly patients who have multiple co-morbidities making them increasingly susceptible to treatment toxicities. Early stage non-small cell lung cancer (NSCLC) (stages I, II and IIIa) and some limited stage small cell lung cancers (SCLC) are considered to be operable and resection of the tumour offers the only cure. Most patients however present with locally advanced or metastatic disease which is inoperable (NSCLC stage IV; SCLC extensive disease). Patients with advanced disease who are considered fit enough (Performance Status 0 – 2) are offered palliative systemic anticancer therapy (SACT) or palliative radiotherapy to improve symptoms and increase overall survival (SIGN137 2014). In the UK approximately 58% of patients with lung cancer receive SACT (National Lung Cancer Audit 2015). Development of at least one SACT-associated toxicity is expected and many patients experience several toxicities (Carlotto *et al.* 2013). Careful monitoring and early intervention of treatment associated toxicity is recommended (Socinski *et al.* 2003).

The West of Scotland lung cancer patient pathway is complex (Appendix 1). Patients are cared for by many speciality teams from hospitals and also engage with palliative care services, community pharmacy and their GP. There are a number of common toxicities associated with lung cancer SACT and knowledge of these is based on adverse events reported in clinical trials (Appendix 3). However, clinical trials generally exclude patients with multiple co-morbidities and do not therefore reflect the “real-life” patient populations treated in cancer centres and units. To enable delivery of a comprehensive package of pharmaceutical care it is important to firstly identify the SACT toxicities experienced by patients which will help define the pharmaceutical care needs of this patient population. Pharmaceutical care can be delivered

by community pharmacists but little is known about the epidemiology of SACT toxicities in the community and potential interventions to address these, which raises the questions: what are the typology of SACT-associated toxicities experienced by community based patients and what are the associated pharmaceutical care issues (PCIs)?

3.2 Hypothesis and aim

The hypothesis was that patients who received SACT for lung cancer experience toxicity, some of which could be managed in primary care by community pharmacists.

The aim of this study was to investigate a lung cancer population treated with SACT in the New Victoria Hospital (NVH), South Glasgow, over one calendar year in terms of choice of SACT, toxicity, pharmaceutical care issues (PCIs) and episodes of unscheduled care to understand the potential for community pharmacists to deliver aspects of cancer pharmaceutical care including toxicity management.

3.3 Methods

The study was carried out in the NVH in Glasgow in 2013. One hundred and twenty patients received a SACT intervention for lung cancer between the dates 1st January 2012 – 31st December 2012.

1. An alphabetical list of all patients who received lung cancer SACT was entered onto a spreadsheet. Data included patient's name, unique patient identifier, SACT regimen and date of treatment.

2. Patients in clinical trials and patients with mesothelioma were excluded as their treatment might not involve SACT.
3. Every second patient was chosen for inclusion in this study to give a breadth of regimen and tumour type.
4. An Excel[®] data collection form was devised after consultation with project supervisors and piloted in 10 patients after which minor revisions were made. Data collected included demographics, prescribed SACT, dose modifications, toxicities, PCIs, admission to an NHSGGC hospital, length of stay and reason for admission. Each patient was entered into a new numbered row.
5. Fifty patients were included in the study.
6. The unique patient identifier used was the Community Health Index (CHI) number. This is a 10 digit unique patient identifier used throughout NHS Scotland. This prevented duplication of data entry.
7. Data were collected from existing sources. Demographics were identified by interrogating the electronic patient record (EPR), a web-based clinical record. Sources of information used included referral letters and laboratory and radiology reports.
8. Patients attended a SACT pre-assessment clinic in the NVH 24 hours in advance of their next scheduled SACT treatment and were assessed for suitability for SACT by a prescriber. Each episode of SACT was identified from the SACT spreadsheet and cross-referenced with the electronic SACT prescribing system (Chemocare[®]) to confirm the actual date of treatment.

9. Toxicity was obtained from clinic letters dictated by prescribers after patient consultations and cross-referenced with the date of treatment listed on the SACT spreadsheet. Prescribers assigned a grade of toxicity according to the National Cancer Institute's Common Toxicity Criteria (Appendix 3).

10. PCIs were identified from electronic cancer pharmaceutical care plans. Each patient had a care plan which was stored in the EPR. PCIs were recorded at each episode of SACT.

11. Episodes of unscheduled care, i.e. admission to an NHSGGC hospital, were identified from the Clinical Summary contained within the EPR which is a list of attendances and admissions to NHSGGC hospitals and clinics.

12. Reasons for admission and length of stay were identified from the Immediate Discharge Letter (IDL) which is a communication sent to GPs.

Ethical approval

Ethical approval was not required for this study as no intervention was made. NHSGGC Board information governance processes were applied in data handling, collection and storage to protect patient identifiable data. Data were stored on an NHS desktop computer in a password protected folder located within the main NHS staff server.

3.4 Results

3.4.1 Demographics

Fifty patients were included in the study (Table 3.1). Twenty-nine patients (58%) had NSCLC; one patient had large cell carcinoma which is a subtype of NSCLC and was included in the NSCLC cohort for purposes of data analysis. Forty-five (90%) patients had their performance status recorded. All patients were performance status 0 – 2. All patients had adequate renal function pre-treatment. Twenty-eight (56%) were known to be current smokers. Cardiovascular and respiratory co-morbidities were the most common.

Table 3.1 Patient characteristics

Patient characteristics, n=50		
Age (median (IQR))	66 (38, 82) years	
Baseline weight (median (IQR))	64.5 (39, 97) kg	
	NSCLC n=30 (60%)	SCLC n=20 (40%)
Gender		
Female (27, 54%)	16	11
Smoker	16	12
Non-smoker	11	4
Not recorded	3	4
Performance status		
0	7	2
1	17	14
2	1	4
Not recorded	5	0
Baseline eGFR		
>60 ml/min	26	16
40 – 60 ml/min	4	4
Co-morbidities		
Cardiovascular	10	11
Cerebrovascular	2	1
CNS	5	1
Endocrine	7	4
Gastrointestinal	4	1
Musculoskeletal	4	3
Renal	1	1
Respiratory	9	3
Skin	2	0

Key

NSCLC: Non-small cell lung cancer

SCLC: Small cell lung cancer

eGFR: estimated glomerular filtration rate

CNS: central nervous system

3.4.2 Prescribed lung cancer SACT regimens

Ten different regimens were prescribed for first or second-line SACT during the study period (Table 3.2). The regimens were appropriate for the mix of pathologies in the study population. Erlotinib (5 patients), CAV and topotecan were prescribed as 2nd line treatment.

Table 3.2 SACT regimens prescribed during the study period

SACT (1st line)	NSCLC n=30	SCLC n=20
Carboplatin & pemetrexed	11	
Carboplatin & etoposide	1	8
Erlotinib	1	
Cisplatin/vinorelbine	4	
Carboplatin/vinorelbine	1	
Carboplatin/gemcitabine	5	
Carboplatin/paclitaxel	1	
Carboplatin	1	7
SACT (2nd line)		
Erlotinib	5	
CAV		4
Topotecan		1

Key

NSCLC: Non-small cell lung cancer

SCLC: Small cell lung cancer

CAV: Cyclophosphamide, doxorubicin, vincristine

3.4.3 SACT toxicity

SACT toxicity is graded 0-5 using the international system Common Toxicity Criteria (CTC). Toxicity was documented by hospital prescribers in their clinic letters but was infrequently graded. Further analysis of the severity of toxicity was not performed due to this being a retrospective study. Toxicity grading would be captured in any future prospective studies. Prescribers documented 12 different categories of toxicity and 83 episodes of toxicity

(Table 3.3). Thirty seven patients (74%) experienced at least one episode of toxicity. Fifteen patients (30%) reported two or more toxicities. Thirteen patients (26%) reported no toxicity, of whom, four (31%) completed the planned number of cycles and five patients received only one SACT cycle.

Table 3.3 Summary of SACT toxicity

Toxicity, any grade	Episodes of toxicity (n (%))
Haematological	18 (21.6%)
Renal	18 (21.6%)
Fatigue	10 (12%)
Nausea & vomiting	9 (10.8%)
Constipation	5 (6%)
Diarrhoea	5 (6%)
Neurological	5 (6%)
Oral	3 (3.6%)
Infection	3 (3.6%)
Skin	3 (3.6%)
Increase in liver function tests	2 (2.4%)
Decline in performance status	2 (2.4%)

Haematological: any change in neutrophils, total white cell count or platelets that delayed SACT or required a dose modification.

Renal: any episode where baseline creatinine clearance decreased by $\geq 10\%$.

Oral: any SACT-induced toxicity to the oral cavity including mucositis.

Skin: any SACT-induced cutaneous toxicity including palmar-planter erythrodysesthesia.

The frequency of occurrence of a toxicity (Table 3.4) indicated that some regimens were associated with multiple toxicities.

Table 3.4 Occurrence of toxicity by regimen

Toxicity, any grade	Regimen and occurrence of toxicity									
	Carboplatin/ pemetrexed n=11	Carboplatin & etoposide n=8	Erlotinib n=6	Cisplatin/ Vinorelbine n=4	Carboplatin n=8	Carboplatin/ vinorelbine n= 1	Carboplatin/ gemcitabine n=8	Carboplatin/ paclitaxel n=1	Topotecan n=1	CAV n=4
Haem	2	6	0	1	2	0	5	1	0	1
Renal	2	6	0	1	2	0	5	1	0	1
LFTs	1	0	0	0	0	0	1	0	0	
Nausea & vomiting	2	0	1	4	0	1	0	1	0	0
Oral	1	1	0	1	0	0	0	0	0	0
Constipation	0	1	1	0	0	1	1	0	0	1
Skin	0	0	3	0	0	0	0	0	0	0
Diarrhoea	0	1	3	1	0	0	0	0	0	0
Neurological	0	2	0	2	0	0	0	0	0	1
Infection	0	0	0	0	1	0	1	1	0	0
Decline in PS	0	0	0	1	0	0	0	0	1	0
Fatigue	0	2	1	2	3	0	1	0	0	1
Total	8	19	9	13	8	2	14	4	1	5

Key: Haem - haematological toxicity
 LFTs - elevated liver function tests
 PS - performance status
 CAV - cyclophosphamide, doxorubicin, vincristine

3.4.4 Pharmaceutical care issues

A total of 60 PCIs were recorded in the study sample's pharmaceutical care plans. The number of PCIs per regimen and the mean PCIs per patient varied however, one way ANOVA with Tukey pairwise comparison test revealed no significant difference in the mean PCIs between regimens (Table 3.5). There was a difference in the number of PCIs and the number of episodes of toxicity for the different regimens (Table 3.6). The shaded regimens in Tables 3.5 and 3.6 have an oral SACT component and the regimens in bold are entirely oral regimens. Although the patient numbers are small, differences in PCIs generated by oral and parenteral SACT can be seen (Table 3.7).

Table 3.5 Number of PCIs by SACT regimen

Regimen	Number of PCIs	Average number of PCIs per patient
Erlotinib (n=6)	16	2.6
Carboplatin & etoposide (n=9)	11	1.2
Cisplatin & vinorelbine (n=4)	10	2.5
Carboplatin & pemetrexed (n=11)	10	0.9
Carboplatin (n=8)	4	0.5
Carboplatin & vinorelbine (n=1)	3	3.0
CAV (n=4)	3	0.75
Carboplatin & paclitaxel (n=1)	2	2.0
Carboplatin & gemcitabine (n=5)	1	0.2
Topotecan (n=1)	0	0

Table 3.6 Comparison of PCIs versus toxicity by SACT regimen

Regimen	Number of PCIs	Number of episodes of toxicity
Erlotinib (n=6)	16	9
Carboplatin & etoposide (n=9)	11	19
Cisplatin & vinorelbine (n=4)	10	13
Carboplatin & pemetrexed (n=11)	10	8
Carboplatin (n=8)	4	8
Carboplatin & vinorelbine (n=1)	3	2
CAV (n=4)	3	5
Carboplatin & paclitaxel (n=1)	2	4
Carboplatin & gemcitabine (n=5)	1	14
Topotecan (n=1)	0	1

Key CAV: Cyclophosphamide, doxorubicin, vincristine

Table 3.7 Number of recorded PCIs for parenteral, oral and combination SACT across the study population

Pharmaceutical care issue	Parenteral SACT	Number of PCIs	Oral SACT	Number of PCIs	Combination oral/parenteral SACT	Number of PCIs
Gastrointestinal: nausea and vomiting; mucositis; diarrhoea; constipation	Carboplatin & etoposide	3	Erlotinib	3	Cisplatin or carboplatin & vinorelbine	7
	Carboplatin & pemetrexed	1				
	Carboplatin & paclitaxel	1				
	CAV	1				
Sepsis	Carboplatin & etoposide	1				
Skin rash	Carboplatin & paclitaxel	1	Erlotinib	6		
Renal/hepatic	Carboplatin & pemetrexed	3	Erlotinib	1	Cisplatin or carboplatin & vinorelbine	3
	Carboplatin & etoposide	2				
	Carboplatin & gemcitabine	1				
	CAV	1				
Neurological	Carboplatin & etoposide	1			Cisplatin or carboplatin & vinorelbine	2
Hypercalcaemia	Carboplatin & pemetrexed	2				
	CAV	1				
Patient education *	Carboplatin & pemetrexed	2	Erlotinib	4	Cisplatin or carboplatin & vinorelbine	1
	Carboplatin	1				
Prescribing error/dose recalculation	Carboplatin	3				
	Carboplatin & etoposide	2				
	Carboplatin & pemetrexed	1				
Drug interaction/non-formulary drug	Carboplatin & etoposide	1	Erlotinib	2		
	Carboplatin & pemetrexed	1				
Pain	Carboplatin & etoposide	1				
Total		31		16		13

* Pro-active education at cycle 1 (not due to an adverse event)

3.4.5 Unscheduled care

The choice of hospital receiving unit for an episode of unscheduled care is based on the patient's postcode and availability of beds. Only admissions to an NHSGGC hospital were identified due to lack of access to data from hospitals external to NHSGGC. Eighteen patients (36%) had one or more episodes of unscheduled care resulting in admission to an NHSGGC hospital (Table 3.8). Seventeen patients had one admission; one patient had two admissions. The range of length of stay was 1 – 23 days. The total number of days in hospital for this study sample was 103 days. Ten admissions (52%) were for infection or sepsis.

Table 3.8 Episodes of unscheduled care, length of stay and reason

Regimen	Number of patients admitted	Number of admissions per patient	LOS (days)	Cause of admission
Carboplatin & pemetrexed, n=11	4 (36%)	1 (Patient 1)	2	Neurological
		1 (Patient 2)	2	Infection
		1 (Patient 3)	1	SOB
		1 (Patient 4)	1	Pain
Carboplatin & etoposide, n=8	5 (62.5%)	1 (Patient 5)	5	Infection
		1 (Patient 6)	12	Neutropenic sepsis
		1 (Patient 7)	9	Haem, diarrhoea
		1 (Patient 8)	23	Not recorded
Erlotinib, n=6	3 (50%)	1 (Patient 9)	9	Haem, infection
		1 (Patient 10)	1	Possible DVT
		1 (Patient 11)	9	Frailty, sepsis
Carboplatin & Vinorelbine, n=1	1 (100%)	1 (Patient 12)	4	Chest pain
		1 (Patient 13)	4	Infection
Carboplatin & Gemcitabine, n=8	2 (25%)	1 (Patient 14)	6	Haem, infection
		1 (Patient 15)	4	Infection
Carboplatin & paclitaxel, n=1	1 (100%)	2 (Patient 16)	5	Haem, infection
			3	Infection
Carboplatin, n=8	1 (12.5%)	1 (Patient 17)	1	Pain
CAV, n=4	1 (25%)	1 (Patient 18)	2	Renal, declining PS
Total	18 (36%)	19	103	

Key

LOS: length of stay; SOB: shortness of breath; PS: performance status;
Haem: neutropenia; DVT: deep vein thrombosis

3.5 Discussion

This study investigated a population of patients with lung cancer treated with SACT to define PCIs and toxicities. Ten different SACT regimens were prescribed across the study population and the reasons for regimen selection were based on disease stage; pathology; performance status and patient preference.

Principal findings

The main finding of this study was the PCIs associated with SACT given for lung cancer. Sixty PCIs were recorded on cancer pharmaceutical care plans by the cancer clinical pharmacists. More PCIs per patient were observed with oral SACT than with parenteral regimens; for example, erlotinib had 2.6 PCIs per patient. This might be considered unexpected as oral SACT is often perceived as less toxic than parenteral SACT and requiring less intervention (Bhattacharyya 2010). However this was not observed with oral vinorelbine regimens and erlotinib in this study. Patients who received oral SACT were offered patient education from the cancer care pharmacist who recorded this as a PCI in the pharmaceutical care plan. The PCIs per patient for erlotinib was 2.0 when patient education was removed. Lung cancer SACT has evolved significantly over the past 10 – 15 years (Johnson *et al.* 2014). Novel therapies include orally administered tyrosine or multi-kinase inhibitors and immunotherapy. The toxicity associated with tyrosine kinase inhibitors is significantly different to conventional chemotherapy (Bhattacharyya 2010). Erlotinib, an oral tyrosine kinase inhibitor, was the regimen with the highest number of recorded PCIs. These were skin, gastrointestinal toxicity and patient education. From the clinical trials, about 50% of patients taking erlotinib experienced diarrhoea and 75% got a skin rash (Shepherd *et al.* 2005). These were generally grade 1 – 2 and required no intervention (grade 1 rash) or required a supportive medicine such as loperamide (grade 1 – 2 diarrhoea) or a topical antibiotic / steroid (grade 2 rash). All interventions were recorded as PCIs. Erlotinib has significant drug

interactions including increased drug clearance in smokers and a reduction in bioavailability when co-administered with drugs that increase gastric pH such as proton pump inhibitors (PPI) (Tarceva, Summary of Product Characteristics,

<https://www.medicines.org.uk/emc/medicine/16781/SPC/Tarceva+25mg,+100mg+and+150mg+Film-Coated+Tablets/> accessed 15.1.17). Three patients (50%) were current smokers when they were commenced erlotinib. All patients were encouraged to stop smoking and were referred to NHS smoking cessation services if they wished help and support. Patients with clinically significant gastrointestinal abnormalities were excluded from the erlotinib pivotal trial (Shepherd *et al.* 2005). None of the patients who were prescribed erlotinib had concomitant gastrointestinal co-morbidities recorded however this did not preclude the possibility of being prescribed a PPI. Lung cancer patients are often co-prescribed steroids for various indications and it is likely that they would also be prescribed a gastroprotectant. The cancer care pharmacist intervened in all cases where a patient was taking a PPI.

There were 12 different categories of SACT-associated toxicity and 83 episodes of toxicity in total. The study was not designed to identify predictive factors for toxicity and patients with lung cancer vary in their disease, co-morbidity and choice of SACT. The grade of reported toxicity was not identified in this study as few of the prescribers recorded this in their clinic letters. Of the 83 episodes of toxicity, 42.2% were haematological or renal toxicity. This reflects the use of cisplatin or carboplatin combination SACT, commonly used in lung cancer (Santos *et al.* 2015). Fatigue was reported on 10 occasions. While there is limited therapeutic intervention for fatigue, it can significantly affect patient's quality of life and concordance with oral SACT. Ten percent of toxicity was nausea and vomiting. This is lower than found in studies conducted outside the USA, which ranged from 39 – 71% (Carlotto *et al.* 2013). Patients were given antiemetics pre- and post-SACT according to the WoSCAN antiemetic policy. Complete emesis control in a population is unachievable but further intervention to support patients post-SACT could be

implemented, for example, patient education to aid concordance with the antiemetic dose schedule. These toxicities occurred when the patients were community based and so there is an opportunity for community pharmacists to provide support. Of the thirteen patients who reported no toxicity, only four completed the planned number of SACT cycles and five of the thirteen received only one cycle. It is likely that the absence of toxicity is related to fewer episodes of SACT given to this group of patients.

There were differences between the prescriber's recorded toxicity and PCIs recorded by the cancer care clinical pharmacists. There were 60 PCIs and 83 prescriber recorded toxicities. Reasons for this difference relate to the nature of PCIs and how toxicity was recorded. PCIs are the interventions for which the cancer care pharmacist had responsibility, such as patient education, drug interactions, and management of skin rash. PCIs generated in cancer care are usually the result of a toxicity graded 2, 3 or 4. The majority of grade 1 toxicities, which are dealt with by the prescribers, were self-limiting and were not captured as PCIs because only the pharmacist's interventions were recorded on the pharmaceutical care plans. A medicine-related problem was categorised as a PCI because the responsibility for that aspect of care rested with the pharmacist; it is important to note that not every occurrence of toxicity requires an intervention by a pharmacist. Conversely, the prescribers recorded all occurrences of toxicity regardless of grade, severity or requirement for an intervention. SACT toxicity, for example fatigue or thrombocytopenia, is addressed by the wider team at the clinic and may involve decision making by two or more clinical staff.

In this study there were 18 renal toxicities recorded by the prescriber but only six renal PCIs. Two PCIs and 16 toxicities were recorded for carboplatin regimens. Implementation of an electronic prescribing system (Chemocare[®]) changed the type of pharmacist intervention needed when renal function changed as Chemocare[®] recalculated carboplatin doses for changes in weight or renal function. The prescriber recorded minor deterioration in renal

function as a toxicity whereas this was not recorded by the pharmacist as a PCI unless further intervention was required.

Eighteen patients (36%) on SACT had an episode of unscheduled care within an NHSGGC hospital. The reasons for admission were varied and 52% were due to infection or sepsis. It is unlikely that any of the admissions could have been prevented because neutropenia is an unavoidable consequence of cytotoxic chemotherapy. The pharmaceutical care plan is viewable in the EPR and would provide adequate information about the patient's cancer care therapy to an NHSGGC out of hours receiving team.

Developmental opportunities for community pharmacists

In terms of targeting community pharmacist's interventions towards patients receiving SACT for lung cancer, oral SACT would be an appropriate patient group. Interventions may include patient education, self-management of skin rash and diarrhoea, and smoking cessation strategies. Community pharmacists would need to be supported to provide pharmaceutical care to patients receiving SACT. Engagement with the Schools of Pharmacy would be helpful to understand if, and where, there are gaps in undergraduate oncology education to ensure it is comprehensive enough to enable all pharmacists to deliver an enhanced role to patients receiving SACT. In addition, most community pharmacists in the UK do not have access to hospital electronic records and cancer care pharmaceutical care plans. Abbott *et al* (2014) found that a substantial proportion of community pharmacists in Canada lacked understanding of oral SACT and required education and training. Similar findings were reported by O'Bryant and Crandell (2008) who surveyed community pharmacists in the United States. They found that community pharmacists were most knowledgeable about dosing and least knowledgeable about adverse effects. These barriers could be overcome through sharing of clinical information and SACT treatment protocols which provide advice on common toxicity, drug interactions, monitoring and red flag symptoms. Broadfield *et al* (2014) developed a web-

based toolkit to support oncology and community pharmacists when dispensing oral SACT. When considering the transfer of care across boundaries, the electronic pharmacy cancer pharmaceutical care plan provides adequate information on regimen, dose, PCIs, toxicity and dates of treatment. A pilot of community pharmacist access to the EPR is underway in NHSGGC Health Board. This will enable community pharmacists to read cancer pharmaceutical care plans and will enhance communication across the interface facilitating truly seamless care. Further work to identify community pharmacists' training needs with respect to oral SACT and their preferred methods of receiving education will be described in Chapter 5.

3.6 Limitations

The sample size was small. Data were collected retrospectively and relied on accurate dictation of clinic letters and not all data were complete. There was variability in the content of prescriber-dictated clinic letters and so some toxicity may not have been recorded. In addition, the patients may not have volunteered the information. Episodes of unscheduled care in a hospital out with the study health board could not be identified from the electronic patient record therefore full capture of these data cannot be confirmed. The clinical pharmacist was not present at each of the patient's clinic appointments to record data independently of the prescribers and relied on the pharmaceutical care plans and dictated letters to extract data. The clinical pharmacy input was provided by one of two cancer care pharmacists. As they worked independently, there was possibility of variation in recording of PCIs. Any future work should be conducted prospectively at the point of prescribing.

3.7 Conclusion

The hypothesis that patients who received SACT for lung cancer experience toxicity which could be managed in primary care by community pharmacists was correct with caveats. Community pharmacists are ideally placed to support patients to self-manage less complex toxicity such as rash, diarrhoea and constipation and to intervene if a drug interaction is suspected or identified. They may need to actively question the patient to seek out more information on the patient's medical and medication needs using, for example, the WWHAM questions (Who is the patient; What are the symptoms; How long have the symptoms been present; Action taken; medication taken). Community pharmacists can reinforce concordance and provide patient education to support patients in managing their medicines. The electronic cancer pharmaceutical care plan provides information suitable for community pharmacists and should be supplemented by access to abbreviated treatment protocols to assist with early detection of toxicity and toxicity management. A shared patient record is the ideal model and the NHSGGC e-health infrastructure supports sharing of electronic patient records.

Chapter 4

Patient questionnaire

4.0 Introduction

Most patients with cancer receive systemic anticancer therapy (SACT) as a day case attendee in a hospital daybed unit. The time spent in the daybed unit ranges from 30 minutes to 7 – 8 hours every 3 – 4 weeks, and therefore patients spend longer periods of time at home than they do in hospital. Typically, most SACT is given in cycles of 21 – 28 days and patients do not have scheduled contact with the daybed unit between cycles. The common SACT toxicities are nausea, vomiting, diarrhoea/constipation, stomatitis (or mucositis), skin toxicity, neurological toxicity (paraesthesia or loss of hearing) and haematological toxicity (neutropenia, thrombocytopenia, anaemia) (Appendix 3). SACT toxicity can manifest days or even months after treatment and it is important that patients and healthcare professionals, including community pharmacists, know how to recognise and treat toxicity to ensure early and appropriate intervention. Patients are supported during treatment administration by the cancer hospital teams but as care moves closer to home, there could be a role for community pharmacists to support patients receiving SACT. *Prescription for Excellence* is NHS Scotland's vision and action plan for pharmaceutical care. There is a focus on integration of primary and secondary care and a desire to up-skill all pharmacists to deliver innovative models of pharmaceutical care (Scottish Government, 2013).

A patient questionnaire was designed to investigate the occurrence and duration of toxicities experienced in the interval between SACT, patient's requirements for medicines, use of Smartphone health Apps and the possible role of community pharmacists in supporting patients with cancer who are receiving SACT.

4.1 Hypothesis and objectives

The hypothesis was some SACT-related toxicity could be managed by a community pharmacist.

The objectives of this study were to identify, in a population of patients receiving SACT,

- The type and frequency of toxicity experienced between SACT cycles
- Where patients accessed advice
- Which medicines patients used between cycles of SACT and where they were obtained
- Possible role for the community pharmacist in supporting patients receiving SACT
- Possible use of a cancer Smartphone App

The study population was adult patients treated with SACT in a cancer daybed unit in New Victoria Hospital (NVH), South Glasgow between November 2014 and May 2015. Clinic P is the South Glasgow cancer daybed unit.

4.2 Methods

1. A two page patient questionnaire and a covering letter was prepared (Appendix 4). The questions were a mix of open and closed questions and some allowed free text responses.
2. The questions were grouped to ask about SACT toxicity, interaction with healthcare professionals and use of technology as a means of self-support. The toxicity descriptors (e.g. toe or finger nail pain or inflammation) used in the different parts of question one were written in patient-appropriate language as found in patient information

literature designed for patients with cancer. Toxicity was reported in the results using the appropriate medical terminology (e.g. paronychia).

3. The questionnaire was piloted in five patients with lung cancer after which minor revisions were made. During the pilot patients were asked the questions directly and their answers were recorded by the investigator.
4. This study did not set out to identify any differences in treatment or toxicity and a power calculation was not needed. Convenience sampling was used and the patients were sequentially included from those receiving SACT on the days that the investigator was present in NVH. The patients included were from a mix of breast, lung, prostate and haemato-oncology cancers receiving parenteral SACT and must have had at least one prior cycle of therapy. Patients at cycle 1 were excluded as they had not experienced any SACT-related toxicity at that time.
5. The questionnaire and covering letter were printed for each patient and an addressed reply envelope was included. These were attached to the patient's case notes/SACT prescription. The daybed unit chemotherapy nurses gave the questionnaire to the patients to complete while they were waiting to start their treatment. Participation was voluntary and patients could choose to remain anonymous. Completed questionnaires were returned to the investigator by the daybed unit chemotherapy nurses or by post.
6. The patient identifier used was the Community Health Index (CHI) number. This is a 10 digit unique patient identifier used throughout NHS Scotland. The investigator recorded the CHI number of each patient given the questionnaire and the date that the questionnaire was issued to prevent patients being asked to complete the

questionnaire on multiple occasions. No patient was asked to complete the questionnaire more than once. These data were not used in data analysis.

7. An Excel data collection form was devised to collate responses. Each completed patient questionnaire was entered into a new row. Each questionnaire was given a unique number to prevent multiple entries and remove the need to include patient identifiable data.
8. Data were coded for ease of analysis and recorded as numbers or NA (1 = yes; 0 = no; 99 = not specified; NA = not applicable). Where a free text answer was requested, the verbatim response was recorded.

4.3 Ethical approval and information governance

Ethical approval was sought for this study. It did not require an application to the Ethics Committee (Appendix 5).

NHSGGC Board information governance processes were applied to protect patient identifiable data (Appendix 6). Data were stored on an NHS desktop computer in password-protected folder located within the main NHS staff server.

Completed questionnaires and the list of patients issued with a questionnaire were stored in a lockable filing cabinet in the investigators office in Clinic P, NVH.

4.4 Results

The total number of questionnaires issued was 112. The study was not time limited but was closed in May 2015 after seven months of data collection when early data analysis indicated that data saturation had been reached, i.e. no new data were obtained from the patient questionnaires. Saturation in qualitative analysis can be reached on a sample size of 60 or fewer (Mason, 2010).

Sixty eight were returned, giving a response rate of 60.7% (Table 4.1). The free-text answers are collated in Appendix 7. All the patients were adult patients with an age range of 43 – 84 years. Seventy seven percent were female. Patients had one of four different cancers and received single-agent or combination SACT. All of the SACT regimens given to patients in this study were approved for use by the West of Scotland Cancer Network (WoSCAN) and no patients received unlicensed or investigational medicines.

Table 4.1 Summary of responders

Tumour type	Number N = 68 (%)	Age range (years)	Gender (female)	Systemic anticancer therapy
All tumour types	68	43 - 84	48	
Breast cancer	38 (56)	43 - 73	38	FEC/FEC-DH Herceptin TC
Lung cancer	13 (19)	55 - 74	7	Docetaxel Platinum single agent or doublet
Prostate cancer	8 (12)	57 - 84	8	Docetaxel
Not known	6 (9)	No data	No data	No data
Haemato- oncology, lymphoma	3 (4)	52 - 82	3	R-CHOP/mini R-CHOP

Key

FEC: 5-fluorouracil/epirubicin/cyclophosphamide

DH: Docetaxel/Herceptin (trastuzumab)

TC: Docetaxel/cyclophosphamide

R-CHOP: Rituximab/cyclophosphamide/doxorubicin/vincristine/prednisolone

Patients indicated that they had experienced a range of toxicity of different durations between their SACT cycles (Table 4.2).

Table 4.2 Occurrence and duration of toxicity between SACT cycles

Toxicity	No. of patients (n = 68)	Duration (days)	Tumour types
Mucositis	34 (50%)	2 - 10 days 10 days: FEC/docetaxel Herceptin regimens	Breast = 24 Lung = 5 Not known = 5
Nausea	23 (33%)	1 - 14 days 14 days: FEC-D	Breast = 16 Lung = 4 Lymphoma = 1 Not known = 2
Constipation	23 (33%)	1 - 21 days 21 days: carboplatin	Breast = 11 Lung = 5 Prostate = 4 Not known = 3
Sore or dry eyes	21 (30%)	2 - 7 days 7 days: docetaxel and R-CHOP	Breast = 14 Lymphoma = 1 Lung=1 Prostate= 3 Not known =2
Diarrhoea	16 (23%)	1 - 6 days 6 days: docetaxel containing regimens	Breast = 13 Prostate = 1 Lymphoma = 1 Not known = 1
Neuropathy	16 (23%)	2 - 21 days 21 days: FEC	Breast = 10 Lung = 4 Lymphoma = 1 Prostate = 1
Infection	10 (14%)	All reported one day	Breast = 9 Lung = 1
Vomiting	8 (11%)	1 - 10 days 10 days: TC	Breast = 6 Lung = 1 Lymphoma = 1
Skin rash	8 (11%)	Not recorded - 7days 7 days: docetaxel	Breast = 5 Prostate = 1 Not known = 2
Paronychia	8 (11%)	1 - 7 days 7 days: docetaxel regimen	Breast = 6 Lung = 1 Not known = 1
Problems obtaining medicines	3 (4%)	Not known	Breast = 1 Lung = 1 Lymphoma = 1
Problems swallowing medicines	2 (4%)	Not known	Breast = 1 Lung = 1

Sixteen patients (23%) used the *Other* option (free text responses). These patients had breast cancer (n = 9); lung cancer (n = 1); lymphoma (n = 1); prostate cancer (n = 3); or chose to remain anonymous (n = 2). Their

responses included headache; bone or muscular aches; nose bleed; dyspepsia; hand & foot syndrome; extravasation and urinary tract infection.

In the questionnaire the patients were asked who, if anyone, they had sought advice from between SACT cycles. Thirty five (51.4%) patients from the study population sought advice. A number of different sources were used including non-healthcare professionals. Advice was most commonly sought from their GP (Table 4.3).

Table 4.3 Advice sought between SACT cycles

Advice options	Yes replies	Tumour type
GP	25 (37%)	Breast = 18 Lung = 3 Lymphoma = 1 Not known = 3
Family or friends	13 (19%)	Breast = 9 Lung = 3 Not known = 1
A chemotherapy day clinic	11 (16%)	Breast = 5 Lung = 2 Lymphoma = 1 Prostate = 2 Not known = 1
A 24 hours cancer helpline	8 (12%)	Breast = 4 Lung = 3 Lymphoma = 1
NHS 24	5 (7%)	Breast = 2 Lung = 1 Prostate = 1 Not known = 1
A hospital cancer ward	4 (5%)	Breast = 3 Lung = 1
Other <i>Out of Hours</i> services	4 (5%)	Breast = 3 Lung = 1
A community pharmacist	3 (4%)	Breast = 2 Lung = 1

Of the 35 patients who sought advice between SACT cycles, 26 (74.2%) were known to have breast cancer; 14.2% lung cancer; 5.7% prostate cancer; and 5.7% lymphoma. More female patients than male patients sought advice (88.5%) but this is skewed by the total number of female patients in the subgroup who sought advice (Table 4.4).

Table 4.4 Advice sought by tumour type and gender

Tumour type (n = 68)	Gender	Number of patients who sought advice by tumour type
Breast cancer (n = 38)	F = 26	26 (68%)
Lung cancer (n = 13)	F = 3 M = 2	5 (38%)
Prostate cancer (n = 8)	M = 2	2 (25%)
Lymphoma (n = 3)	F = 2	2 (66%)

Patients were asked if they had either bought medicines (18 (26%)) and/or had them prescribed (34 (50%)) (Table 4.5). This was an open question. There were a number of medicines which were both purchased and prescribed. These include paracetamol, Bonjela and Diffiam oral products.

Table 4.5 Medicines obtained between SACT cycles

Medicines purchased		Medicines prescribed	
Cough preparations		Infection	
Benylin Dry Cough		Amoxicillin	Augmentin
Cough bottle (not specified)		Penicillin V	Nystatin
Robutussin for cough		Antibiotics (not specified)	
Codeine linctus		Fluconazole	
Analgesics		Analgesics	
Ibuprofen	Anadin Extra	Paracetamol	Solpadol
Paracetamol	Co-codamol	Dihydrocodeine	
GI medicines		GI medicines	
Gavison Advanced liquid		Lactulose	Laxido
Milk of magnesia		Antiemetic (not specified)	
Movicol		Omeprazole	Nexium
Anusol cream		Ondansetron	Cyclizine
		Indigestion tablets (not specified)	
Mouth preparations		ENT and mouth preparations	
Bonjela		Bonjela	Nose spray
Zovirax cream		Biotene	Difflam
Difflam mouth spray		Caphasol mouth wash	
Other mouthwash			
		Skin and eyes	
		E45	
		Fucidin	
		Cream for dry lips	
		Eye drop for dry eye (not specified)	
		Diprobase	
		Hydrocortisone cream	
		Cream for rash (not specified)	
Others		Others	
Multivitamins		Letrozole	Sertraline
		Ramipril	Atenolol
		Iron tablets	Piriton
		Metformin	GTN spray
		Steroids (not specified)	

Patients starting SACT are given advice and counselling by either the prescriber, cancer care pharmacist or their chemotherapy nurse on what side effects to expect and how to manage them. The questionnaire asked patients if they believed that they had been given enough information about how to manage SACT side effects. Sixty patients (88%) indicated that they had been given enough information about how to manage chemotherapy

side effects. Patients who answered *No* were given a free text option to explain what information was missing. Their responses included additional help with side effects.

Patients were asked if they thought that a community pharmacist could offer them support during chemotherapy. Twenty five patients (37%) agreed that a community pharmacist could support them. A free text option allowed patients to suggest what a community pharmacist could do for them; help with managing side effects and to provide general advice were common themes. Thirty three (48%) patients did not believe that a community pharmacist could offer them support during their chemotherapy.

If Yes, what would you like a community pharmacist to do for you?

Advice and help with side effects

- *General advice about managing side effects and medicines for them*
- *A helpline*
- *A form of professional to phone/visit and see condition*
- *To be aware you have cancer and you are having chemo*
- *Advice on all medicines and possible interactions*

Access to medicines

- *Have prescription ready when required*
- *Prescribe for things like diarrhoea or constipation*
- *Medicines delivery*

Two further questions asked patients about their community pharmacist. Most patients (51, (75%)) attended the same community pharmacy. Almost all patients (66, (97%)) said they would allow the hospital team to share information about their medicines with their community pharmacist.

The questionnaire asked about access and attitude to technology (Table 4.6). Patients were asked if they had a Smartphone and about use of a health App. Thirty patients (45.4%) said they had a Smartphone. Twenty six patients (39.3%) said they might use a health App designed to record information about their medicines. The age range of the patients who

answered Yes to using an App was 44 - 73 years. Twenty of these patients had breast cancer; three patients had lung cancer; three patients had prostate cancer; and one patient remained anonymous.

Table 4.6 Use of a Smartphone and a health App

Do you have a Smartphone	Response (n = 68)	Would you use an App?		
		Yes	No	Non-response
Yes	30 (45.4%)	22	7	1
No	36 (54.5%)	4	31	1
Non-response	2 (3%)	1		1

Patients were asked what they would record on a purpose designed health App (Table 4.7). Of the 26 patients who said they might use an App, one patient did not answer this question. Contact telephone numbers were top of the list followed by a list medicines and test results. Patients in NHSGGC are currently offered a paper diary to record the name of their SACT, test results and appointment dates and times.

Table 4.7 Smartphone App functionality

Responses n = 26	Yes	No
Contact telephone numbers	25	1
A list of your medicines	24	2
Test results	24	2
The common side effects	20	6
Appointment dates	23	3
Your side effects	22	4
A treatment timetable	20	6
Other	1	25

4.5 Discussion

The aim of this study was to investigate a population of patients with cancer treated with SACT to understand what, if any, common toxicity was experienced, how patients interact with other healthcare professionals and patient's requirement for medicines between SACT cycles. The spread of tumour types reflects the cancers treated in the NVH daybed unit. The most common cancer was breast cancer followed by lung, prostate then lymphoma. The number of patients with a haematological cancer in this study was small for two reasons: the majority of these patients attended on a day that the investigator was not present on the NVH site; and convenience sampling was used.

The focus of question one was the common SACT toxicities as these are generally non-complex, self-limiting and amenable to intervention with an over-the-counter or *Pharmacy-only* medicine. There are many suitable medicines available from the NHS Minor Ailments Service (MAS) including

those for constipation, diarrhoea, cough, pain, mouth ulcers, cold sores and dry eyes (<http://www.gov.scot/Publications/2006/06/26102829/1>, accessed 25.11.16). The MAS has a Formulary published on NHS Scotland Health Board websites which is accessible to patients and healthcare professionals (<http://www.communitypharmacyscotland.org.uk/nhs-care-services/services/minor-ailment-service/mas-prescribing-and-formularies/>, access 25.11.16). Patients receiving SACT could be signposted to this service. There are currently some restrictions on patient eligibility which is under review by the Scottish Government, and, all patients must be registered with a GP. Thirty patients (44%) in this study were aged 60 years or greater and were eligible for MAS. It is not known if the remaining 38 patients were in receipt of any benefits or were excluded from MAS.

The most common toxicity experienced by patients between SACT cycles was mucositis. Routine use of mouthwashes is not current practice within WoSCAN but use is recommended if a patient experiences an oral toxicity. Mouth care advice could have been given to patients by a community pharmacist. Nausea and constipation were reported by a third of patients. Nausea is more complex to treat by a community pharmacist, unless they are an independent prescriber, as most of the recommended therapeutic options are prescription-only medicines. However, constipation can be managed with an over-the-counter laxative and Grade 1 diarrhoea (increase to 2 – 3 bowel movements per day over pre-treatment baseline) can be treated with loperamide and oral fluids.

In the absence of eye infection, patients could have obtained relief from sore or dry eyes by purchasing artificial tears from a community pharmacist. Some toxicities, such as infection, neuropathy and vomiting, should be managed by a prescriber with experience in cancer care as additional prescription-only medicines might have been required. Nail infection/changes or paronychia could have been managed in primary care jointly by a GP and community pharmacist; the GP to prescribe an antifungal

or antibiotic if required. Skin toxicity was limited to 7 days in this study and consideration could be given to management by community pharmacists using topical emollients.

A number of sources of information on management of SACT-associated toxicity including WoSCAN treatment protocols, MacMillan Cancer Support and guidance from the United Kingdom Oncology Nursing Society (UKONS) were available. However, access to this information is sometimes restricted to members or accessed via an NHS intranet which is not accessible to all community pharmacists due to firewalls. It had been recognised for a number of years that community based cancer services were not generally well established and could be improved (*NHS Cancer Plan, 2005*). In addition, community healthcare professionals might not have the competence or confidence to offer specialist support to patients having active cancer treatment. This aspect is discussed in Chapter Five.

Patients were asked where they sought advice between SACT cycles. Thirty seven percent contacted their GP and only 4% spoke to a community pharmacist. This is disappointingly low and reflects how community pharmacists are underestimated. When the actual toxicities experienced are considered, it is likely that many could have been resolved by a community pharmacist, in particular, constipation, diarrhoea, sore mouth and sore/dry eyes. The hospital cancer team advised patients when and where to seek advice if they became unwell whilst at home. The three main sources of help were the GP, the chemotherapy daybed unit and the Beatson Cancer Helpline (established in 2014). More female than male patients sought advice but this was skewed by the greater number of patients with breast cancer who were all female. Despite that, only four male patients are known to have sought advice between SACT cycles.

Patients were not signposted to a community pharmacist and there is perhaps a lack of awareness within hospital cancer teams of the potential

role for community pharmacists. However, a survey of community pharmacists in Canada found that community pharmacists needed more education and training on anticancer agents (Abbot *et al.* 2014). It would be prudent to ensure that NHSGGC community pharmacists have the appropriate skills, education and information to enable provision of pharmaceutical care to cancer patients in the community before hospital teams referred patients to community-based pharmacists.

Some patients had purchased or were prescribed medicines between SACT cycles. It is not known where the medicines were purchased or who prescribed them e.g. GP, cancer specialist. Fifty percent of patients had had a medicine prescribed. Patients were not asked if prescribed medicines were obtained to treat SACT toxicity or another concomitant illness so some medicines might have been prescribed on a routine repeat prescription completely unrelated to cancer treatment. Over a quarter of the patients (26%) had purchased a medicine and most of the medicines obtained were available from a community pharmacist. Given the range of e.g. mouth preparations obtained, there is merit in providing patients and community pharmacists with more detailed information on management of common toxicity. Eighty-eight percent of patients said they were given enough information about how to manage chemotherapy side effects. There was no distinction made between information on how and who to call if a problem or toxicity arose, or if the information was about supported self-management of toxicity.

It was both interesting and reassuring that most patients used the same community pharmacy for their repeat medication or other ad hoc prescription medicines. Whilst not generalisable over a whole population, this brings a degree of comfort in that clinical information could be transferred to the patient's regular community pharmacist. Patients of course can choose to attend any community pharmacy and this freedom of choice brings with it some difficulties in proactively communicating with a community pharmacist

on a regular basis. *Prescription for Excellence* introduces the concept of a "named pharmacist" and if taken up by patients, will facilitate the sharing of clinical information between hospital and community pharmacists. Ninety-seven percent of a patients said they would allow the hospital team to share information about their medicines with their community pharmacist. Zero patients answered *No* to this question. Data protection and information governance must be in place before sharing of clinical data with community pharmacists, such as pharmaceutical care plans, is routine practice. Pilot work is underway in NHSGGC to share the immediate discharge letter with community pharmacists and GP practice pharmacists already have access to hospital electronic pharmaceutical care plans via the Clinical Portal.

Patients were asked if a community pharmacist could offer support during their chemotherapy. Those who answered *Yes* were invited to list what they would like a community pharmacist to do for them. Most of the responses were about help with side effects. Reflecting on the side effects experienced by the patients in this study, this is achievable with the appropriate support systems in place to up-skill community pharmacists on cancer treatments.

In the questionnaire the patients were asked if they had a Smartphone and about the likelihood of them using a health App. Thirty patients (45.4%) had a Smartphone and 22 of these patients would use an app. Thirty six patients (54.5%) patients said they did not have a Smartphone but four of this group of patients answered *Yes* to using an App. The age range of the patients who would use an App was 44 – 73 years and most of these patients had breast cancer (76.9%). Breast cancer was the most common cancer in this study group hence the data is skewed towards this tumour type.

This study suggests that a Smartphone App is not desirable for every patient and the healthcare community do not intend to replace written patient information with digital technology. The patients who indicated that an App would be useful provided some very helpful information about the desirable

functionality of a purpose designed health App (Table 4.7). These data are similar to the patient stories gathered when scoping the cancer App (Chapter 6). Contact details for cancer healthcare specialists are very useful to have when a patient experiences toxicity. Having a patient-held list of medicines which is current, complete and includes medicines supplied in both primary and secondary care is desirable for all healthcare professionals as well as patients and is a key component of medicines safety. Test results were chosen by 92.3% of patients. This is not surprising given that patients are increasingly educated about cancer, SACT and side effects. Healthcare professionals talk to patients about their full blood count and the need to reach certain limits before SACT can be prescribed.

These data will be used for future work within NHSGGC e-health and digital technology services.

4.6 Conclusion

The hypothesis that some SACT-related toxicity could be managed by a community pharmacist was correct. The most common toxicities reported by patients in this study were mucositis, nausea, constipation, sore or dry eyes and diarrhoea. They were not graded so conclusions cannot be drawn on their severity. However, given the range of medicines obtained by the patients between SACT cycles, it is not unreasonable to assume that the toxicities were likely to be grade 1 – 2, which are mild to moderate. Only 4% of the study patients contacted a community pharmacist for advice but suitably trained community pharmacists are ideally placed to support safe and effective self management of common, non-complex grade 1 SACT toxicity such as those experienced by the patients.

Other aspects of community-based pharmaceutical care of patients with cancer include encouraging concordance with SACT and provision of advice on lifestyle factors. Community pharmacists are independent contractors and

enhanced services might need to be commissioned locally or be delivered via specialist hub pharmacies. This model would facilitate directed education and training of community pharmacists and could mirror the established GGC Palliative Care Network whereby 71 pharmacies participate in the delivery of palliative care services to patients with cancer (http://www.palliativecareggc.org.uk/?page_id=10, accessed 28/1/17).

Hospital teams should educate patients to seek advice from their community pharmacist and utilise available MAS. With regards to availability of clinical data to enable decision making in primary care, the NHSGGC hospital electronic patient record hosts pharmaceutical care plans and pilot work is underway to create a single medicines record. The technology is there to assist with the delivery of shared pharmaceutical care and the necessary clinical information is available to enable informed decision making in primary care for early detection and management of non-complex SACT toxicity. Further patient support might take the form of a Smartphone App.

4.7 Putting research into practice

In December 2016 the NHSGGC Lead Cancer Care Pharmacist (F MacLean) and the NHSGGC Lead Pharmacist for Community Care met to discuss this thesis and to consider how community pharmacists could contribute to the pharmaceutical care of patients with cancer. Referral from the hospital cancer pharmacy team to community pharmacists for patient follow-up or medication reviews was deemed to have limited value at that time due to lack of access by community pharmacist to patients' records and medication lists. Instead, an iterative process utilising GP practice-based pharmacists in the first instance with a desired future roll-out to community pharmacists was agreed.

Four actions were approved:

- review of the NHSGC minor ailment formulary
- wider engagement with *Improving the Cancer Journey* project team
- investigation of direct referral to GP practice pharmacists by hospital pharmacists
- contributing cancer care clinical vignettes for the NHSGCC Community Pharmacy monthly bulletin

Review of the NHSGCC Minor Ailment Formulary

In January 2017, the NHSGCC MAS list of medicines was cross-referenced against the UKONS SACT toxicity guidance and gaps in MAS medicines formulary were identified. This was discussed with the NHSGCC Lead Pharmacist for Community Care who requested that the additional medicines were added to the MAS formulary (Appendix 8).

Wider Engagement with ICJ

Also in January 2017, representatives from NHSGCC cancer and palliative care pharmacy teams, the community care lead pharmacist and some GP practice pharmacists met with the *Improving the Cancer Journey* (ICJ) project team who are employed by Glasgow City Council. ICJ is a collaboration between health and social care, NHSGCC and Glasgow City Council, whereby patients identified as having a diagnosis of cancer are invited for a holistic needs assessment (HNA) undertaken by an ICJ project officer. The medicines review aspect of the HNA had proved difficult to implement. It was agreed that a patient referral pilot project would take place between the South Glasgow lung cancer team and ICJ. The ICJ project officer would conduct the HNA of patients with lung cancer. Patients identified as having medication needs would be referred directly to the GP practice pharmacists based in the South Glasgow GP practices where the patient is registered. The practice pharmacists would invite the patient in for a medicines review and engage with the NHSGCC lead cancer pharmacist (F MacLean) in a

two-way sharing of patient information using the electronic cancer pharmaceutical care plans (Appendix 9). An evaluation of this will be undertaken by researchers from University of the West of Scotland. The practice pharmacists were chosen over community pharmacists as the GP practices have access to patient's medical and medication records. Extending this to community pharmacists will be considered as an iterative process in the future and will depend on community pharmacists gaining access to the EPR and medication lists.

Direct referral to GP Pharmacists

Direct referral of patients with medication review needs from hospital to GP practice pharmacists was raised with the NHSGGC Lead Clinician for Prescribing Services in February 2017. There was no electronic system for referral from hospitals to primary care. Discussion took place with NHSGGC IT services in May 2017 and a formal proposal to develop an e-referral system from hospitals to primary care was written and submitted.

Communication and education for community pharmacists

More needs to be done to make community pharmacists aware of the available SACT resources. There is detailed, helpful advice available for healthcare professionals from United Kingdom Oncology Nursing Society on the management of SACT toxicities and the WoSCAN SACT treatment protocols, available on an intranet, could be published securely on an NHS website for community-based teams.

A monthly Community Pharmacy bulletin is produced for NHSGGC. The Lead Cancer Care Pharmacist (F MacLean) agreed to lead on writing cancer care clinical vignettes for the bulletin. The audience is community pharmacists and their support staff. The first article was a short introduction to SACT, the patient pathway and management of sore or dry eyes (Appendix 10). Ocular toxicity was chosen as 30% of patients in this study experienced sore or dry eyes and appropriate eye drops are already

available on the NHSGGC MAS formulary. Future articles will include constipation, diarrhoea, skin rash and mucositis. Cancer care clinical pharmacists from across NHSGGC will be invited to contribute to writing the clinical vignettes and editorial control will remain with F MacLean and the primary care lead pharmacist.

Future research

Future research or audit projects might include evaluating a pilot of directing selected patients to community pharmacists for non-complex toxicity management. This was raised by F MacLean at the GGC Area Pharmaceutical Committee (APC) in December 2016 and was received with enthusiasm by community pharmacist members in attendance. A full proposal would need to be developed and agreed prior to implementation. Changes in uptake of MAS medicines and outcomes of community pharmacy referral could be measured.

Chapter 5
Community pharmacist questionnaire and focus group

5.0 Introduction

Patients with cancer who receive systemic anticancer therapy (SACT) move between different care providers. Good communication and record keeping is important to help achieve the intended outcomes of therapy, with minimal toxicity. Most patients are in a community setting and only have contact with hospital services when SACT is scheduled. A survey of ambulatory care patients showed that about 25% of patients had experienced a drug related problem; 39% of the drug related problems were thought to be preventable (Gandhi *et al.* 2003). The Scottish community pharmacy network can support the wider NHS team by providing local and accessible high quality healthcare to community-based patients. Referral of patients from hospital to community pharmacy would enable directed care. An electronic referral initiative from hospital to community pharmacy was implemented in the North East of England in 2014 (Pharmaceutical Journal, 2015a). This service was set up to avoid readmissions. There are no similar systems in NHS GGC and community pharmacists currently have limited or no access to patients' health records which is a barrier to providing pharmaceutical care. An understanding of current levels of transferred clinical information and desirable methods of future information delivery to community pharmacy was required to inform e-health service developments within Acute Services and Primary Care.

5.1 Hypothesis, aims and objectives

The hypothesis was that community pharmacists have limited access to patient's clinical information and that they have a low level of clinical knowledge of cancer therapeutics.

The aims of this study were to:

- (1) identify current sources of clinical information, preferred methods of delivering information and training needs of community pharmacists working across NHS Scotland for supporting patients receiving SACT.
- and
- (2) explore current and future uptake of e-health technologies to support the delivery of pharmaceutical care by community pharmacists to patients with cancer using a deep dive into experiences and attitudes of a small group of community pharmacists from NHS GGC.

Objectives

- Ask community pharmacists if they currently received any clinical information about their patients from other healthcare professionals (e.g. hospital pharmacist)
- Ask community pharmacists what were their preferred methods for the delivery of clinical information about their patients
- Ask community pharmacists what (if any) were the gaps in their knowledge of cancer care and their perceived training needs to enable them to support patients in the community, who are receiving SACT
- Ask community pharmacists how they currently record interventions made on behalf of a patient (e.g. electronic patient record)

5.2 Methods

A questionnaire was used for part one and a focus group was used for part two of this study.

5.2.1 Methods – questionnaire

1. An electronic questionnaire with 19 questions and covering letter was designed using Qualtrics® software (Appendix 11). Advice on the structure and content of the questions was sought from an experienced community pharmacist who provided services to patients with cancer and who was a member of the British Oncology Pharmacy Association Committee. The questions were a mix of open and closed questions and some allowed free text responses. The questionnaire was piloted on community pharmacist attendees at an NHSGGC community pharmacy palliative care annual update training day in January 2015. No changes were made after the pilot.
2. A link to the questionnaire was emailed out by Community Pharmacy Scotland (CPS) to all their members in January 2016 and again in July 2016 by NHSGGC to GGC community pharmacists in an attempt to improve the return rate. Participation was voluntary and respondents remained anonymous.
3. Qualtrics® software was used to collate and analyse the responses. The software assigns the total number of responses and % of respondees to each question. A report of the responses was downloaded to present the data.

5.2.2 Methods – focus group

1. Community pharmacists who attended a community pharmacy palliative care annual update training day in a Glasgow hotel in February 2015 were invited to participate in a focus group. These pharmacists were chosen for convenience as they were in attendance at the training day and did not need additional time off or locum cover.
2. Interested pharmacists were given an invitation and information sheet which explained the purpose of the focus group (Appendix 12).
3. The participants who agreed to take part in the focus group completed a consent and demographics form (Appendix 13).
4. A separate room was used for the focus group which was recorded using an Olympus digital voice recorder.
5. An NHS hospital pharmacist, independent of the study, acted as a note taker and took field notes including the opening sentences from each participant to enable accurate assignment of each response to the participants.
6. A focus group structure and questions sheet was prepared in advance to enable opinion and thoughts on e-health, pharmaceutical care and *Prescription for Excellence* to be sought (Appendix 14). The anticipated duration of the focus group was about 60 minutes.
7. The digital recording was uploaded to a PC and imported into Audacity® software to facilitate transcription into a MS Word® file. Data were transcribed verbatim and there was no data editing or cleaning. Incomplete sentences, random words and characteristics of the spoken word remained true (Appendix 15).

8. The transcript was imported into NVivo® software (version 10) for coding and content analysis.
9. The transcript and the analysis was tested and verified by an experienced qualitative researcher employed by University of Strathclyde and independent of this study.

5.3.1 Results – questionnaire

CPS sent the questionnaire to 1800 email addresses in January 2016; NHSGGC primary care pharmacy services sent it to 290 email addresses in July 2016. The study was not time limited but was closed in December 2016 for analysis purposes and the Qualtrics® questionnaire analysis report was run on 1st December 2016. Forty six questionnaires were returned electronically. Twenty six (56.5%) pharmacists were independent pharmacist contractors; 18 (39.1%) worked for multiples and 2 did not answer this question. The pharmacy multiples included Boots; BPL; Davidsons; Lindsay and Gilmour; Lloyds; locum/self employed; Rowlands; Superdrug; Stronvar Ltd; WHB Sutherland Ltd; and Well Pharmacy. The postcodes of the pharmacy premises indicated a reasonable geographical spread across Scotland. Only the first four digits were requested. Some premises had the same postcode (Table 5.1).

Table 5.1 Community pharmacy premises postcodes

Area	Number of pharmacies
Glasgow and surrounding area	18
Paisley	5
Edinburgh and Lothians	4
Inverness and Highlands	4
Fife	4
Ayrshire	3
Lanarkshire	3
Aberdeen	2
Other	2
Borders	1

There was a wide range of the number of years that the pharmacists had been registered for. Forty-two replied to this question and the range was 2 - 43 years (Table 5.2).

Table 5.2 Number of years registered

Number of years qualified	Number of participants
1 – 9	7
10 – 19	12
20 – 29	12
30 – 39	8
40 and over	3

The next section of the questionnaire focussed on the transfer of clinical information about patients who are prescribed systemic anticancer therapy. Forty two pharmacists replied to this question; none of the community pharmacists received clinical information. Skip logic was applied to the questionnaire so that everyone who answered *No* would be taken to question 12 therefore questions 6 – 11 had a nil response.

The pharmacists were asked if they were to receive clinical information about SACT, what would they want to know about. Thirty-six (78.2%) pharmacists replied to this question. Eight options and a free text option of *Other* were offered (Table 5.3).

Table 5.3 Desirable clinical information to receive about SACT

Options	Count (%)
The name of the anticancer medicine	36 (100)
Common toxicities	35 (97.2)
Allowable supportive medicines for managing simple toxicity e.g. mouth care	35 (97.2)
How long the anticancer treatment will continue for e.g. 6 months, until the cancer progresses	34 (94.4)
Referral pathways for complex toxicities e.g. extreme fatigue, temperature, bruising	33 (91.7)
How the anticancer medicine is given e.g. oral, injection	32 (88.9)
Contact details for the hospital pharmacist	32 (88.9)
How frequently the anticancer medicine is given, e.g. every day, every 3 weeks	31 (86.1)
Other	
<ul style="list-style-type: none"> • Cancer being treated • Named specialist nurse and contact details • Current adverse effects experienced • Likely interactions with other regular medicines 	4 (11.1)

The application of patient's clinical information was explored further using an open question to dive deeper into how it might impact on the delivery of pharmaceutical care to patients with cancer. Specifically, what might having clinical information on e.g. common toxicities, referral pathways and hospital contact details do to help the community pharmacists care for their cancer patients? Thirty-three pharmacists replied to this question. Data are grouped into three main themes, understanding cancer treatments better, managing toxicity and tailored education. Some direct quotes are given to illustrate the responses.

Understand cancer treatments better

15 responses

Across NHS Scotland, cancer medicines are initiated by specialist clinicians in Acute Care. The ongoing prescribing is often undertaken by hospital-based cancer care pharmacist or nurse non-medical prescribers and on rare occasions and, only under the instruction of Acute Care, dispensing of oral SACT is undertaken by community pharmacists. Specialist information is available to support hospital-based prescribers but is generally on hospital Intranets and is not widely accessible out with the hospital. Community pharmacists might not know that their patient has cancer and that they are receiving SACT. The community pharmacists who responded wanted to know the name of the SACT medicine that their patient was prescribed and most wanted to know the common toxicity that the SACT might cause. The community pharmacists wanted baseline knowledge, such as duration and frequency of SACT treatment, to improve their understanding of cancer treatments. They wanted to know which medicines could be recommend for minor ailments unrelated to cancer, or minor SACT side effects. The community pharmacists wanted to know when to refer patients back to specialist care should a patient present with a problem that could not be resolved in the community.

Illustrative quotes

I would have a background knowledge of their treatment and this would help me to answer any questions they may have and recommend treatments for minor ailments/side effects.

I feel if this type of information was available to me then I would be in a better position to identify any issues that arose during the course of treatment, and refer on where appropriate.

Manage toxicity or side effects of SACT

10 responses

Managing toxicity is defined as early recognition and prompt intervention of the toxicity. This requires both knowledge of the patient and of their prescribed SACT. Patients who experience toxicity or a side effect from a cancer medicine might present to their community pharmacist to ask for advice. Some toxicities are very severe but might be slow in onset and therefore recognition of the problem and prompt action is necessary. The community pharmacists wanted to know about the common side effects or toxicity of the SACT which their patients were prescribed. This would facilitate early identification and intervention of a SACT-induced toxicity and give the community pharmacists the knowledge and confidence to reassure, treat or refer their patient. Knowledge of the common minor side effects would be used to reassure patients who presented to their community pharmacist with a grade 1 toxicity and to give them appropriate advice on self-help measures or assist with providing a medicine on the minor ailment list to the patient. The community pharmacists said that they could use knowledge of SACT toxicity to refer patients back to hospital if the suspected toxicity was serious and required specialist intervention.

Illustrative quotes

The information could be entered in the patient's PMR. It would allow a clinical check on any acute meds prescribed by GP or on eMAS. As community pharmacists we have little/no knowledge of anticancer meds as we have little dealings with them. It would be useful to have more info on common toxicities to help improve our knowledge and to allow us to reassure/treat/refer as appropriate in line with hospital protocols ensuring the patient is receiving consistent messages for the healthcare professionals at a distressing and confusing time.

It would help us give self help advice, minor ailments and know if there are any interactions with their other prescribed medication.

Gives ability to recognise symptoms patient may present with and treat appropriately. Could stop potential interactions and ADRs if we are aware of other medications.

Enable tailored patient education

10 responses

The community pharmacists described how receiving clinical information about their patients with cancer would help them support their patients better and provide education tailored to individual patients. The unique access to pharmaceutical care offered by community pharmacists to patients without appointments and at weekends and evenings is compromised by lack of knowledge of the patient and of specialist medicines prescribed and managed by the hospital cancer teams. Having access to patient's clinical information would enable the community pharmacists to confidently counsel their patients and answer questions that the patient might have.

Illustrative quotes

Help us provide adequate counselling confidently to patients who are on systemic cancer treatment, recognise ADRs, toxicity. We are located in such a way of ease of access and we want to support our patients with help and advice to support them through their cancer journey. We often have a close relationship with our patients who want to confide in us and sometimes feel inadequately prepared to recognise or advise.

Allow me to counsel patient or carer effectively and enable me to deal quickly with questions I was unable to answer.

At present we have no idea to be able to care for the patient. It would allow us to be able to give better advice and support for our patients.

Lack of access to patient notes is a major flaw in the current system and this information would support us in delivery of appropriate information and supportive care and in so doing, may help to build capacity in secondary care.

The question on how clinical information would help community pharmacists provide pharmaceutical care to patients with cancer was analysed using the Qualtrics® visualisation functionality to produce a word cloud of the 30 most common words. Knowledge, information, side effects, better support and advice were commonly cited (Figure 5.1).



Figure 5.1 Word cloud – how clinical information would support pharmaceutical care

There is potential for clinically significant drug interactions between oral SACT and concomitant medicines. Some oral SACT medicines are taken continuously until the cancer becomes more active (disease progression), which might be long term. Community pharmacists are ideally placed to intervene when a new medicine is purchased or dispensed. The questionnaire asked what sources of information they used to check for potential drug interactions e.g. product literature, *Medicines Complete*, specialist text book. Thirty-six replied to this question (Table 5.4): some responders used multiple sources.

Table 5.4 Current sources of information used by community pharmacists

Medicines Complete	eMC
Stockley	Martindale
PCF4 Symptom management in advanced cancer	BNF
Medicines Information services	Pharmaceutical Journal
Clinical knowledge summaries	PMR system
Product literature	Manufacturer
Internet search	Chemotherapy handbook
Cegedim Quick Interaction Check	

On identifying a drug interaction, the community pharmacists would attempt to contact a variety of healthcare professionals, most commonly the patient's GP (Table 5.5). Some pharmacists would contact more than one person. The GP was cited many times due to lack of contact details for hospital specialists including cancer specialists, other medical staff and hospital pharmacists.

Table 5.5 People contacted if a drug interaction was identified or suspected

Response	Number
GP	24
Hospital	12
Prescriber	6
Hospital pharmacist/ pharmacy	2
Patient	2
Specialist clinical pharmacist	2
Lead palliative care pharmacists	1
Nurse specialist	1
NHS24	1

There are multiple ways to transfer patient's clinical information from hospital to community pharmacists but it was not known which methods were preferred. This question asked the pharmacists to rank six ways of transferring clinical information from 1 (most preferred) to 6 (least preferred). Thirty three community pharmacists answered this question. Their preferred method was email followed by access to the hospital electronic patient record or fax. The least preferred option was via a patient-held App.

Table 5.6 Preferred route for transfer of clinical information to community pharmacists

Options	Most preferred option
Email	14 (42.4%)
Fax	12 (36.3%)
Via access to the hospital electronic patient record	12 (36.3%)
Letter by post	10 (30.3%)
Via a patient-held App	5 (15.1%)
Other	
<ul style="list-style-type: none"> • <i>Patient brings in via letter or app</i> • <i>Phone call</i> • <i>Letter via patient</i> 	5 (15.1%)

Hospital pharmacists generally record their interventions on pharmaceutical care plans or directly into patients' records. If the community pharmacists made an intervention for a patient receiving SACT, most of them (94.3%) would record the intervention in the community pharmacy electronic patient record (Table 5.7).

Table 5.7 How interventions are recorded by community pharmacists

Response (n = 35)	%	Count
Community pharmacy electronic patient record	94.3%	33
Phone call to GP	77.1%	27
Phone call to hospital pharmacy	37.1%	13
Community pharmacy paper patient record	8.6%	3
Email/letter to GP	8.6%	3
Other, please state	8.6%	3
Patient-held paper SACT record	2.9%	1
Email/letter to hospital pharmacy	2.9%	1
I don't record my interventions	0%	0

Only 4 (11.1%) community pharmacists agreed that they felt confident in providing pharmaceutical care to patients prescribed SACT. Thirty-six replied to this question. The remaining community pharmacists were evenly split between *No* and *Sometimes* (44.4%). Reasons for a lack of confidence were given. Thirteen pharmacists cited lack of knowledge as the most common reason for not having the confidence to provide pharmaceutical care to patients receiving SACT. This included both lack of knowledge of what treatment the patient was on and a general lack of knowledge about SACT. One responder mentioned being unsure of the validity of a website/internet page.

Training can be provided by specialist cancer care pharmacists but delivering training to a Scotland-wide community pharmacist workforce requires knowledge of what content is desirable and how the training should be delivered. A range of training formats was suggested from formal events to

e-learning. The core content of training should include the common cancers, current therapies, management of side effects and drug interactions, and service/contact details. Details of the community pharmacist's training requirements are given in Table 5.8.

Table 5.8 Mode and content of training for community pharmacists

Mode of training
Online training to include easy access resources
NHS Education Scotland study evening or tutorial
Palliative care training day
Written information to cover the topics listed in Table 5.3
Webinar/ e-learning/distance learning
Content of training
Common cancer therapies
Common toxicities and side effects
Safe OTC treatments for common side effects
OTC treatments to avoid and why
How cancer services are provided
When to treat and when to refer
The patient experience
Common interactions
Patient resources such as patient Apps
Contact details for specialist support

5.3.2 Results – focus group

Five community pharmacists consented to participate in the focus group.

Three were female; 2 were male.

		Code
Participant 1:	did not complete a demographics form	P1
Participant 2:	Pharmacy manager; 9 years qualified	P2
Participant 3:	Locum pharmacist; 12 years qualified	P3
Participant 4:	Pharmacy manager; 15 years qualified	P4
Participant 5:	Pharmacy manager; 5 years qualified	P5

The focus group ran for 72 minutes. The sound file was imported into Audacity® software to enable data transcription into a Microsoft Word® document (Appendix 15). The Word® file was imported into NVivo® software.

Synopsis of the focus group

The participants were in agreement that the communication about patients medicines is lacking from both hospital and GPs. They often have to rely on the patient to tell them about changes in medicines and they have to use guesswork to find out if their patient has cancer, for example, if the patient is prescribed opiates. This resulted in some of the participants being hesitant to make decisions despite wanting to provide the best care. There was variable access to ECS and KIS. They would like to have one single medication record for their patients that is always up to date and one electronic patient care record used by all healthcare professionals, including community pharmacists, GPs and hospitals. The participants said this would be an incentive for them to keep their records current as a shared record would be more impactful. They were disappointed that there was a perceived lack of trust from primary care colleagues with regards to access to GP records and all participants agreed they would never misuse patient's information. When a patient is discharged from hospital they wanted to know their medical condition, the medicines that the patient was discharged on and

any follow up arranged and to receive this information as soon as the patient is discharged. They agreed that the role of the community pharmacist is changing and needs to move away from dispensing volume to delivering care. When asked about systems for prioritising patients according to clinical or medication needs, the participants did not have any IT systems to flag patients on high risk medicines. The participants defined high risk medicines as oral anticoagulants, methotrexate, insulin, lithium and anything with a narrow therapeutic index. There was a clear disconnect between the ways in which NHSGGC hospital clinical pharmacists prioritised patients and how community pharmacists do it, due in part to hospital pharmacy triage policies and the availability IT systems to allocate a priority rating to each patient. The participants agreed that technology such as patient Apps could be very useful especially if hospital contact details were included.

Data were analysed using content analysis to ascertain recurrent instances of words and phrases and determine the frequency of words. Data were coded as *challenges*, *context/values/beliefs* and *solutions*. An illustrative quote was included for the most common threads or where further explanation was required.

5.3.2.1 Challenges

Data coded as *Challenges* were subdivided into *communications not joined up*; *prioritising patients*; and *technology/IT systems*.

Communications not joined up

At the time of conducting the focus group, community pharmacists did not have access to either GP or hospital patient records whereas hospital pharmacists have accessed patient's hospital records for decades. The purpose of exploring this in the focus group was find out what this meant for community pharmacists. They felt there was a risk to patient safety and were

reliant on the patient or their carer telling them about their illnesses and medicines. They said that receiving a copy of the discharge letter would be helpful especially in an out hours situation where the GP surgery was closed. They cited lack of a single patient record as being a problem five times.

"The big thing for us is information and actually that bridge of communication that's not always successful and that's quite often where we feel things go wrong and is the biggest risk to patient safety" (P4)

"There's multiple ways we can find information but no one's definitive and a single medication care record would help that if it was available to us and it could be executed right" (P2)

"You're not then reliant on letters being sent to GPs and a copy of it going to the patient...sometimes that's what you're at the mercy of...sometimes you've got pharmacists in hospital that will contact the community pharmacy and that's great cause you've got that information and you know then to expect a change but we're not always lucky, it doesn't always happen" (P4)

"To an extent it's a bit patient reliant, you rely on your patients telling you that they're going for this investigation or something's happening so that when they then come back you can check in with them or see changes" (P5)

Prioritising patients

Hospital pharmacists in NHSGGC worked with a triage and referral system designed to prioritise high risk patients according to an agreed set of criteria based on prescribed medicines, clinical conditions and co-morbidities. This enabled directed pharmaceutical care to patients with the greatest clinical needs. Hospital IT systems (Trakcare) permitted allocation of triage codes against a patient so that the wider clinical team could follow the care of individual patients. In NHSGGC, all patients on SACT are considered to be high risk. The purpose of including this in the focus group was to identify how community pharmacists identify patients with the greatest clinical needs and prioritise those patients. They cited barriers to doing this as volume of patients and workload, lack of systems, procedures and knowledge. Participant Two stated that high risk medicines were oral anticoagulants, methotrexate and anything with a narrow therapeutic index. Participant Three added opiates to the list of high risk medicines and described how she verified the prescription before dispensing it.

"I look at opioids. I'm always having to go out and ask the patient "have you been on this opioid before". I don't even know whether it's something that the doctor has prescribed or what's happened. I have to chase it with another community pharmacy "have you seen this prescription before?" That's one of my main barriers. So if I knew this is the dose and it's been slowly going up, yes it's alright it's not too bad as I thought. So I would...high risk medication like opioids" (P3)

Technology/IT systems

The participants talked about their lack of access to electronic records and general lack of access to IT. Community pharmacists can create a patient record (PCR) with the patient's consent.

"If you've got the person's consent you are able to create a PCR for anybody. So I suppose looking at locally enhanced schemes that how we documented a lot of the issues" (P4)

5.3.2.2 Context, values and beliefs

Data coded under *Context*, *Values* and *Beliefs* were divided into four further categories, *scared to make decisions*; *wanting to provide the best care*; *trust issues*; and *role or changing perception of community pharmacy*. One participant talked openly about lack of confidence in decision making especially when a patient has cancer (P3). Participant four wanted information about patients so that she could provide the very best care for her patients and she believed that knowing more about the patient's time in hospital and any subsequent changes to medication would be valuable. They were all disappointed at the perceived lack of trust from general practice with respect to community pharmacists having access to patient's records. Patient confidentiality and patient safety were each cited twice. The group were cognizant of the changing role of community pharmacy, moving away from volume based dispensing to delivering directed care to patients.

Scared to make decisions

"If you come across, you mentioned minor ailments there, at the weekend somebody comes in and they've got constipation you can so easily just give senna but then you find out they are on opioids and then you start worrying is it bowel obstruction? Am I competent enough to just give a laxative and you do worry about those things and maybe for ease of mind if we just had access to they were discharged from hospital and yes they were on this and they were already prescribed lactulose or senna, it's OK for me to give that out or you know sometimes you kind of hesitate and you get a wee bit worried when it's a cancer label especially" (P3)

Wanting to provide the best care

"I suppose just that community pharmacy we want to know the information so that we can help the patient and having that helps us do that to best of our ability. We might not always get it right first time but the more used we get to actually using it then we get familiar with it we can only benefit patients and not just those going through cancer but any type of admission or change in medicine actually it would be so useful" (P4)

"I understand there's a big thing round about patient safety and patient confidentiality but I think if we are all working in the same disciplines we are there to be doing the right thing about patients and actually trusting that the

individual you are sharing the information with is using it for the benefit of the patient and not for any other purpose I mean that's one of our big hurdles" (P4)

Trust issues

"We are professionals, why would we misuse the information? I don't really see why people have a real big issue with giving the community pharmacist information. We're not there to cause a problem" (P5)

"And show that we're capable of using the information accordingly and not being distrustful with information as well. We want to do the right thing for the patient. That's why we need the information...it's not to be nosy or to know what's going on ...it's about having up to date every minute information that you can make competent and confident decisions about your care" (P4)

Role or changing perception of community pharmacy

"I agree with you in terms of, community pharmacy was always based on volume previously and actually people who are in community pharmacy now don't really want to be based on volume but that's still, we still have two systems that are not quite met in the middle yet, so while you still have the volume on what your reimbursements from that, but there's this whole aspect of being clinical and we want to be doing what we should be doing" (P4)

5.3.2.3 Solutions

Data coded under *Solutions* included IT solutions, access to contact details and re-evaluation of the role of the community pharmacist. Access to systems or information was cited 11 times and Participant 3 stated that patients had the expectation that their community pharmacist already had access to shared information about them. One single record was cited 4 times and this led to discussion of what it might look like and how it might be useful. A national network was suggested as a solution by Participant 2 whereby you would log in using the patient's name to source one single record. Participant 1 said having access to the community pharmacy PCR in hospital pharmacies would benefit both parties. Two participants cited having viewing access to the patient's Immediate Discharge Letter as a

solution. Apps were spoken about 3 times and it was stated twice that it would be helpful if the App had contact details for specialist services.

Participant 3 described how their work had changed with having ACTs in the dispensary. This has allowed a re-evaluation of the pharmacist's role and has freed up time to talk to patients.

"They have that expectation that we have got shared information and we don't and if they've got that expectation it should be met, we should have access to it" (P3)

"All the different pharmacies use different systems so you need to drag that information over....so if we have a PCR system that you can all use and actually it's health board driven surely that would be great starting point" (P4)

"If they had something, and it's an app that showed all their kind of history of admissions, you know drugs on discharge and so on that's be great, be great" (P3)

"I suppose going down the route of the app that you talked about it would be quite good if on an app it could state that this is my GP surgery, this is the pharmacy I use" (P5)

"I think just having the information then allowing you to put that into the care plan would just be amazing cause we don't always have that information" (P4)

5.4 Discussion

Community pharmacists are ideally placed to detect, prevent and resolve medicines-related problems. Clinical interventions were recorded by 185 Australian community pharmacists over a 12-week trial period (Williams *et al.* 2012). The intervention frequency was 0.3% and about 1.6 recommendations were made per intervention. The most common interventions were related to drug selection or educational issues. However, lack of access to clinical records impedes community pharmacists working in NHS Scotland from delivering a full package of pharmaceutical care.

The aim of the questionnaire and focus group were to identify where e-health solutions could be used to enable and support the delivery of pharmaceutical care across traditional boundaries. In 2012 the Royal Pharmaceutical Society (RPS) launched *Keeping patients safe when they transfer between care providers – getting the medicines right* (Picton and Wright, 2012). RPS aimed to raise awareness of the need for consistent transfer of information about medicines when patients move between care locations. Some individual hospitals or health boards in the UK have addressed this and Newcastle hospitals have implemented an electronic referral system for post-discharge medicines reviews (Royal Pharmaceutical Society, 2015). There is no Scotland-wide single system for transferring care between primary and secondary care despite electronic patient record technology.

Desirable shared clinical information

The questionnaire was distributed to over 1800 community pharmacist email accounts and there were about 1200 community pharmacies in Scotland. The response rate was very low at 2.5% despite a reminder being issued by CPS. The respondents were from localities across Scotland and the pharmacists ranged from 2 – 43 years qualified. No respondents currently received clinical information about their patients who had cancer. This was perhaps an expected result given there is no established system of routine

sharing of clinical information from cancer care pharmacists to primary care in NHS Scotland. To address this and take forward future e-systems, the community pharmacists were asked what clinical information they wanted (Table 5.2). All of them wanted the name of the anticancer medicine that their patient was prescribed and most wanted to know how it was given (e.g. tablet, injection). Ninety-seven percent wanted to know the common toxicities and any allowable supportive medicines for managing simple toxicity e.g. mouth care. Ninety-four percent wanted to know how long the anticancer treatment would continue and 86% wanted to know how frequently it was given. The frequency of administration is an important piece of information to have if a patient presented with a toxicity. If the toxicity was attributed to the cancer treatment (e.g. fever), it might require a very urgent intervention. Duration of therapy is of increasing importance as many new SACT are oral medicines, some of which continue until disease progression which can be months or years. This brings a new set of complexities involving polypharmacy and drug interactions with drugs prescribed for co-morbidities (e.g. warfarin) or prescribed for an acute presentation of an illness such as an infection (e.g. clarithromycin, azole antifungals). Some interactions are highly clinically significant and can result in vastly increased or decreased plasma concentrations of either drug. In NHS Scotland 61,000 (11.2%) non-elective admissions were due to medicines (Healthcare Improvement Scotland, 2015). Therefore knowledge that the patient is prescribed SACT is of great importance to avoid unintended toxicity or therapeutic failure.

The results of this questionnaire were verbally fed back to the Chief Executive Officer of CPS in December 2016. The message from CPS was that the one key item of information that above all should be communicated to community pharmacists is that the patient has cancer and is on active treatment. The level of detail after that would be tailored to the individual patient's pharmaceutical care needs.

The community pharmacists were asked how clinical information would help them provide pharmaceutical care for their patients. It was clear that not being aware of the patient's diagnosis and SACT was a barrier to providing individualised pharmaceutical care. There are two quotes from the questionnaire which summed up many of the responses (anonymous):

"Help us provide adequate counselling confidently to patients who are on systemic cancer treatment, recognise ADRs, toxicity. We are located in such a way of ease of access and we want to support our patients with help and advice to support them through their cancer journey. We often have a close relationship with our patients who want to confide in us and sometimes feel inadequately prepared to recognise or advise"

"The information could be entered in the patient's PMR. It would allow a clinical check on any acute meds prescribed by GP or on eMAS. As community pharmacists we have little/no knowledge of anticancer meds as we have little dealings with them. It would be useful to have more info on common toxicities to help improve our knowledge and to allow us to reassure/treat/refer as appropriate in line with hospital protocols ensuring the patient is receiving consistent messages from the healthcare professionals at a distressing and confusing time"

Knowledge of the diagnosis and treatment would enable early recognition of toxicity and appropriate referral; intervention to prevent or manage drug interactions; educate patients; recommend appropriate supportive medicines; and communicate back to specialist cancer services. It was reassuring to see that use of the patient medication record (PMR) was suggested as it will offer a permanent record of treatment and interventions and is in line with e-health technologies.

As previously discussed, drug interactions involving SACT can be clinically significant and are a cause of morbidity and mortality (van Leeuwen *et al.*

2013). Drug-drug interactions are cited as the cause of death in 4% of patients with cancer (Buajordet *et al.* 2001). The community pharmacists who responded used a variety of medical information sources to check drug interactions. The sources were mostly recognised resources (http://www.ukmi.nhs.uk/filestore/ukmiacg/EssentialInformationResourcesforMIServices_v1.13_Nov07.pdf, accessed 15.12.16.). *Internet search* was offered as one source but the respondent did not give any further detail to indicate which websites. Pharmacists should assure themselves of the quality of websites before using them. Hospital teams can signpost community pharmacists to recognised quality sources of medicines information. On identifying a drug interaction, 70% of community pharmacists would contact the patient's GP. The GP was cited many times due to lack of contact details for the cancer specialist team. During working hours, the GP was an appropriate professional to contact in the first instance and would know which cancer consultant was responsible for the hospital care of the patient. The GP, however, would not be available at weekends and out of hours which leaves a gap. Only two respondents said they would contact a hospital pharmacist and NHSGGC has taken action to address availability of contact details for the hospital cancer care lead pharmacists by publicising their contact details.

Referral pathways

Nearly 92% of community pharmacists wanted to know what the referral pathway for complex toxicities, such as temperature, was. This information will vary across the different Scottish Health Boards and would usually be given to patients. It would be helpful for Health Boards to publish their pathways on the Board websites to enable triage and fast access to the appropriate service. Contact details for the hospital pharmacist were wanted by 88.9% and some community pharmacists said that they wanted the contact details for the patient's named specialist nurse. Again, this could be published on the Board's web pages and some cancer care pharmacists now give their patients a business card with contact details.

Preferred method of information transfer

The pharmacists were asked which was their preferred route for the transfer of clinical information to them from the hospital team. The most highly favoured route was via email followed by access to the hospital EPR and by fax. Secure email is available and is very helpful to send for example, a scanned list of medicines. Use of faxing is discouraged due to it being unsecured. Moving forward to the delivery of comprehensive pharmaceutical care by community pharmacists relies on access to the EPR and it was reassuring to know that community pharmacists rated this as an ideal way of transferring clinical information. Having made an intervention, 94% said they would record this in the community pharmacy EPR. This is accessible only to staff in the premises which limits the usefulness to the wider clinical community. Seventy-seven percent said they would phone the GP and 37% said they would call the hospital pharmacy. A shared electronic record would be invaluable to record interventions and remove the need for telephone calls.

Community pharmacist's confidence and training needs

Included in the questionnaire were three questions which focussed on confidence in providing pharmaceutical care to patients prescribed SACT and community pharmacist's training needs. These questions were included after discussion with an experienced community pharmacist who is an active member of the British Oncology Pharmacy Association and who had recent treatment for cancer. Eleven percent said they felt confident and there was an equal split between *No* (44.4%) and *Sometimes, depends on the patient* (44.4%).

Those who answered *No* or *Sometimes*, were asked to give further detail by way of explanation. The main reasons cited were lack of knowledge/information and the complexity of SACT. Twenty responses were received on the training that community pharmacists would like to receive. A study evening, on-line training and a webinar were suggested as training

methods (Table 5.8). A mix of training types is needed to provide the depth of knowledge that community pharmacists need to confidently provide pharmaceutical care to patients with cancer. Training can be facilitated by NES but the challenge is reaching out to the whole country, consolidation of learning and the practical application of training to individual patients. There is also a challenge in moving from knowing what to do to putting this into practice with patients and doing it. Teaching methods used to build confidence and capability include teach and treat and observation/shadowing. These are resource intensive and not readily accessible for all community pharmacists across Scotland (e.g. those working on the islands). A model for training to enable maximum attendance and participation is a series of e-learning modules delivered by experienced cancer care pharmacists, each building on the previous one to increase the depth of knowledge. This could be supported further in geographical localities by peer to peer support from hospital cancer care pharmacists in a face to face environment, ideally with "expert patients" in attendance to tell their story and ensure that the patient's experience is understood. Achievement of learning outcomes could be assessed by on-line questions and linking community pharmacists with a locality-based hospital pharmacist mentor to discuss patient-based scenarios.

The content of the training asked for by the study pharmacists is consistent with the knowledge community pharmacists should have when caring for patients with cancer and is deliverable. Keeping this training current and relevant to community pharmacists is necessary and therefore training will be discussed with Community Pharmacy Scotland, NHS Education Scotland, the Scottish Oncology Pharmacy Practice Group and the British Oncology Pharmacy Association to identify current resources and seek opportunities for collaboration and to avoid duplication. Post-research work has included participation in a UK and Ireland-wide community pharmacist sub-group of BOPA with a remit to support and educate community pharmacists to bridge the gap between specialist hospital cancer services and community

pharmacy. In addition, a series of workshops for community pharmacists will be run in Ireland in 2018 by cancer care pharmacists and a specialist nurse. In Ireland, community pharmacists dispense some oral SACT under the "high tech" Irish health system scheme. A pre- and post workshop questionnaire will be used to gain an understanding of the community pharmacist's baseline knowledge and to evaluate their learning over the educational evening and workshop. A large number of community pharmacists in Ireland (over 1800) are registered for an online resource called *Pharmabuddy* which could be utilised to signpost community pharmacists to useful clinical resources, e.g. treatment pathways and protocols. For Scotland, similar resources could be supported by CPS or local NHS Board websites.

Focus group - access to patient data

A focus group was chosen as a technique to gain data on the experiences and opinions of community pharmacists. The interaction between the participants was valuable in exploring professional attitudes and to gain insight into community pharmacy practice. The participants ranged from 5 years to 15 years qualified. The most common theme was lack of joined up communications and no single patient record. This was cited by one of the participants as the biggest risk to patient safety. Community pharmacists had to rely on other healthcare professionals or the patient to share clinical information. Community pharmacist's lack of access to health records was highlighted by the Royal Pharmaceutical Society (RPS) Scotland in 2015 in their response to the Scottish Parliament's Health and Sport Committee Inquiry into palliative care (Pharmaceutical Journal, 2015b). RPS Scotland stated that this posed a "significant risk" to patient safety. The focus group participants said that some of their patients have the expectation that clinical information is already shared with community pharmacists. The participants recognised that the role of community pharmacists is evolving from a volume based dispensing service to a more clinical focussed role and access to health records is required to do this effectively. Interestingly, some participants mentioned being scared to make decisions due to lack of

information and clinical competence in providing care to a patient with cancer. The participants stated they wanted to provide the best care and to do that, they needed at the very least, information on the patients medicines. The summary care record is an electronic patient care record used in NHS England and contains up-to-date information about patients medicines, adverse drug effects and allergies. A pilot project in 2014 in England whereby 140 community pharmacies were given access to the Summary Care Record (SCR) reported that in 18% of cases, access to the SCR prevented a prescribing error (Andalo *et al.* Pharmaceutical Journal 2015). Over a six month period, 2.9 SCRs were accessed per month. Most of the pharmacists involved in the pilot agreed that using the SCR helped avoid medication errors and improved the service they provided to their patients.

None of the focus group participants raised liability issues resulting from having access to patient's records. Failure to check a record might result in harm and standards of care should be set. Patient confidentiality and trust issues were spoken about at the focus group. One participant was very vocal about being a professional and that information accessed would not be misused. Of note, the second quote cited in 5.3.2.2 around trust issues summed up the group consensus that up-to-date information allows community pharmacists to make competent and confident decisions about patient care. The group were clear that information sharing was for the benefit of patients only.

There were no unexpected findings from the focus group but worth noting for future work was the different IT systems, internet access and firewalls used across the different community pharmacy businesses. This could be an initial barrier for access to electronic health records if access is dependent on navigating specific information technology pathways.

5.5 Conclusions

The hypothesis that community pharmacists have limited access to patient's clinical information and that they have a low level of clinical knowledge of cancer therapeutics was correct. The pharmacy profession has long held the view that wider access to health records enables safer care. Pharmacists are experts in medicines and can help patients take their medicines safely, effectively and as the prescriber intended. Hospital and GP practice pharmacists have had access to patient's records for years and use this information to provide pharmaceutical care to achieve the optimum outcomes for patients. There are controls in place to protect patient confidentiality. Community pharmacists offer accessibility to expertise in medicines in a face-to-face environment.

This study has shown that community pharmacists received limited or no clinical information about their patients who have cancer and who are prescribed SACT. Community pharmacist's confidence in providing pharmaceutical care to patients with cancer is at a low level and they both desire and require training on cancer treatments and patient care. Some cancers, such as chronic leukaemia, might be considered a long term condition and almost all patients undergoing treatment for cancer will be resident in the community for all or part of SACT therapy. Whilst supply of SACT has traditionally remained under the auspices of hospital pharmacy, NHSGGC is moving dispensing of some non-complex oral SACT to community pharmacy in 2017. Community pharmacists will be asked to support patients who have cancer and as accessibility is one of the key strengths of community pharmacy, they might be the initial port of call out-of-hours and at weekends.

Hospital cancer teams can proactively signpost patients to community pharmacists but the patient needs to communicate their diagnosis and treatment to community pharmacists to enable a comprehensive package of pharmaceutical care to be delivered. A shared electronic pharmacy record

would be a positive development and the ultimate aim is *read and write* access to the patient's EPR by all healthcare professionals to enable joined up care across all sectors. Cancer care specialist pharmacists should contribute to the education and training of their community based colleagues.

5.6 Limitations

The community pharmacist questionnaire response rate was very small. Some reasons for that were that the questionnaire emailed via NHSGGC primary care went into the pharmacy's generic mailbox. This might not be checked on a regular basis. Boots did not have access to a generic mailbox and so questionnaires for Boots were sent to the Area Manager who decided whether to cascade to the individual pharmacists. LloydsPharmacy had only just moved over to the generic mailbox system and so responses might have been sporadic.

5.7 Future work

F MacLean and the NHSGGC Primary Care Lead Pharmacist met in December 2016 to discuss this thesis and how Acute Care can support community pharmacists. The two NHSGGC LCPs for cancer will be named as key contacts in communications with community pharmacists and their contact details were made available on the NHSGGC pharmacy web-based contact list. F MacLean agreed to co-ordinate writing cancer contributions for the NHSGGC Community Pharmacy monthly bulletin to address management of common SACT-toxicity. The first article on dry eyes was written in February 2017. The NHSGGC minor ailment formulary was updated to include recommended laxatives and ocular products for dry eyes.

The British Oncology Pharmacy Association intend to set up a short-life task and finish group in early 2017 to address care of the cancer patient in the community. The findings of this thesis will be discussed and opportunities for

UK collaboration to address the gaps and deficiencies in information exchange will be sought.

The training needs of community pharmacists to enable them to confidently support patients with cancer and provide pharmaceutical care will also be addressed and opportunities to work with NHS Education Scotland and the Scottish Oncology Pharmacy Practice Group will be identified.

Early discussion has taken place with the pharmaceutical industry to support innovative ways of delivering education and training, such as clinical vignettes presented as You Tube videos and use of social media.

Chapter 6
Development and evaluation of a health App

6.0 Introduction

Almost all patients with cancer who are prescribed SACT experience a treatment-related toxicity (Carlotto *et al.* 2013). Some patients experience multiple toxicities which might result in dose delays, dose modifications and a negative impact on quality of life. Patients require support to manage SACT toxicity and there is increasing interest in self management facilitated by health apps (mobile applications). The significant number of people owning Smartphones or tablet devices has led to an increase in available health apps (Ismail, 2012). Innovative digital health solutions can be used to provide patients with access to their records and treatment schedules; to offer education via proactively signposting patients to validated health websites; and facilitate supported self management with access to care plans and health guidance. Technology for health and wellness can support independent living and can help change behaviours.

Patients have contact with many healthcare professionals throughout their cancer journey and enhanced communication can improve the patient experience. Using a single data repository removes the need for patients to repeat their story to multiple individuals. In 2011, the Health Secretary for NHS England called on healthcare professionals, patients and app designers to suggest ideas for health-related Smartphone apps resulting in almost 500 entries. The variety and quality of health apps has raised issues such as accreditation and endorsement by the NHS and apps that have for example, a calculation functionality, are considered to be medical devices and must comply with the European Union Medical Devices Directive (Ismail, 2012). At the time of this study there was no app available that brought together, in an electronic form, all the paper support materials that patients receiving SACT are given by the NHS.

NHSGGC Pharmacy Prescribing and Support Unit (PPSU) was offered an opportunity to collaborate with the Department of Computer and Information Science at the University of Strathclyde whereby a final year software

engineering student would work with the NHS (the external client) to design a purpose built health app. This formed the basis of the software engineer student's final undergraduate project and was included in the awarding of their degree. Interested pharmacists in PPSU were invited to submit an outline of the app specification and intended use (Appendix 16). There was no resource attached to the project in terms of finance or protected time for the NHS personnel.

It is acknowledged that a health App is not suitable for everyone and it was not the intention of the healthcare community to switch to entirely digital solutions.

6.1 Aim

To design, build, test and evaluate a Smartphone health application for patients receiving SACT to view and record:

- all medicines both prescribed and purchased
- toxicity and side effects from SACT
- appointments and clinical visits with all HCPs

The initial App concept was that it would contain detailed information for patients on SACT linked to disease libraries, for example, swiping on "*My breast cancer*" would open up a series of treatments for breast cancer allowing the patient to select the individual SACT which they were prescribed and would include information on supportive medicines such as anti-emetics.

6.2 Methods

There were multiple methods used for this study as it involved both DPharm and software engineering undergraduate project work. The initial requirement gathering was undertaken by the software engineering department and involved face to face discussions with the NHS lead investigator to scope out the desired App functionality. Design, build and computation testing was solely carried out by software engineering. This included user interface and screen layout. The lead NHS investigator explored integration with other NHS IT systems, in particular, Chemocare®. App evaluation and usability was a shared responsibility.

6.2.1 App scoping and specification

1. A paper was submitted to the Department of Computer and Information Sciences in Spring 2014 which outlined the requirements of a health app designed to support patients receiving SACT (Appendix 16). Scottish cancer care pharmacists were invited to contribute to the paper. The first version of the app specification was an extensive list of functions which was extensively modified to become a companion app to record and view SACT toxicity, patient's appointments and interactions with healthcare professionals. The app was intended to bridge the gap between hospital care and patients coping with their medicines at home. The functionality of the app was refined to allow users to:
 - Record their side effects including both the date and frequency of toxicity experienced per day
 - View recorded side effects in a diary and as a graph
 - View statistics on recorded side effects such as most frequent and least frequent side effects
 - Record past and future appointments e.g. GP, visits to A&E and visits to their local pharmacy

- Edit and delete recorded appointments and visits
 - Allow the user to clear all entered data
2. The lead investigator (FM) was invited to meet with Department of Computer and Information Sciences senior academic staff at University of Strathclyde in April 2014 to discuss in detail the NHS requirements of the app and to hear the potential opportunities for both undergraduate and postgraduate students to undertake project work with the NHS. The project was assigned to a final year undergraduate student (Liam McCann).
 3. The lead investigator (FM), Dr Marilyn Lennon and L McCann met or teleconferenced at least monthly between October 2014 and March 2015 to agree modifications to the specification and functionality of the app. The app had to be technically novel with evidence of advanced computation to meet the University regulations for the software engineering degree. L McCann produced a set of user cases defining who would use the app and how they might interact with it and a final agreement was reached on the functionality taking into consideration the University time frames and available resources in terms of finance, capacity (F MacLean) and NHS IT support. The app interface, layout and design were agreed in terms of colour, font and swipe versus stylus/icon touch.
 4. Consideration was given to the app's potential to interface with the NHSGGC electronic chemotherapy prescribing system (ChemoCare®) and other NHS systems. A conference call took place with the NHS, University of Strathclyde and *CIS Oncology* in November 2014 to discuss the possibility for an interface with Chemocare®. *CIS Oncology* is the company which owns Chemocare®.

5. A list of common SACT toxicities and a list of healthcare professionals who patients might interact with were supplied by the lead investigator (FM) to allow the build of the systems for recording side effects and appointments. The app was developed in a modular way to optimise faster coding and to facilitate independent testing of the component parts before full integration of the app functionality. The code was created with Adobe Phonegap® which is not platform specific and therefore permitted deployment cross platform.

6. Consideration was given to inclusion of functionality to permit the app to give advice to patients such as what to do if the patient experienced a fever, a bleed or other serious toxicities. The lead investigator (FM) discussed this with other pharmacists who had experience of working with app developers and concluded that the risk to the NHS was too great to include this at this stage of the app development due to potential liability and litigation issues.

6.2.2 Patient stories

1. The lead investigator (FM) sought permission from the Lead Clinician for the Teenage Cancer Trust (TCT) in NHSGGC to interview patients to gather their views and insights into what they might want a cancer app to do. The TCT unit is housed within the Beatson West of Scotland Cancer Centre (WoSCC) in Glasgow.

2. Open interviews took place on 10th November 2014. Four in-patients were interviewed immediately after the Lead Clinician had examined the patients on his ward round by the same investigator to ensure there was consistency across the interviews. Verbal consent was given from each patient. The interviews were not recorded and field notes were taken. The patient stories were used to inform decisions around app functionality.

6.2.3 User testing and evaluation of the app

1. A self-completed 10 point questionnaire was used to evaluate the app in terms of usability and system capabilities in three different populations. The questionnaire was adapted from a validated System Usability Scale provided by Dr Lennon (Appendix 17). A consent form was used for the students and non-healthcare professionals (Appendix 18).

2. L McCann carried out evaluation testing on students and non-healthcare professionals on a one-to-one basis within the University of Strathclyde in 2015. Four students were interviewed to gain app usability feedback and to test the app for operating problems. The students were given the app and were asked to perform the following tasks:
 - record that they were sick three times yesterday
 - add a doctor's appointment for two weeks hence
 - clear all their data

The students were observed as to how well they performed the tasks and were asked to record if they had experienced any difficulties while completing the tasks. They were asked if they had any comments as to how to improve the system to make these tasks easier.

The professionals included a lecturer, graphic designer and a software architect. These participants were interviewed to ask their opinion on the overall work flow of the app, the software used and general feedback. The professionals were interviewed in the same manner as the students and they were asked to do the following tasks:

- record a side effect 3 times yesterday
- record a side effect 3 times 7 days ago

- clear all the data
- view all the recorded side effects

The professionals were observed as to how well they performed these tasks and were asked to record any difficulties they found while doing so or any comments they had on how to improve the system to make the tasks easier.

3. TCT patients were invited by the TCT Clinical Nurse Specialist to a user testing session held in the TCT patient lounge in the Beatson WoSCC in April 2015. This was led by FM with L McCann and Mark Mochan (NHSGGC IT Support) in attendance. This was considered to be internal service evaluation and as the patients chose to attend, implied consent was applied and signed consent was not required. L McCann completed a University of Strathclyde ethics form to permit him to work with F MacLean and the TCT patients (Appendix 19). After a brief overview of the project, the patients were given the opportunity to test the app on mobile devices, tablets and a touch screen desktop computer. Each patient was given a sheet of paper to freely record their comments and thoughts during the testing sessions which lasted about 15 minutes per device.
4. The patients were informally interviewed by FM, L McCann and M Mochan after the testing session had ended and then they were invited to complete the evaluation tool (Appendix 17).
5. After the patient's one-to-one interviews, an open group evaluation session took place at which all the patients were given the opportunity to share their thoughts and ideas about the app.

6.3 Results

6.3.1 Scoping and specification

The app was named *My Wellness Tracker* to promote feelings of health and wellbeing rather than cancer and disease. It was a bespoke app designed to support patients during their SACT journey and provided patients with a single source of data for their pharmaceutical care needs. The app was designed to be professional with no music or pop ups. Modern app techniques such as drag and drop, swiping and clicking were chosen as the preferred method of data entry. The screen colours were chosen as yellow and black in line with the Beatson Cancer Charity. Colours which were associated with a specific cancer e.g. pink which was used by breast cancer charities were all actively avoided. The app was designed to run on all platforms (Android, iOS and Blackberry), mobile devices and PCs/tablets. The app, when published, would be publically available to download and was free of charge. The design security was via a log-in so that only authenticated users could open the app and it was designed to run on individual devices. There was no interface with NHS servers and users were responsible for the security and back up of their own data in the event of a data breach.

An alert alarm to remind patients to take medicines was not included on the advice of the NHSGGC Director of Pharmacy due to the risk involved if the alarm malfunctioned. CIS Oncology, the supplier of Chemocare®, did not permit any interface with their prescribing system based on potential risk to their product. Communication with other NHS systems, for example, SCI-Store where blood test results are stored was not explored given the tight time frames for completion of the app design and the risks attached to data security.

On opening the app, users had 6 options to choose from:

- Record side effects
- View side effects
- Record appointments
- View appointments
- Settings
- About

The toxicity list included:

- Diarrhoea
- Nausea/sickness
- Other skin/nail toxicity
- Neuro toxicity
- Low blood count
- Sore mouth/stomatitis
- Fever/infection
- Hand-foot syndrome

A two-way communication of SACT toxicity between the patient and their clinician was not pursued given this would require interface with NHS IT systems and would require information governance permissions out with the scope and scale of this study. Visual and textual representations of SACT toxicity were preferred including toxicity icons but this was changed to textual only using a tile with the SACT toxicity written in words due to potential infringement of icon copyright (Figure 6.1 & 6.2).

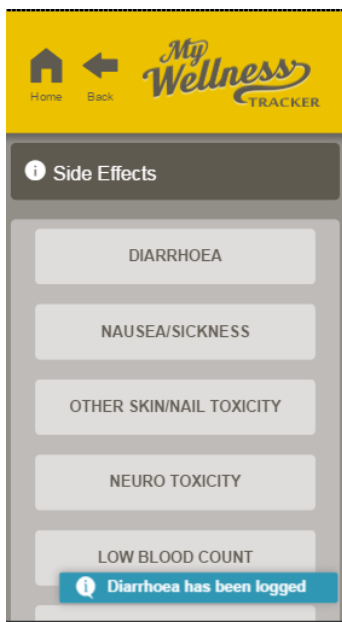


Figure 6.1 App system for recording toxicity

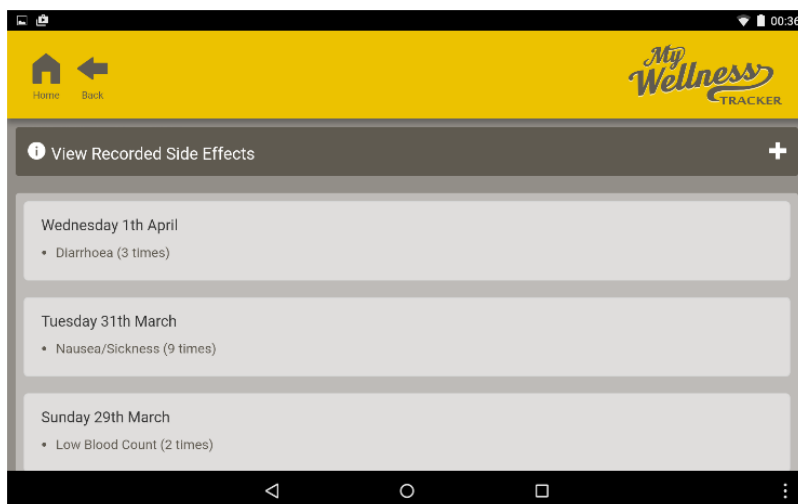


Figure 6.2 View of recorded toxicity

Users could record current encounters with healthcare professionals and future appointments using the date picker.

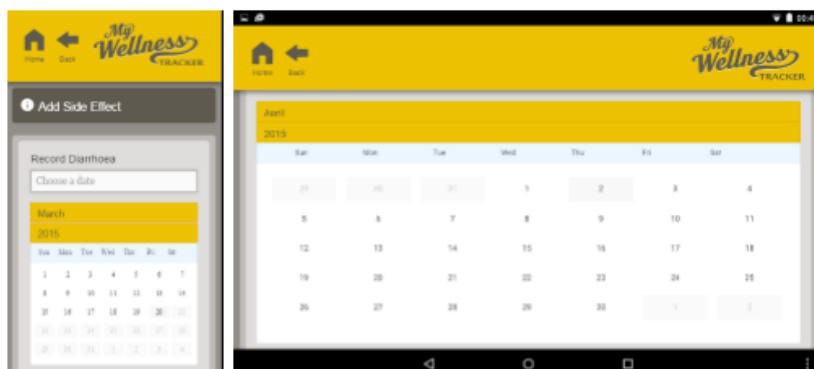


Figure 6.3 Date picker

6.3.2 Patient stories

Four patients were interviewed on 10th November 2014 in the TCT in-patient ward in Beatson WoSCC. A semi-structured interview was chosen to collect qualitative data which would allow the respondent time to talk about their opinions on the proposed cancer app (Table 6.1). The interview took the form of a conversation and the individual responses led to further questioning. Not all respondents were asked the same questions as their individual diseases, treatments and personal circumstances led to different conversations.

Table 6.1 Patient stories

Patient number	Gender	Diagnosis	Preferred App content	Desirable functionality	Comments
One	Female	Acute lymphoblastic leukaemia	Introduction to what chemotherapy is Timetable of when to take medicines Alert/alarm as a medicine reminder Common side effects How to reduce toxicity Self management tips e.g. exercise Contact details for HCPs	Swipe functionality Interactive Icons and pictures Touch icon when medicines taken No pop ups or music	Peripheral neuropathy made touching icons difficult App would be a great resource to dip in and out of
Two	Female	Not discussed	Recording of vital signs e.g. temperature List of all medicines Side effects of medicines Do's and don'ts	Diary style Swipe/click or icons preferred over typing	
Three	Male	Not discussed	Common side effects especially on steroids Self help advice e.g. keeping active	Options for both typing and click/swipe No pop ups No adverts Interface between App users to communicate	Useful to share information with his GP and HCPs not in TCT
Four	Male	Acute myeloid leukaemia	Common side effects and their likely timing Description of medicines e.g. tablet, injection Alert/alarm when to take medicines Blood results Explanation of e.g. saline flush, bone marrow	No pop ups No music Day-by-day diary of treatment	

The content that all the patients wanted in an App were the common side effects of SACT, a timetable of treatments (day-by-day) and self help suggestions.

6.3.3 User testing and evaluation

Testing was carried out on students (n = 4), non-healthcare professionals (non-HCPs, n = 3) and TCT patients (n = 6). A self-completed 10 point questionnaire (Appendix 17) evaluated usability and system capabilities (maximum score = 38). This questionnaire was used on the advice of the academic staff from Computer and Information Sciences. It was a validated scoring system used specifically to test and evaluate IT systems usability and capability. Questions 1 to 7 scored between 1 and 5 points; questions 8 to 10 scored between 1 and 3 points. The patients tested the app on a tablet, Smartphone and PC.

The App was deemed to be slow to run by the students but that was due to it being designed to run across all platforms i.e. on iOS, Android and Blackberry. A suggestion by the non-HCPs to reduce the size of banner at the top and decrease the size of the menu items on the main page was not actioned as the specification required items to be relatively large to enable users to see and interact with given that some users may have visual impairments.

Table 6.2 User testing and evaluation

User	Actual score	% satisfaction	Comments
Students (n=4)	36.75/38	96%	Easy to use Slow compared to native apps Preferable to a paper diary
Non-HCPs (n=3)	35.33/38	92%	Almost perfect Some pausing when loading Liked the branding
Patients (n=6)	33.5/38	88%	Ability to record when side effects were recovering "Other" option in Side Effects Customise the colour Add an activity planner Add feelings charts Add an alarm for treatment days and appointments Glossary of side effects terms List of medicines List of treatments

During the TCT open discussion the following suggestions were made:

- Introduce "My favourites" to avoid repeat typing
- Include functionality as an auto-populate data entry system to self-input medicines by patients as an "organised note pad" for e.g. supportive medicines
- One patient asked for a social network forum within the app
- Add "other" to the list of side effects
- Introduce functionality whereby a tap on the tile will bring up a description of the toxicity e.g. "pins and needles"
- Change "low blood count" to fatigue and infection
- Add cough, nose bleed and headache to the list of side effects
- Introduce a search function rather than a scrolling list
- Group common side effects together
- Include treatment times as a day planner
- Add a brief description of more complicated side effects

6.4 Discussion

App design

Actively engaging patients in their own treatment has been shown to increase the efficiency and effectiveness of health care (Singh *et al.* 2016). Technology for health and wellbeing can support an ageing population and support both independent living and patients in hospital. Healthcare providers currently signpost some patients to bespoke health apps or websites for example, *my diabetes my way*, set up by NHS Scotland (<http://www.mydiabetesmyway.scot.nhs.uk/Userguide/Caslogin.asp>). Mobile health apps offer an alternative choice to paper systems for patients to be an active participant in their health care, for example, tracking symptoms and recording results such as self testing of blood glucose. However, they have to offer more than traditional print or video media and the usefulness of interactive functionality is key to keeping patients engaged (Singh *et al.* 2016). The App design specification (encompassing quality, safety and functionality) should be considered at the outset of the engagement and design stages. If an app is considered to be a medical device it is required to be CE marked in line with the EU medical device directives to ensure they are regulated and acceptably safe to use and also perform in the way the manufacturer/developer intended them to. (MHRA https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/564745/Software_flow_chart_Ed_1-02.pdf, accessed 8th April 2017). Health related apps that are not medical devices fall outside the scope of the Medicines and Healthcare Products Regulatory Agency (MHRA). For these reasons, alerts, pill reminders, advice and logarithms for when to access emergency care were not included in the app design.

A 2016 mobile consumer survey indicated that UK Smartphone user adoption by all adults is at 81%, and is at 91% of 18 - 44 year olds. The app has been pivotal to the commercial success of the Smartphone but a typical UK user downloads 20 or fewer apps (Deloitte, 2016). IBM estimated that a mobile

phone user engages with their device 150 times a day (Neilson, 2013). Apps are more likely to be used when they are simple and are used for tasks which are repeated frequently. This was considered and implemented at the design stage of the *Wellness Tracker*.

User-centred design and good user experience is key to building a successful app. The semi-structured interviews with the TCT patients prior to moving forward with the app planning were essential to get the design and functionality correct for patients with cancer. Some pre-determined questions were used as an icebreaker and to start the conversation. The interviews allowed the respondents time to talk freely about their opinions on a purpose designed cancer app and the interview became more like a conversation. It was important to build a rapport quickly with the patients and be flexible in questioning as they were of different ages and different stages in their treatment. All of the respondents were in-patients and were receiving intensive SACT. The interview was deliberately less formal to be sensitive to their needs and emotional status on the day. Their comments were invaluable and provided a clear insight to some of the side effects of cancer treatments which might make using a touch screen difficult, such as peripheral neuropathy which can adversely affect manual dexterity. The outcome of the interviews and the patient's comments were presented to L McCann and M Lennon to inform the app design.

App testing

App testing was a key part of this study. Any issues that a user found with the app would impact on usability and so it had to be free of bugs and be relatively intuitive to use. Testing using students and non-healthcare professionals was exclusively carried out by L McCann and the results are reported in this thesis for completeness. This testing was considered to be testing of the computing functionality of the app. As mentioned before, integration with other systems was explored but was not included in this version of the app due to data security and information governance

requirements which were out with the scale and scope of this study. Additionally, if the app allowed remote access to real-time patient data via a systems interface this might have meant that the app became a medical device which was neither intended nor desirable at this stage.

The testing with the TCT patients was extremely helpful and these patients represented the likely users of the app. This session was relatively informal to engage better with the teenagers. All of the patients were invited to attend by their Clinical Nurse Specialist so none of them were in-patients at this stage in their treatment. The patient's overall satisfaction score was lower than the student's and the professional's scores. While not explored, reasons for this might include that the patients tested the app in a "real-life" situation in that they had a diagnosis of cancer and were looking for specific functionality, whereas the other groups tested the app for computing ability. The suggestions offered for app development by the patients during the open discussion were all valid and useful for this patient group and would be used to inform future iterations of the app.

Recording toxicity using the App

The toxicity list was chosen to give a broad range of common SACT-induced toxicity. Initially, icons were considered as they would offer a clear visual representation of the toxicity and had been used by Roche in their patient information for capecitabine, an oral SACT. Due to potential copyright infringement this was not pursued and instead the toxicity was named using words. The toxicity list had to be chosen very quickly due to time constraints and it was understood at the time that it would need a revision prior to publication or commercialisation of the app. In future versions of the app, further patient engagement would be needed to ensure that the words used were patient-friendly and were clearly understood. For example, one of the tiles was "*Neuro toxicity*" but this will mean different things to different patients and would need to be broadened out to include neuropathy, perhaps labelled as "*Pins and needles*". One of the TCT patients suggested changing

"Low blood count" to "Fatigue" and "Infection" as these are two clinical consequences of a low blood count which have more meaning for a patient. "Cough", "Nosebleed" and "Headache" were also suggested by the patients to add to the toxicity list. The West of Scotland Cancer Network has published many SACT treatment protocols on the NHS Intranet, some of which could be digitised for future versions of the app. This would offer a selection of NHS approved protocols and remove the need to duplicate work already available.

The app, at this stage, was designed only to record toxicity when it occurred and did not offer any interaction with patients or any feedback or advice. A mobile phone-based advanced symptom management system (ASyMS[®]) was tested in patients receiving SACT for breast, lung or colorectal cancer in 2006 by researchers from University of Stirling (Kearney *et al.* 2009). The mean age of the study participants was 56 years. After completion of an electronic symptom questionnaire, patients received immediate feedback via their mobile phone tailored to their individual reported toxicity. Despite the number of patients contributing data to the study declining steadily from baseline, the ASyMS[®] system provided an accurate means of monitoring SACT toxicity. Moving forward, consideration of a similar type of functionality within the Wellness Tracker would be desirable but would require inclusion of decision-support tools which would almost certainly mean the app would become a medical device.

Patient self-reporting of adverse drug reactions is openly encouraged and contact was made with the MHRA to explore embedding a link to the Yellow Card adverse drug reaction reporting system for patients. This was not followed up due to lack of further dialogue with the MHRA but should be considered for inclusion in a future version of an NHSGGC health app. There is a Yellow Card mobile app which can be downloaded for android and Apple devices and patients could be signposted to this if they have experienced an adverse drug event.

6.5 Conclusion

This was the first purpose designed patient app in NHSGGC and it was considered to be the first iteration of the cancer app. User experience and user-centred design is key to building a successful app. Involvement of both clinical experts and patients in the app development assured the reliability, integrity and relevance of the app for patients receiving SACT. The app was designed to be a companion app for patients receiving SACT and therefore was targeted at a specific group of patients with cancer who were prescribed SACT as opposed to all patients who have had a diagnosis of cancer. Apps designed to address specific patient needs are more effective (Singh *et al.* 2016). The app was designed to be easily maintained and updated. The options selected by patients for inclusion in an app will inform future app updates. The patient questionnaire (Chapter Four) showed that electronic options are not suitable or desirable for all patients and so apps are not for every patient. Technologically advanced patients are likely to be early adopters of apps but paper systems should still be offered to patients to avoid digital exclusion and patients will still have the choice to use the paper SACT record. NHSGGC did not have a policy for app design and implementation and, at the time of completion of this thesis, the app had not been published.

This study represents extremely successful collaborative research and partnership between two separate departments within the University of Strathclyde. The Research and Knowledge Exchange Office at University of Strathclyde drafted an assignment and working collaboration agreement for this study for the shared working with the NHS. This was to set out ownership of the app idea (F MacLean), technical design (L McCann) and joint testing and evaluation (University and NHSGGC) to enable release into the population for future testing and eventual publication.

6.6 Future work

The app was considered to be the first iteration of a bespoke NHSGGC health app. Future work should involve re-labelling the toxicity tiles in a more patient-friendly language, adding more toxicity options and inclusion of quality cancer websites (e.g. Macmillan, Beatson West of Scotland Cancer Centre) for patient signposting. In addition, the contact information for the 24 hour cancer helpline for NHSGGC would be included.

Future versions should include medication history and searching functionality for patients to find out more about their medicines; Frequently Asked Questions; healthy living advice including nutrition, exercise and alternative medicines to avoid. Functionality to locate the nearest community pharmacy would be a valuable option. F MacLean and M Lennon discussed and agreed further collaboration between the NHS and the department of Computer and Information Sciences. Ideally, this would be opened up to the wider clinical pharmacy team, for example, the neurosciences pharmacists who have shown early interest in the use of apps to support patients with multiple sclerosis and myasthenia gravis.

Exploration of patterns of use and types of data accessed by patients would be helpful in maintaining the usability of the product and ensuring it remains fit for purpose. Information on when the app is accessed, where, pages visited and downloads are all very valuable pieces of information for an app developer to improve the app and might bring in some investment. However, compliance with the Data Protection Act must be met and implementation of data encryption and secure servers were out with the scope and scale of this study. NHS Fife has taken a two-step approach to publishing a smoking cessation app. In the initial release, no patient data will be logged. At phase two, with full ethics approval, patients can opt in/opt out of data collection which will be stored on a secure university server. Prior to app publication, the NHS would need to write a suitable section detailing Terms & Conditions

and consent to be agreed by patients at the first download. Within this section, a disclaimer about updates should be included as the app was developed as a native application, that is, it will work directly from the device it is downloaded on, and will only be updated if the user accepts regular updates.

App usage tends to be skewed to the evening and whilst no alerts or alarms were built into the design, a future iteration might have the option of a reminder alarm to alert the user to sign in and record toxicity after, for example, 7pm.

Partnering with cancer charities for future funding and development work should be given consideration, for example, the Beatson Cancer Charity or Macmillan. The app was not given any branding with NHS logos or endorsements to allow flexibility in future developmental work with an external partner. Endorsement by the NHS would provide clinical validity and accreditation and it would be desirable for the app to be available from the NHS app store.

Chapter 7

E-health technologies to support the delivery of pharmaceutical care

Research outcomes and reflections

7.0 Research outcomes

The hypothesis that e-health technologies are enablers of efficient seamless delivery of pharmaceutical care and support pharmacists in all healthcare settings was correct. This thesis brings together the outcomes of a series of investigations designed to follow the treatment journey taken by patients with cancer. For the first time, this research has captured data from both patients and pharmacists and has crossed traditional healthcare boundaries. The model of pharmaceutical care prior to this research was delivery of care in discrete sectors with minimal overlap, cross-communication and very limited shared documentation. This impact of this research has been a change in the traditional model to one whereby electronic capture of pharmacist's interventions is now a standard of care across NHSGGC clinical pharmacy teams using the Clinical Portal e-forms to document care. Further impact will be realised when direct referral from hospital pharmacists to GP based pharmacists takes place and there is transfer of ongoing pharmaceutical care issues to the community-based teams. The final iteration will be the agreement and implementation of pharmaceutical care bundles with three levels of tiered pharmaceutical care delivered by community pharmacists, empowered to do so by their enhanced levels of competency and training.

Methodology and presentation of data

The research aims of the NHSGCC Pharmacy and Prescribing Unit (PPSU) are to develop capacity and capability. This involves innovation, collaboration and evaluation. Practice based health services research aims to solve problems and seek out solutions to challenges that impact on safety, quality of service and capacity. Practice research in clinical pharmacy is evolving and the service demands evidence to support policy and practice (Chen & Hughes, 2016). This thesis describes qualitative studies which were undertaken to explore and evaluate e-health technologies and electronic solutions to support the delivery of pharmaceutical care to patients with

cancer. Qualitative methods were chosen to enable observation of clinical pharmacists performing their duties and to conduct surveys of both patients and community pharmacists.

Strategies to ensure validity of the studies included peer debriefing which was applied to the focus group. A recognised qualitative researcher was actively involved in the set up, running and analysis of the focus group and provided guidance and critique of the thematic analysis. Whilst the studies were conducted on patients with cancer, the conclusions and suggestions for future work should be considered as generalisable across other disease areas and therefore should not be seen in isolation as only suitable for patients with cancer as the focus was on e-systems enabling delivery of care and not on individual's practice and behaviours. The NHSGGC Clinical Portal contains admission and discharge details for all patients who have an interaction within an NHSGGC acute hospital and therefore the principles of electronic records and communication across care boundaries are applicable across the wider NHSGGC clinical pharmacy teams, and there is international recognition of the need for systems to accurately transfer medicines information at the care interface (Clark 2016).

Use of IT to enhance efficiency of clinical pharmacy practice

Clinical pharmacy leaders are responsible for developing and evaluating patient-facing services and practice research is key to driving innovation. Delivery of pharmaceutical care in a modern NHS is facing greater challenges today than ever before in terms of faster movement of patients through in-patient wards, a shorter length of stay which affords limited time for individualised care, and financial constraints. Clinical pharmacists can improve the efficiency of their practice by reducing duplication and improving record keeping thereby performing a task once and ensuring a permanent record is available in the electronic patient record for the wider clinical team. The process mapping and examination of the clinical pharmacists who

worked without access to mobile IT kit as described in Chapter Two, demonstrates inefficiencies in delivering the service. Whilst there was no follow-up study after the deployment of laptops to clinical pharmacists in 2015, other researchers have reported that access to tablet PCs has improved pharmacist satisfaction and enhanced patient care (Cummings *et al.* 2008; Cockerham 2009). The NHSGGC clinical pharmacists now have access via their laptops to real time clinical information and there has been widespread adoption of use of the electronic pharmacy continuation form which was one of the recommendations from the process mapping for service improvement (Table 2.4). Further work to update the NHSGGC standards for pharmaceutical care to ensure that electronic documentation of pharmaceutical care is a core standard should be undertaken.

Use of electronic pharmaceutical care plans to communicate at care transitions

NHS Scotland's vision is care close to home. This has seen a shift from in-patient to ambulatory care where many more patients receive treatment, including SACT, on an out-patient basis. One of the consequences of this shift is that post-SACT toxicity is experienced at home, not in hospital in-patient wards. The availability or transfer of clinical information between care settings is essential to patient safety and delivery of comprehensive pharmaceutical care will be realised when all pharmacists regardless of setting have access to key patient information. The lung cancer patient pathway (Appendix 1) was illustrative of the many points of care that a patient encounters throughout their cancer journey. Medicine safety is often weakest at transfers of care and collaboration between hospital and community pharmacists is vital. This needs joint consultation about medicines and establishment of professional links (Clark, 2016). The case for electronic patient care plans which are accessible to the wider clinical team is made by observing the number of care transitions a patient will typically experience.

A selection of pharmaceutical care issues associated with lung cancer SACT could be managed out-with specialist cancer services and delivered close to home by suitably supported and trained community-based pharmacists. The model for this is a step-wise and controlled approach to moving care delivery away from specialist hospital pharmacists to generalist pharmacists based in general practice in the community. NHSGGC has adopted this step-wise approach asking pharmacists who are not cancer specialists to deliver pharmaceutical care directly to patients with cancer under controlled conditions via a formal electronic referral. The initial step is to refer patients to general practice pharmacists. *Improving the Cancer Journey* is a collaboration between Glasgow City Council and the NHS and is an example of joint health and social care working. Patients from the Glasgow Southside lung cancer clinical team who have medicines concerns will be referred by the cancer care pharmacist to their GP practice pharmacist for a medicines review. The electronic pharmaceutical cancer care plan will be used to document the pharmaceutical care issues for transfer to primary care and will be used for two-way communication. The input from the practice pharmacists will be evaluated by other researchers and the outcomes will be used to help inform future delivery of care from community pharmacists.

Enhanced role for community pharmacists

The analysis of the lung cancer patients identified pharmaceutical care issues and SACT toxicity but, as it was a retrospective study without patient interaction, was unable to ascertain how patients dealt with toxicity experienced in the community and if they required additional medicines. The questionnaire issued to patients with cancer was reported in Chapter Four and this direct questioning of patients enabled a deeper understanding of who patients sought help and advice from in the intervals between SACT and explored the potential roles of the community pharmacist in this scenario. Most patients (37%), as expected, sought advice from their GP while only 4% of patients sought advice from a community pharmacist. Despite this low number, 37% of respondents agreed that a community pharmacist could

support them during their cancer treatment and 97% agreed that their clinical information could be shared with their community pharmacist. Some patients required additional medicines between hospital appointments. Twenty-six percent of patients purchased medicines and 50% of patients were prescribed medicines in the interval between SACT. As there is no single patient record for listing all medicines that a patient is taking, it is possible that patients might experience therapeutic duplication as they encounter multiple prescribers during the cancer journey. The South Glasgow lung service has had episodes of patients prescribed multiple medicines from similar therapeutic classes, for example, both domperidone (from the GP) and metoclopramide and ondansetron (from the cancer day ward). This greatly increased the risk to the patient from QT prolongation. A single medicines list might have prevented this from happening.

Barriers to care and some solutions

Community pharmacists in NHSGGC at the time of this thesis did not have access to Clinical Portal although a pilot of controlled access to some clinical data fields in Portal was planned. Community pharmacists have identified the lack of effective communication as a key challenge in their interaction with patients and carers. Their lack of access to systems and information is a barrier to patient care and their patients have an expectation that the community pharmacist has access to the necessary information. The community pharmacist focus group and questionnaire (Chapter Five) was conducted to provide further dialogue between the hospital specialist clinical pharmacist and community pharmacists to identify how best to communicate clinical information and to identify training needs to enable community pharmacists to confidently support patients through SACT. The response rate for the questionnaire was disappointing low despite three reminders. Only 11% of community pharmacists who responded to the questionnaire claimed to be confident in providing pharmaceutical care to patients prescribed SACT. Lack of patient contact and experience was cited most

commonly as the reason for this lack of confidence and that ranged from not knowing that the patient had cancer to lack of knowledge of SACT and how to manage toxicity. The community pharmacists were asked what training they would like to address confidence and educational needs. They suggested a range of training options from specialist evening sessions to web-based learning. NHSGGC pharmacists have engaged with NHS Education Scotland (NES) to initiate early dialogue as to how NES can support the training needs of community pharmacist with respect to cancer care.

Specialist support for community pharmacists

A patient might seek advice from a community pharmacist for relatively simple SACT toxicity. For example, 50% of patients experienced mucositis between SACT cycles and a range of mouth preparations were obtained by the patients from the community. Grade one and two mucositis could be managed by a community pharmacist with the appropriate training and access to treatment protocols. Cancer care pharmacists in NHSGGC have started to write clinical vignettes for publication in the Community Pharmacy electronic bulletin which is emailed to all NHSGGC pharmacists. The first publication was how to manage grade 1 dry eyes and when and how to refer to specialist cancer out of hours services. Future vignettes will be written and the topics will be informed by this thesis and direct communication with interested community pharmacists who have asked to work directly with the South Glasgow cancer care Lead Clinical Pharmacist. The first vignette has been shared with cancer care lead pharmacists across NHS Scotland.

Health and wellbeing Apps

This thesis explored e-health solutions in terms of both systems controlled by the NHS and patient-held health and wellness mobile phone applications. Innovative digital solutions can enhance patient's interactions with healthcare and can improve efficiency by providing a single repository for clinical data. Appropriately designed health and wellbeing Smartphone applications should

be explored when considering e-health technologies to support the care of patients. The *Wellness Tracker App* was designed as a companion App to regular engagement with healthcare professionals and was not intended to replace a consultation with a doctor or a community pharmacist. Telehealth should improve health and wellbeing, not replace face-to-face engagement with healthcare professionals. The App was purposely designed to be simple, safe and risk-free with respect to the NHS. Despite this, the positive feedback from those invited to test the App was reassuring and provided enough confidence to consider the *Wellness Tracker* to be the first iteration of this App. It will remain with PPSU e-health colleagues to take forward pharmacy-initiated health and wellbeing Apps.

Pharmaceutical care bundles

The Scottish Oncology Pharmacy Practice Group initiated work in collaboration with the Directors of Pharmacy in May 2017 to develop pharmaceutical care bundles to support delivery of SACT out with specialist cancer centres and units. The levels of pharmaceutical care to be delivered by community pharmacists will be considered in conjunction with existing and future e-health technologies so that patients will be equally supported in all care environments and all providers of that care have appropriate access to the relevant clinical information. Seeking positive outcomes from drug therapy and reducing harm from medicines is central to pharmacy practice: e-health technologies can assist with making this happen. Collaboration between hospital pharmacists and primary care and community pharmacists will reduce the risks encountered at the transfer of care. However, all pharmacists must have access to electronic health records and a fully integrated single electronic patient record is still the ideal. Behavioural changes for pharmacists in all care settings are required to affect change and gaps in digital literacy should be identified and addressed.

Adoption of health information technology by pharmacists is vital to maximise the benefits from current and future e-health technologies. Future research

might include illustrative case studies exploring the actual benefits of sharing patient's clinical data in terms of medicines safety, patient satisfaction and enhanced pharmaceutical care.

7.1 Reflections from research

The research plan was agreed in 2012 with the Director of Pharmacy and the University supervisors. Subsequent to that, NHSGGC underwent significant changes in how healthcare was delivered with closure of five hospitals and the opening of the Queen Elizabeth University Hospital in 2015. Clinical Portal was rolled out to GP practices and the implementation of *Prescription for Excellence* resulted in a significant shift of pharmacist resource to primary care starting in 2016. The lack of access to patient's data by community pharmacists is a barrier to providing a holistic medicines review and was cited by some community pharmacists as one of the reasons for their lack of confidence in providing pharmaceutical care to patients with cancer. On reflection, conducting research with GP practice pharmacists would have been a valuable addition to this thesis although this role is still developing. In addition, requesting a direct referral system from hospital to primary care sooner might have re-focussed the research and could have provided data to support this type of referral which was not in place within NHSGGC. It was unfortunate that the *Wellness Tracker* App was not published and encouragement should be given to others who look to Apps as a way of supporting patients' health and wellbeing.

The research journey and defence of this thesis has afforded opportunities to grow both as a researcher and as a pharmacist. At the outset of this work I had mostly conducted small scale audits and service evaluations. The desire to take on a much larger project culminating in a research degree was borne out of a desire to improve patient care through measured and meaningful changes which would provide inspirational models of care for my pharmacist peers to work towards. I have developed project management skills and

clarity of thought with regards to hypothesis generation and testing. I have achieved skills in data extraction and analysis; use of specialist research software such as Qualtrics® and NVivo® and I have had the opportunity and privilege of cross-functional working with researchers and academic staff out with the Institute of Pharmacy and Biomedical Sciences. This has laid the foundations for future collaboration and I hope to support and encourage pharmacists into research in the future. I will also maintain a relationship with my supervisors, my internal examiner and the postgraduate peer group who have been great a source of support and encouragement throughout the DPharm.

In summary, clinical pharmacists in NHSGGC have benefited from mobile IT kit and the foundations of delivering pharmaceutical care across the primary and secondary care interface are in place. The e-health solutions implemented include e-pharmaceutical care plans and electronic referrals between pharmacists. It is hoped that health apps will follow and that all the potential benefits to patient will realised.

7.2 Future research recommendations

The impact of mobile IT kit on clinical pharmacist's work patterns could be assessed. This might include time to complete tasks and the use of electronic medicines sources whilst on ward rounds.

Usefulness of the NHSGGC clinical vignettes could be evaluated using an electronic questionnaire to all NHSGGC community pharmacists; by random sampling of some community pharmacists; or directly targeting questions at community pharmacists who expressed an interest in receiving cancer clinical information.

Future research could include evaluation of direct referral from hospital pharmacists to GP practice pharmacists to identify the types of referrals, the

scale of referral patterns, outcomes and the impact on patient care. Some of this might be evaluated by the Improving the Cancer Journey team.

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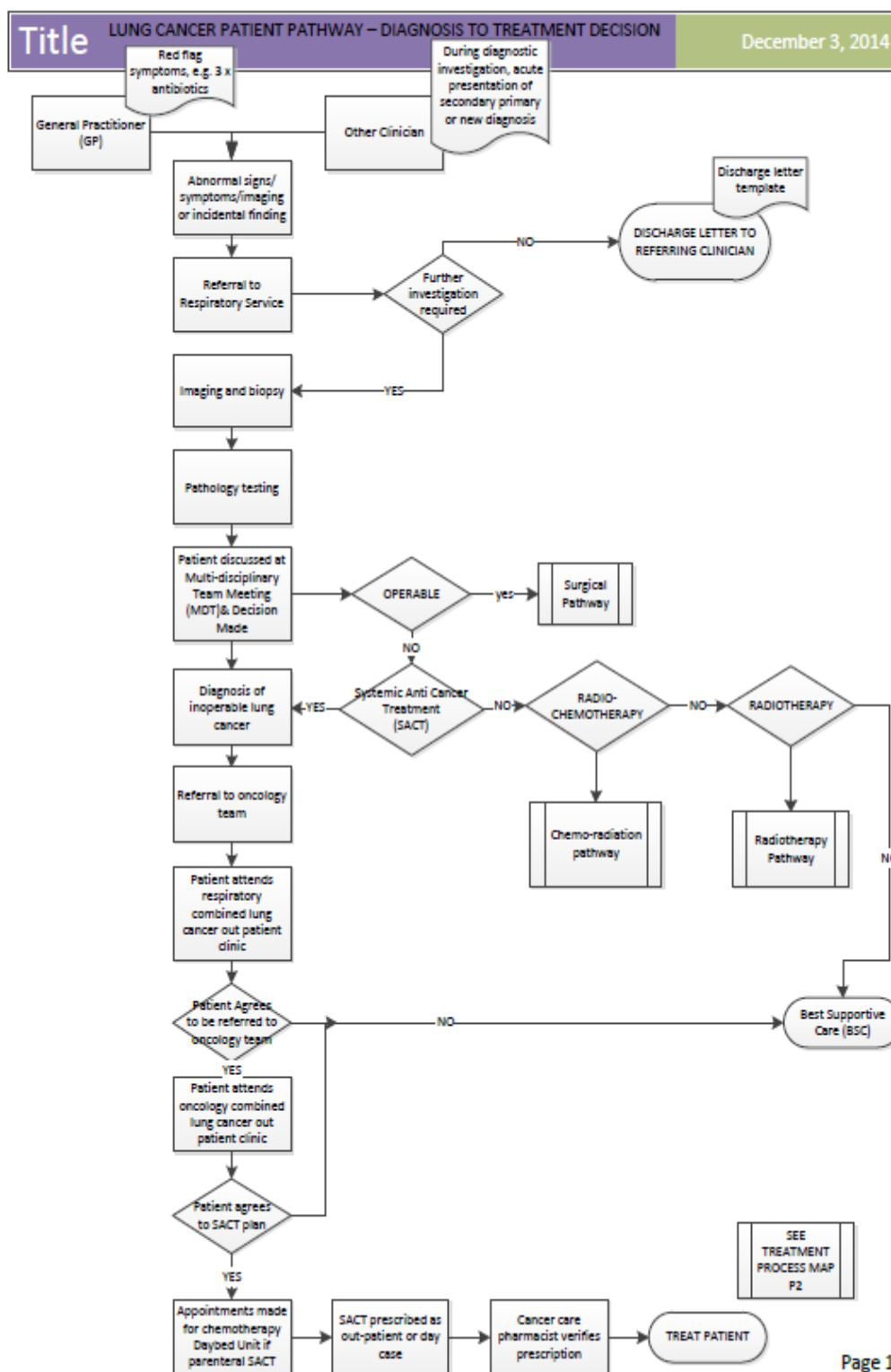
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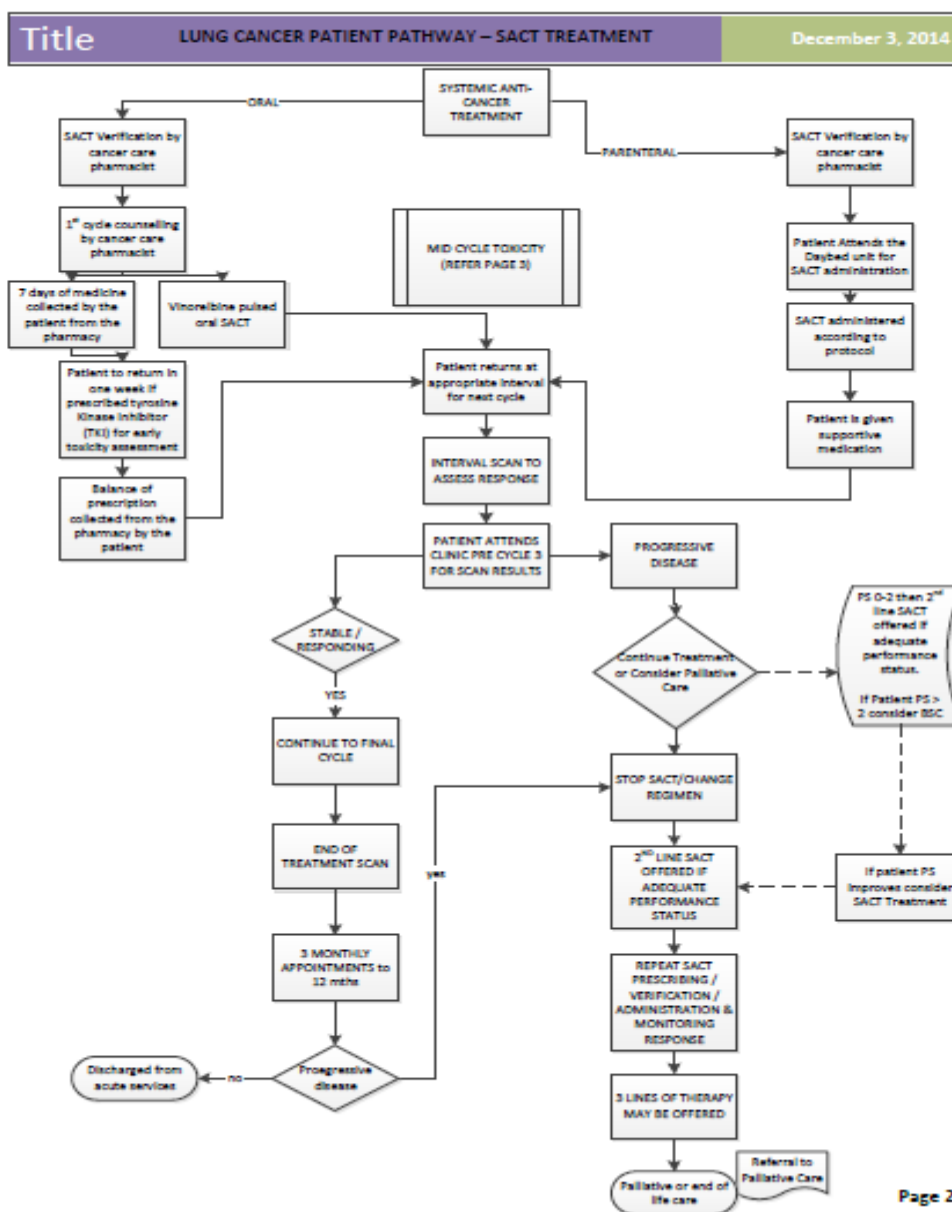
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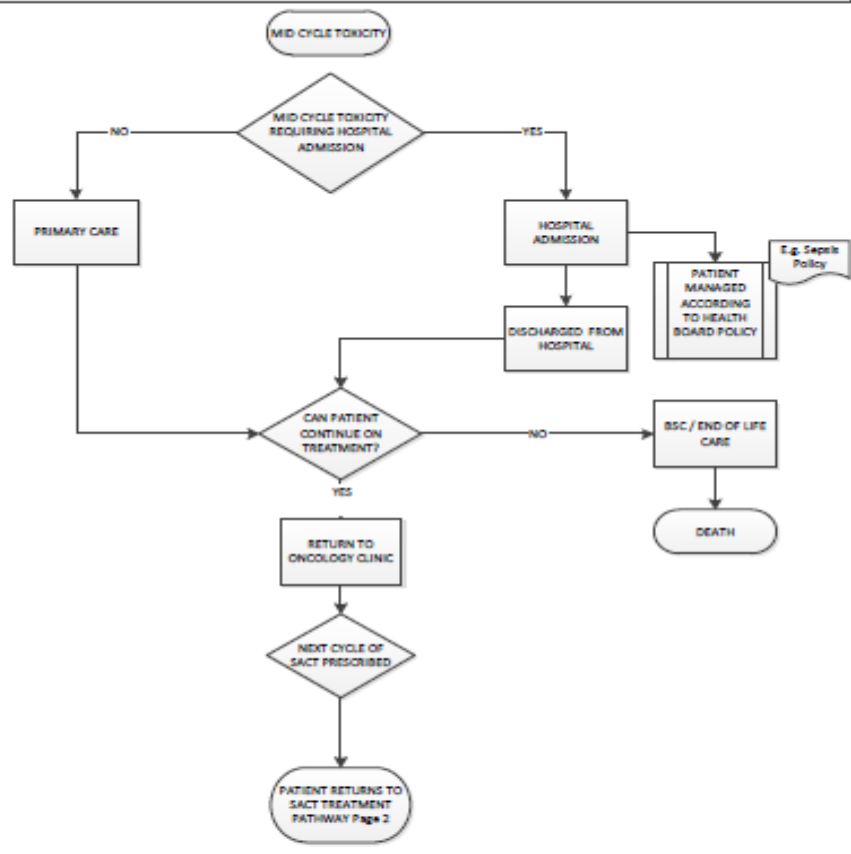
Appendices

Appendix 1

Lung cancer patient pathway, NHS Greater Glasgow & Clyde, relating to Chapters 1 and 3.








Appendix 2

Submission paper for mobile IT kit prepared for NHS Greater Glasgow and Clyde Pharmacy e-Health Group, relating to Chapter 2.

	<p>NHS Greater Glasgow & Clyde Pharmacy & Prescribing Support Unit (PPSU)</p> <p>SUBMISSION PAPER</p>
<p>FROM:</p>	<p>Alister MacLaren/Angela Munday/Fiona MacLean on behalf of PPSU eHealth Group</p>
<p>TO:</p>	<p>PPSU Executive</p>
<p>DATE:</p>	<p>Oct 2014</p>
<p>SUBJECT:</p>	<p>Mobile computers for clinical pharmacists within acute hospitals</p>
<p>Situation:</p>	<p>The strategic direction of the NHSGG&C Acute Services Division is towards paper light/free working as evidenced by implementation of the TrakCare Patient Management System, and the roll out of Electronic Patient Records (EPR) viewed through the clinical portal. The new South Glasgow Hospital due to open in 2015 will require all services to be paper light/free from day one.</p> <p>The average length of stay (LoS) for inpatients is due to become shorter, across GG&C, prior to the new hospital opening</p> <p>These developments require changes to the way in which clinicians work and create opportunities to improve the quality of services. PPSU Acute Pharmacy services have been responding to these changes and have identified new ways of practice, but access to computers, particularly in clinical areas, is problematic and a barrier to progressing new ways of working. There is due to be an increase in computers on wards within the new hospitals, but as all ward staff are required to be paper-lite, pharmacy is unsure how much access will be available</p> <p>Pharmacists require real time access to electronic systems which is consistent with the peripatetic nature of their work, and facilitate decision making at the patient bedside (see appendix 1). This paper highlights the need for mobile devices for clinical pharmacists.</p>
<p>Background:</p>	<p>In their day to day practice, clinical pharmacists require access to TrakCare, the Clinical Portal, electronic prescribing systems such as ChemoCare & SERPR, information resources on the internet, etc. Changes to the way we provide clinical pharmacy services is</p>

	<p>based on the assumption that pharmacists can access these electronic systems easily and in real time.</p> <p>Recent developments to which this is fundamental include clinical pharmacy triage and referral, clinical pharmacy team working, verification of electronic medicines reconciliation, checking electronic Immediate Discharge letters (IDLs) and pharmaceutical care planning. Pilots of triage and referral show the systems are beneficial, but labour intensive and cannot be rolled out without appropriate IT support.</p> <p>Clinical pharmacists are peripatetic moving between clinical areas, pharmacy and meetings throughout the day. They are often in a particular area for a short period of time and need dedicated real time access to a computer to facilitate their workflow and prevent delays in providing their service. Access is required at short notice to remotely check IDLs and support timely discharge of patients.</p>
<p>Assessment:</p>	<p>There is ongoing liaison between pharmacy and IT, resulting in pharmacy staff currently involved in a number of pilots for different mobile devices</p> <p>The Transforming Clinical Administration team have shadowed clinical pharmacists and their report recommends the need for mobile technology to support safe and efficient clinical pharmacy practice (appendix 1)</p> <p>The LCPs have recommended that 115 laptops/tablets are required to support their teams across NHS GG&C (see appendix 2), which includes sharing between pharmacists</p> <p>IT has advised of approx costs (appendix 3). Estimated costs: 115 tablets x £818 (tablet) + £461 (software) + £60 (docking strn) = £154,000</p>
<p>Recommendations</p>	<p>Funding is released to support mobile devices within the acute sector to allow modernised working, and meet the needs of patients.</p> <p>Funding for the hospital staff moving to the new hospital is required urgently to allow these practitioners to adopt this way of working 6 months prior to the move. If sufficient funding is not available for all hospitals, we would request that the hospitals moving to the new hospitals are funded this year (56 tablets required equating to approx £75,000) and the remaining hospitals in the next financial year, to allow for full roll out of triage and referral</p>

Appendix 3

Common toxicity criteria scoring system, relating to Chapters 3 and 4.

NCI Common Toxicity Criteria

TOXICITY	GRADE 0	GRADE 1	GRADE 2	GRADE 3	GRADE 4
Nausea	none	able to eat reasonable intake	intake significantly decreased but can eat	no significant intake	_____
Vomiting	none	once in 24 hours	2-5 times in 24 hours	6-10 times in 24 hours	>10 times in 24 hours requiring IV support
Diarrhoea	none	increase of 2-3 stools/day over pre-RX	increase of 4-6 stools/day or nocturnal stools or moderate cramping	increase of 7-9 stools/day or incontinence or severe cramping	increase of >10 stools/day or grossly bloody diarrhoea or need for parental support
Stomatitis	none	painless ulcers, erythema or mild soreness	painful erythema, oedema or ulcers, but can eat	painful erythema, oedema, or ulcers, and cannot eat.	requires parental or enteral support
Skin	none or no change	scattered macular or papular eruption or erythema that is asymptomatic	scattered macular or papular eruption or erythema with puritis or other associated symptoms	generalised symptomatic macular, papular or vesicular eruption	exfoliative dermatitis or ulcerating dermatitis
Alopecia	no loss	mild hair loss	pronounced or total hair loss	_____	_____
Neuro-hearing	none or no change	asymptomatic hearing loss on audiometry only	tinnitus	hearing loss interfering with function but correctable with hearing aid	deafness not correctable
Neuro-sensory	none or no change	mild paresthesia, loss of deep tendon reflexes	mild or moderate objective sensory loss; moderate paresthesia	severe objective sensory loss or paresthesia that interfere with function	_____
Haematological					
white blood cells	>4.0	3.0-3.9	2.0 - 2.9	1.0 - 1.9	<1
platelets	normal limits	75 - normal	50 - 74	25 - 49	<25
Haemoglobin	normal limits	10.0 - normal	8.0 - 10.0	6.5 - 7.9	<6.5
Granulocyte	>2.0	1.5 - 1.9	1.0 - 1.4	0.5 - 0.9	<0.5
Lymphocyte	>2.0	1.5- 1.9	1.0 - 1.4	0.5 - 0.9	<0.5
Other	none	mild	moderate	severe	life-threatening

Non CTC Graded Criteria

Grade 1 = mild

Grade 2 = moderate

Grade 3 = severe

Grade 4 = life threatening

WHO PERFORMANCE STATUS

- 0 Able to carry out all normal activity without restriction
- 1 Restricted in physically strenuous activity but ambulatory and able to do light work
- 2 Ambulatory and capable of all self-care but unable to carry out any work. Up and about more than 50% of waking hours.
- 3 Capable of limited self-care, confined to bed or chair more than 50% of waking hours
- 4 Completely disabled. Cannot carry on self-care. Totally confined to bed or chair.

KEY TO ABBREVIATIONS

- LFTs liver function tests
- bili bilirubin
- m² square metres
- creat creatinine
- NTE not to exceed
- GFR renal clearance
- SA surface area in m²
- Hb hemoglobin
- WNL within normal limits
- neut neutrophils
- wt weight
- plat platelets
- wbc white blood count

Appendix 4

Patient questionnaire and covering letter, relating to Chapter 4.



Patient questionnaire

Medicines used to manage cancer can cause some side effects and it is important that patients, doctors and pharmacists know how to recognise and treat the side effects.

Your answers to these questions will be used to help hospital pharmacists and community pharmacists support patients during their treatment with chemotherapy.

The questions are about the time period between your last chemotherapy treatment and today.

Your participation is completely voluntary and you can choose not to complete this questionnaire. It will not impact on your care or on your medicines if you choose not to participate.

Your name and date of birth will not be used in any analysis and is needed only to link your treatment with any side effects experienced. You may choose to leave this blank.

All answers are confidential and all data will be anonymised.

I will be happy to answer any questions you might have.
Thank you,

Fiona MacLean

Fiona MacLean, Lead Cancer Care Pharmacist
Telephone: 07983 520479

Appendices

1	Since your last chemotherapy treatment, have you had any of the following: (please tick only the ones that apply):		
		√	For how many days?
a	Infections		
b	Feeling sick		
c	Being sick		
d	Constipation		
e	Diarrhoea		
f	Sore or dry mouth		
g	Skin rash		
h	Numbness or tingling in fingers or toes		
i	Toe or finger nail pain or inflammation		
j	Sore or dry eyes		
k	Any problems swallowing medicines		
l	Any problems obtaining medicines (please give details)		
m	Other (please give details):		
2	Since your last chemotherapy treatment, did you ask for advice from any of the following (please tick only the ones that apply):		
		√	
a	Your GP		
b	A community pharmacist		
c	A hospital cancer ward		
d	A chemotherapy day clinic e.g. Clinic P in New Victoria Hospital		
e	NHS 24		
f	A 24 hours cancer helpline		
g	Family or friends		
h	Other <i>Out of Hours</i> services		
3	Since your last chemotherapy treatment, have you bought any medicines from a pharmacy or other shop?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, what did you buy?			
4	Since your last chemotherapy treatment, have you been prescribed any medicines other than your chemotherapy?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If yes, what medicines were you prescribed?			
5	Do you think you were given enough information about how to manage your chemotherapy side effects?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If No, can you describe what information was missing:			

Appendices

6	Do you attend:		
a	The same community pharmacy	Yes <input type="checkbox"/>	No <input type="checkbox"/>
b	Different pharmacies (depending on convenience for example)	Yes <input type="checkbox"/>	No <input type="checkbox"/>

7	Would you allow the hospital team to share information about your medicines with your community pharmacist?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
---	---	---------------------------------	--------------------------------

If No, please explain why:

8	Do you think that a community pharmacist could offer you support during your chemotherapy?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
---	--	---------------------------------	--------------------------------

If Yes, what would you like a community pharmacist to do for you?

9	We are designing a Smartphone App to record medicines and management of chemotherapy side effects. Do you have a Smartphone? A Smartphone is a phone that connects to the internet, for example an iPhone, Blackberry.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
---	--	---------------------------------	--------------------------------

10	Do you think you might use an App designed to record information about your medicines?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
----	--	---------------------------------	--------------------------------

11	What would you like recorded on the App? (please tick all that apply)	
	A list of your medicines <input type="checkbox"/>	The common side effects <input type="checkbox"/>
	Your side effects <input type="checkbox"/>	Contact telephone numbers <input type="checkbox"/>
	Appointment dates <input type="checkbox"/>	Test results e.g. blood counts <input type="checkbox"/>
	A treatment timetable <input type="checkbox"/>	
	Other:	

(Optional)

Name: _____

Date of birth: _____

FOR OFFICE USE ONLY

CHI		Date of questionnaire	
Regimen & cycle number		Date cycle 1	

Appendix 5

Ethics approval letter, relating to Chapter 4.



WoSRES
West of Scotland Research Ethics Service

West of Scotland Research Ethics Service
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT

Ms Fiona MacLean
Lead Clinical Pharmacist
Regional Services Directorate
New Victoria Hospital
Grange Road
Glasgow G42 9LF

Date 21st May 2014
Our Ref WoS ASD 952
Direct line 0141 211 2126
Fax 0141 211 1847
E-mail Judith.Godden@ggc.scot.nhs.uk

Dear Ms MacLean

Full title of project: An Evaluation of the Suitability of an Electronic Pharmaceutical Care Plan on the Delivery of Pharmaceutical Care to Patients with Lung and Blood Cancers in the New Victoria and Southern General Hospitals.

You have sought advice from the West of Scotland Research Ethics Service Office on the above project. This has been considered by the Scientific Officer and you are advised that based on the submitted documentation (email correspondence 16th May 2014) it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees (A Harmonised Edition). This advice is based on the following.

The project is an evaluation seeking the views of patients on their pharmaceutical care. Recruitment is invitational and responses to the questionnaire are fully anonymous so that the respondent's identity is fully protected.

Note that this advice is issued on behalf of the West of Scotland Research Ethics Service and does not constitute a favourable opinion from a REC. It is intended to satisfy journal editors and conference organisers and others who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Kind regards

Dr Judith Godden, WoSRES Scientific Officer/Manager

Appendix 6

Information governance approval, relating to Chapter 4.

Appendices

Hi Fiona

I assume questionnaires will be given out when attending services and if no identifiable data is to be collected on this, then you would not require Caldicott approval.

Regards

Isobel

[Isobel Brown](#) | Information Governance Manager | NHS Greater Glasgow & Clyde |
Western Infirmary | Management Building | Dumbarton Road | Glasgow | G11 6NT |
T: 0141 211 1790 | E: isobel.brown@ggc.scot.nhs.uk | W: www.nhsggc.org.uk

[Home - Information Governance](#)

From: Maclean, Fiona
Sent: 19 May 2014 14:51
To: Brown, Isobel
Subject: Research proposal, Caldicott approval

Dear Isobel Brown

I am undertaking a Doctor of Pharmacy degree with Strathclyde University. I have attached a letter outlining my research proposal and my question is does this require Caldicott Guardian approval? Please let me know if you require any further information.

Kind regards, Fiona MacLean

Fiona MacLean

Fiona MacLean MRPharmS, MSc, IPres
Lead Clinical Pharmacist, Regional Services Directorate - Cancer South & Clyde, and Neurosciences

Appendix 7

Free text answers from the patient questionnaire, relating to Chapter 4.

Questionnaire number	Question	Response
1	4	Lactulose, Bonjela, E45
2	1(m)	Sore arm
	4	Antiemetic
3	1 (d)	Most days
	8	The management of any side effects – an extra line of help
5	4	Amoxicillin
6	1(m)	Body weakness
	4	Paracetamol
7	1(m)	Heartburn
	3	Gavison Advanced liquid, Benylin Dry Cough
	8	A helpline
8	3	Cough bottle (not specified)
	4	Amoxicillin
9	4	Antiemetic
11	4	Augmentin, dihydrocodeine, Solpadol, letrozole
12	1(m)	Nose bleed
	4	Sertraline
	5	Help with GI problems
	8	Advise re handling/resolving common side effects
13	3	Ibuprofen/paracetamol
14	4	Omeprazole
15	4	Cream for dry lips
	8	Have prescription ready when required
16	4	Penicillin V
17	3	Co-codamol, ibuprofen
	4	Omeprazole
	8	Discuss side effects and medicines for them
18	4	Fucidin topical for rash
20	8	To be aware you have cancer and you are having chemo
22	4	Antiemetic, heart tablet (from care plan, ramipril)
23	1 (m)	Very tired
24	4	Antibiotic for chest infection
25	1 (m)	Headaches, tenderness in skin, feeling that the top half of my body is all bruised
26	3	Milk of magnesia
	5	I felt I was trying to take too much in at once on my first visit
27	1 (l)	GP takes time to get from local chemist
	3	Bonjela
	4	Iron tablets
28	3	Robutussin for cough
	4	Eye drops for dry eyes (not specified)
31	1(m)	Sore bones, very dry skin, peeling, especially hand & feet, skin breaking open – painful.

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	3	Paracetamol & ibuprofen for bone pain
	8	General advice about managing side effects
	11 (h)	Advice about managing side effects i.e. what over the counter medicines would be beneficial
32	1 (m)	Muscle pain
	3	Paracetamol
	8	A form of professional to phone/visit and see condition
33	4	Nystatin
34	4	Atenolol, ramipril, metformin, blood pressure medicine
35	1 (l)	Exemestane
	4	Nose spray
36	3	Cough bottle, paracetamol, Anusol cream, cold sore cream
	4	Mouth drops for thrush
	8	Prescribe for things like diarrhoea or constipation
38	3	Paracetamol & ibuprofen
39	3	Multivitamins
40	4	Ondansetron
41	1 (l)	Had to wait 45mins after treatment finished on one day
	8	Ran out of normal medicines and had to have it renewed when I was away from home
42	4	Biotene, Diprobase
45	4	Antibiotic
46	4	Hydrocortisone cream
47	1 (m)	Burn on vein used for chemo
	3	Movicol
48	1 (m)	Nose bleed
	8	Offer any relevant help with your treatment
50	1 (m)	Urine infection
	4	Antibiotic
51	1 (m)	increased reflux & indigestion
	3	Difflam mouth spray and Zovirax cream
	4	Difflam mouthwash
	8	Just advice if required
52	4	Antibiotics
	5	Pain relief before effects of treatment
54	1(m)	Very heavy cold and chest cough; this was the cause of my sticky eyes.
	4	Antibiotic
	8	Only on occasions when I need extra medicines due to other illness. To be aware of drugs I take and offer advice about how supplementary drugs may affect me.
55	4	Nystatin suspension Fluconazole 50mg caps
56	5	You only get told when you ask about specific issues, other than standard issues

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58	1(m)	Streaming eyes
	8	Reassure with side effects, mouth/eyes, rashes
59	1(f)	Mouth ulcers
	1(j)	Chronic dry eyes
	3	Mouth wash, paracetamol, Bonjela
	4	Caphasol, Nexium (to swap with omeprazole)
60	1(j)	Occasional dry eyes
	3	Paracetamol with caffeine
	8	They already give excellent support during our chemotherapy
61	1(g)	Intermittent, comes & goes
	4	Laxido, cream for rash (hands)
63	1(m)	Tiredness
64	1 (m)	Previous treatments caused constipation so now I take lactulose the night before, for 2 more nights and now no problem
	4	GTN spray
	8	Deliver prescription
65	3	Codeine linctus
67	4	Cyclizine, steroids, Piriton, indigestion tablets, moisturising cream
	8	Oncall to answer questions
68	3	Anadin Extra
	8	As I didn't have any problems unsure

Appendices

Appendix 8

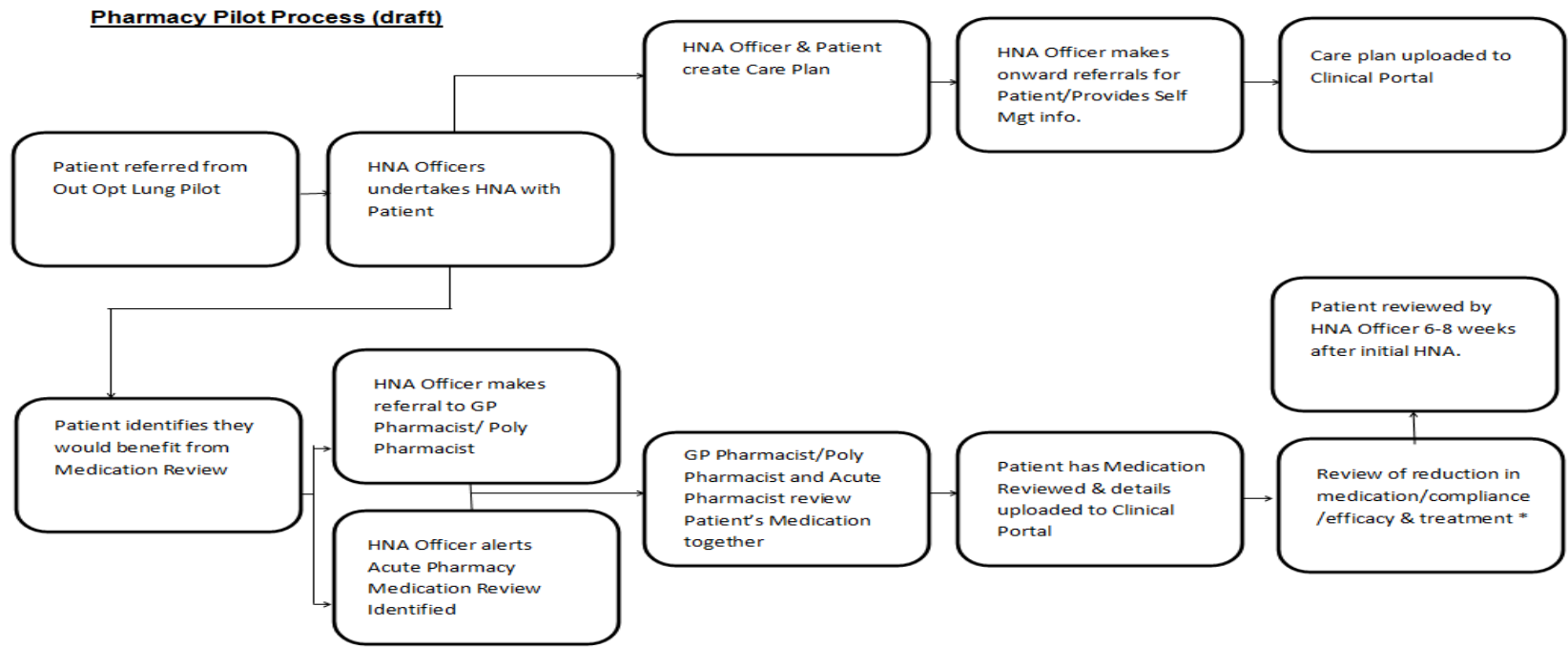
Minor Ailment Scheme Formulary, relating to Chapter 4

Symptom management therapies for cancer patients available on MAS

Symptom Grade	Recommended therapy	Available on MAS
Constipation		
Grade 1 – no bowel movement within 24 hours	• Laxido®	• Laxido® – NO
Grade 2 – no bowel movement within 48 hours	• Lactulose	• Lactulose - YES
Diarrhoea		
Grade 1 – increase of 2-3 bowel movements	1. Loperamide	1. Loperamide - YES
Grade 2 – increase of 4-6 bowel movements	2. Codeine phosphate	2. Codeine phosphate - NO
Mucositis		
Grade 1 – painless/mild soreness ulcers, able to eat	• Mouthwash	• Benzydamine 0.15% • Chlorhexidine 0.2% • Anbesol®
Grade 2 – Painful erythema but able to eat		
Nausea		
Grade 1 – Loss of appetite without alteration in eating habits	• No pharmacological therapy advised	Refer to oncology team for further assessment and management
Grade 2 – Oral intake decreased without significant weight loss, dehydration, malnutrition	• Advise self help measures	
Skin rash		
Grade 1 – scattered macular/papular eruption or asymptomatic erythema	Recommend patient to speak to oncology team and advise:	• 50:50 ointment • Zerobase® • Hydromol® / • Hydromol® bath • Dermal® 200 shower
Grade 2 – scattered macular/papular rash or erythema with pruritis	• Self help measures • Simple moisturiser for dry skin • Antihistamine for erythema/pruritis	• Cetirizine tabs/liquid • Loratidine tabs/liquid • Chlorphenamine tabs/liquid
Dry eyes		
Grade 1 – Mild, not affecting activities of daily living (ADL)	• Simple lubricant	• Clinitas Gel® • Lacri-Lube® ointment
Grade 2 – Symptomatic but not interfering with ADL		

Appendix 9

Improving the cancer journey process chart, relating to Chapter 4



*Review of reduction in medication, compliance, efficacy and treatment in line with Pilot Aims. A further process will determine how this information is captured and reported.

Appendix 10

Update Community Pharmacy clinical vignette, relating to Chapter 4

Management of Dry Eye Syndrome in Cancer Patients

This article is the first in a series of updates on the management of common toxicities experienced by patients receiving Systemic Anti-Cancer Therapy (SACT). SACT encompasses both biological therapy (therapies which use the body's immune system to fight cancer) and cytotoxic chemotherapy. Most SACT is prescribed and dispensed in hospital. These articles are designed to support community pharmacists in managing simple toxicity and should be used in conjunction with standard 'WWHAM' questions.

Try to obtain a full medication history from patients being treated for cancer. Some patients carry alert cards or have a pocket sized chemotherapy diary containing details about their treatment.

Dry eye syndrome is a toxicity that is reported by some patients who are receiving SACT. Whilst it is possible to manage mild (grade 1) dry eye, it is important to establish which patients require referral for specialist review.

When to treat in a community pharmacy

Grade 1 symptoms include dryness in both eyes, grittiness, eyelids sticking together in the morning and blurred vision which improves after blinking. These symptoms can be managed with Clinitas Gel® and Lacrilube® ointment. Patients should also be advised to report this at their next clinic appointment.

When to refer

Patients with grade 2 symptoms, such as mild pain and burning, or persistent grade 1 symptoms despite treatment should be referred to their GP or optometrist for specialist review.



Red flag toxicity

Patients presenting with severe grade 2 symptoms, prolonged visual disturbance or photophobia should be referred for urgent medical attention. Corneal ulceration and uveitis have been reported with some SACT.

There is a Cancer Treatment Helpline that all patients prescribed SACT and healthcare professionals can call:

Beatson West of Scotland Cancer Centre
National

8am-8pm 0141 301 7990
8pm-8am 0800 917 7711

Appendix 11

Community pharmacist questionnaire and covering letter

Community Pharmacist Questionnaire

Patients prescribed systemic anticancer therapy (SACT) often experience toxicity related to their treatment. It is important that patients, doctors and community pharmacists know how to recognise and manage toxicities. Drug interactions might occur between SACT and the patient's regular medicines. Communication from hospital to community pharmacy is often limited and there are gaps in the clinical information which would help your interventions when patients with cancer approach you for advice.

This questionnaire will identify where e-health solutions to the delivery of pharmaceutical care across traditional boundaries can be found.

Your participation is completely voluntary and you can choose not to complete this questionnaire.

Your personal details will not be used in any analysis. You may choose to leave this blank.

All answers are confidential and all data will be anonymised.

I will be happy to answer any questions you might have.

Thank you,

Fiona MacLean

Fiona MacLean, Lead Clinical Pharmacist (Cancer/Neurosciences)
Telephone: 07983 520479

An evaluation of e-health solutions to meet the information needs of community pharmacists supporting patients receiving systemic anti-cancer therapy

General questions			
1	Are you an independent pharmacy contractor?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2	If No, which company do you work for?		
3	What is the postcode of your main premises? (first 4 digits only)		
4	How many years qualified are you? (to the nearest year)		

Questions about systemic anti-cancer therapy (SACT)					
5	Do you currently receive clinical information about any of your patients who are prescribed SACT? If Yes – go to Question 6 If No - go to Question 12	Yes <input type="checkbox"/>	No <input type="checkbox"/>		
6	Who supplies this information? Please tick all that apply				
a	Hospital pharmacist				
b	Hospital doctor				
c	Patient				
d	Hospital nurse				
e	GP				
f	Other – please specify:				
7	How is this information supplied? Please tick all that apply				
a	Fax from the hospital				
b	Letter from the hospital				
c	Email from the hospital				
d	Paper patient SACT record				
e	Telephone call from the hospital				
f	Electronic patient SACT record				
g	Patient App				
h	I have access to the hospital patient record system				
i	Other – please specify:				
8	Is clinical information supplied for all your patients receiving SACT?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>	
9	Is information supplied for a selected group of your patients receiving SACT?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Don't know <input type="checkbox"/>	
10	If for a selected group, which patients? e.g. lung cancer, oral treatments Please list:				

11	Does the clinical information help you if the patient presents at your pharmacy with:		
a	A question about their medicines		
	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
	Comments:		
b	A toxicity resulting from their medicines		
	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
	Comments:		
c	A request for an OTC medicine		
	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
	Comments:		
12	Thinking about the content of transferred clinical information, what do you want to know?		
	Please tick all that apply.	Yes	No
			How would this help you care for your patient?
a	Name of SACT		
b	How SACT is given e.g. oral, injection		
c	How long SACT will continue for e.g. 6 cycles, daily until disease progresses		
d	How frequently SACT is given if not every day e.g. every 3 weeks		
e	Common toxicities		
f	Contact details for the hospital pharmacist		
g	Supportive medicines for managing simple toxicity e.g. mouth care		
h	Referral pathways for complex questions e.g. extreme fatigue, temperature, bruising		
i	Other – specify		
13	Thinking about drug		

	interactions with SACT and regular medicines, what are your sources of information to check if the presence or absence of a possible drug interaction? e.g. product literature, Medicines Complete, Stockley.	
14	If you identified a drug interaction who do you contact?	
15	What is/would be your preferred route for transferring clinical information about patients from the hospital to you? Please number your responses from 1 to 6; number 1 is your most preferred method; number 6 is your least preferred method.	
a	Fax	
b	Letter by post	
c	Email	
d	Via a patient-held App	
e	Via access to the hospital electronic patient record	
f	Other, please state:	
16	If you currently do/were to make an intervention for a patient receiving SACT, how is this recorded? Please tick all that apply.	
a	Community pharmacy electronic patient record	
b	Community pharmacy paper patient record	
c	Patient-held paper SACT record	
d	Letter to GP	
e	Email to GP	
f	Letter to hospital pharmacy	
g	Email to hospital pharmacy	
h	I don't record my interventions	
i	Other please state:	
17	Do you feel confident enough now about providing pharmaceutical care to patients prescribed SACT? Yes <input type="checkbox"/> No <input type="checkbox"/>	
18	If no, please explain why? e.g. lack of knowledge of SACT	
19	What training would you like to receive to maximise your input to the pharmaceutical care of patients with cancer?	

I might like to follow up this questionnaire with specific questions.
If you are happy to be contacted directly please supply your contact details below:

Appendices

Name:

Pharmacy name:

Telephone:

Email:

Thank you for your participation.

Fiona MacLean

Lead Clinical Pharmacist - Cancer/Neurosciences
NHS Greater Glasgow & Clyde

Appendix 12

Focus group information and invitation sheet

Exploring current use and future uptake of e-health technologies to support the delivery of pharmaceutical care

Focus Group Invitation and Information Sheet

You are invited to take part in a research project focus group to help hospital pharmacy understand if, and how best, we can use technology to support pharmaceutical care in all care settings and facilitate delivery of *Prescription for Excellence*.

Please take time to read the following information carefully. Please ask me there is anything that is not clear or if you would like more information. Take time to decide if you wish to take part in the focus group.

Purpose of the research

I am conducting patient and community pharmacist surveys and I am running one focus group with community pharmacists to explore opportunities and barriers to greater use of e-health technologies to support pharmaceutical care. A key action from *Prescription for Excellence* is to deliver a single medications care record available at each point of care. Improved communication from hospital to community pharmacists will improve medicines safety but the methods of communication are not uniform.

I am interested in gathering opinions, both good and bad, on the potential use and usefulness of technology. I am also interested in any concerns you may have.

What does the focus group involve?

If you decide to take part you will be asked a series of questions. Your responses will be audio-recorded and transcribed. I will look at the data and pull out common themes to identify the main opportunities and barriers. The focus group will last between 60 and 90 minutes.

You can change your mind about taking part at any time without giving a reason.

Do I have to take part? No, it is up to you to decide.

Will anyone know I have taken part?

No. The focus group will be audio-recorded and detailed notes will be written up. Anything that could identify you will be taken out. Everything you say remains confidential. The information will be held securely on an NHS server accessed only by the researcher.

What will happen to the results?

The data will be used to inform and shape the delivery of pharmacy services in NHS Greater Glasgow & Clyde to support *Prescription for Excellence*. I will prepare conference presentations and academic publications. I may use

Appendices

quotes from the information provided but no individual will be identified or named.

Who is running the research?

The research is being conducted by a pharmacist researcher from NHS Greater Glasgow & Clyde as part of a Doctor of Pharmacy degree. The researcher is Fiona MacLean (Lead Clinical Pharmacist, NHS Greater Glasgow & Clyde).

The study has been reviewed by NHS Greater Glasgow & Clyde Ethics officer and the Information Governance Lead.

Contact information

Mrs Fiona MacLean
Pharmacy Workstation, Clinic P
Level 2
New Victoria Hospital
Grange Road
Glasgow G42 9LF

Email: fiona.maclean2@ggc.scot.nhs.uk

Appendix 13

Focus group consent and demographics forms

**e-Health evaluation – Community Pharmacy Focus Group
February 2015**

Consent Form

Please initial each box

1. I confirm that I have read and understand the participant information sheet. I have also had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw from the study without giving a reason.
3. I understand that the interview will be audio-recorded and transcribed.
4. I understand that the interview will be anonymised and I will not be identified from the transcript.
5. I understand that the results of this study may be published and any part of this interview used will be anonymised.
6. I agree to take part in the interview.

Name of Participant

Date

Signature

Researcher

Date

Signature

Demographics Sheet

About You

Gender: _____

How long have you been working in this pharmacy?: _____

How long have you been working in pharmacy overall? _____

Current Job Title: _____

Do you currently work in more than one pharmacy? YES / NO

Appendix 14

Focus group structure and questions

Exploring current use and future uptake of e-health technologies to support the delivery of pharmaceutical care

Focus group structure and questions

Structure & Preamble

Thanks for agreeing to participate
Introduction and aims of the research

Participants to complete *Consent and demographics form*

Write names on cards
Can I first ask all of you to go round the table to introduce yourselves?

Reminder about audio-recording & confidentiality
Lesley as “turn taker” – will focus on the sequencing of the dialogue
Remind participants to talk one at a time for purposes of deciphering the audio recording.
Try to respect each other, try to avoid interrupting each other – apply a code of behaviour

Coffee is available from 1115am so hope to wrap up by 11am.

Questions

You've all been invited to this discussion group as you are community pharmacists participating in palliative care network and so will engage with patients who have cancer.

Patients with cancer, especially those who are having chemotherapy, move between care providers and are often given quite toxic treatments, be that chemotherapy, radiotherapy or both.

Good communication and record keeping is vital to ensure the intended outcomes of therapy are achieved with minimal toxicity.

I want to explore your experiences and opinions, good and bad on the current and potential usefulness of technologies.

Stimulus material

Show participants a cancer care plan & chemo script to start the discussion. This is a sample hospital chemotherapy prescription and the cancer pharmaceutical care plan used in hospital pharmacy.

The chemo prescription is made up of anticancer drugs and supportive medicines.

Prompts

Generic questions

Appendices

1. What sort of things have helped you as community pharmacists to deliver pharmaceutical care?
 - other HCPs? - who?
 - Information - what sources?
2. What affects your ability to provide pharmaceutical care?
3. How do you prioritise your patients for pharmaceutical care?
How could IT help with this?
4. Would it be helpful if there was a system at discharge to highlight priority patients for early review or input by community pharmacy?
5. What information would you like about your patients at discharge?
6. What difference would it make if you had access to the Emergency Care Summary/Key Information Summary?
7. What benefits/problems do you perceive in enabling hospital pharmacists to access your PMR/PCR for patients admitted to hospital? How might this inform what you record about your patients?

Prescription for Excellence, single medications record

8. Thinking about technology, PfE and the desire to have a single virtual medications care record:
 - What electronic systems or forms do you currently have access to?
 - Do you use these for all patients or just some? If some, which groups?
 - Do you think an integrated record would improve the safety of medicines and improve medicines efficacy?
 - Do you think an integrated record would help monitor adverse effects and outcome of therapy?
 - Do you think an integrated record would prevent predictable side effects?
9. Do you think an integrated record would reduce prescribing or monitoring errors at the point of transfer of care?

Apps

10. What do you think about patient Apps – supporting self management (p37 PfE)?

**** explore apps in greater depth if the group wishes to ****

SACT questions

1. How would you know if one of your patients was having chemotherapy?
2. Is clinical info sent out? By whom and how is it supplied?
3. What ways have you developed to deal with patients with chemotherapy or cancer side effects?

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- What do you do?
- What do you avoid?
- 4. Have you developed these yourself or been given useful advice?
- 5. Looking back on the last time a patient approached you for advice wrt cancer/chemotherapy
 - Any useful hints that have helped?
 - Any mistakes made??
- 6. Do you know about chemotherapy side effects?
- 7. Are there any changes you'd like to see made to pharmacy services for patients undergoing chemotherapy?

Conclusion

Thank all participants.

Inform them of the next steps

- write up and publication
- report submitted to GGC Pharmacy e-health group

Appendix 15

Focus group transcription

Focus Group of community pharmacists working in the NHS GGC palliative care network, 18.2.15

Five participants welcomed by F MacLean (I, interviewer).

- I: You have been asked to come along as you are community pharmacists who participate in the MacMillan Network and you engage with patients with cancer and cancer is a group that I thought would be quite helpful to start with, you know, to use as an example group of patients who get treatment in different locality settings and move between episodes of care, you know from hospital to outpatient facility to radiotherapy and then perhaps to hospice so there is a need to transfer information across those boundaries.
So it's to explore your experiences and opinions, good and bad on current and potential usefulness of technologies.
So I thought I'd start off with just a couple of questions just to see where you are with general things about delivery of pharmaceutical care (PC) and thinking about how you work as a community pharmacist what things in particular help you deliver PC to your patients. Is it e.g. information supplied on an individual patient basis or support from other healthcare professionals. Is there anything you want to kick off with?
- P4: The big thing for us is information and actually that bridge of communication that's not always successful and that's quite often where we feel things go wrong and is the biggest risk to patient safety not being delivered is because 2 people out of 3 might have been informed (*inaudible*) and the sharing of information maybe isn't always as good as it could be and part of might be because we use different systems or the patient doesn't communicate to us particular thing like hospital admission and discharge. It can start off as simple as that and then that can be extrapolated back and be quite a significant thing that can get missed if that information isn't shared. I understand there's a big thing round about patient safety and patient confidentiality but I think if we are all working in the same disciplines we are there to be doing the right thing about patients and actually trusting that the individual that you are sharing the information with is using it for the benefit of the patient and not for any other purpose I mean that's one of our big hurdles.
- P5: I agree along the same lines. From GPs we find have issues with them that they are not communicating medication changes always very well. You can just get a prescription comes up from the surgery and you then have to take the initiative to contact them, Is this a change? has something been stopped? before you actually get any information a lot of the time you are relying on the patient coming in saying I was in hospital or I went to an appointment with different care facilities and they've taken me off this and started me on that. I find that really hard. We could be missing something that should have been stopped 2 weeks ago because nobody's told us about it.
- P2: I agree with the previous statements. Hit the nail on the head really. There's multiple ways we can find information but no one's definitive and a single medication care record would help that if it was available to us and it could be executed right.

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- P3: I work out of hours I work at the weekend and I see a lot of prescriptions coming in I've got to guess if the person is actually a palliative care patient or indeed a cancer patient. I don't know whether that person has cancer or not. If I knew I'd probably go out of my way to take them to a consulting room and give them more advice. I'd ask more about the dose and so on. And there's a recent audit where they said that most of the prescriptions that are written for CDs, most of the errors that happen are out of hours that's a big issue. So I would really really value information being shared especially as a locum pharmacist at the weekend.
- P4: I think going along what you are saying out of hours particularly quite often if does involve a medication change or particularly palliative care patients, we deal with lots of care home patients and from that the information isn't necessarily always available as well because you've got different disciplines dealing with it and you've then got the added pressure of the family maybe having to get their heads round that the patient's on end of life care perhaps. And when there's issues what we quite often find is that NHS24 and out of hours are quite unwilling to make any decisions to help facilitate you to give the best possible care to the patient because it involves end of life care it involves CDs and that can be very very difficult because you, they want you to make a quick decision, you are kind of hanging in the balance you want to do the right thing for the patient. Obviously there's a legality aspect to that as well. So while you wouldn't want to flout any rules you need to do the thing that's safe for you. As a person you want to do thing that's going to ease that suffering a bit more as well particularly when you work with SOPs the minute you break that you don't have leg to stand on. So it's about understanding the different disciplines and trying to get answers and making sure everybody working out of hours is all working and using the emergency care summary and things like that to be able to give the most up to date information to allow you to then take the next necessary step forward.
- I: So, it would make a difference if you had access to the emergency care summary or key information summary then?
- P4: But for that to be up to date as well and for the person at the other end of the phone to be willing to perhaps make a decision when something's not right and that is our own experience where we found a lot of difficulty because you maybe have different GPs who are not familiar with the person, because it involves palliative care, people's strengths maybe lie differently, maybe they get a bit frightened by it so they don't necessarily want to make decision in case that decision might be wrong but understanding that if we don't make some kind of decision and find a half way house that person at the end of the bed actually is the person that is going to suffer and the family are round about witness to that.
- I: Can I just confirm, do any of you have access to the ECs or KIS?
- P2: Only by phone
- P1: NHS professional to professional link
- P4: And it's only if the person has recently accessed out of hours or accessed emergency care will we have an up to date care summary.

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P2: The ECS I've found it handy in the branch I work is open til 11 at night 365 day a year so at 10 o'clock at night somebody comes in I've found it useful. You know I think it needs to be built upon there are a lot of shortcomings. I think that would be a good foundation you know for the, what is it you call it again, this thing you are trying to do Prescription for Excellence I think.

P3: Have you not found it difficult though when you use the professional to professional link? I find it difficult....to get the right information...

All: Agree.

P2: Initially..yeah it does take time.

P3: It's only a half day I work on Saturday it can be extremely difficult to get that information I need.

I: So what difference do you think it would make if you had your own access to ECS?

P3: It would be quicker it would be quicker for the patient, quicker for their carer, for the family.

P2: you'd be more inclined to use it.

P4: Yes, rather than having to phone and then trying to find out who to speak to.

P2: Time is still precious.

P4: ..in a community pharmacy environment.

P4: I think as well you know we've got CMS and actually we're probably not using that to the best of what we can so there needs to be system where we create a PCR and actually all the disciplines use the same PCR because GPs are able to see what we document but we can't see what GPs document. Hospitals are able to see what GPs document but we can't see then what happens so we've got a system it's not perfect but we've got a system actually that we can all use and it would beit's not a massive step change in what we're already doing rather than introducing something new and getting people to buy in to the confidence of using it. CMS is going to be about for the next while it's been about people are getting comfy using PCRs and creating PCRs and updating them and just getting using the point if we are updating them all the time that should be your first port of call to use that as your current PMR rather than using your computer system that you have because the PCRs, you need to input all that information manually through the information systems you use just now there is not one. All the different pharmacies use different systems so you need to drag that information overso if we have a PCR system that you can all use and actually it's health board driven surely that would be great starting point.

I: Staying with PCR then, what benefits do you think there would be for allowing the hospital pharmacists access to it for your patients that come into hospital?

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- P2: Well there's a problem. We'd have to have the patient registered on our PCR wouldn't we to be able to see that so that's a barrier right away.
- P4: You can create a PCR without then being registered to CMS because you can create a care record for them.
- P2: So who would have to create the PCR then for the patient?
- P4: Well it could be from either side you know if there is something that is significant but anybody who is in any type of care setting should automatically I think the way it should go we should automatically have a care record for them because it's only right rather than an opt in/opt out type of thing and relying on community pharmacies making sure that actually we sell the benefits of it... it's not a perfect service but the more experience we have of using it and actually we can then as community pharmacies, sometimes you get a bit overlooked as not really being very clinical but actually we can be and it's about using that for the best of its ability and using your knowledge and not just saying with or after food that's not what that patient's care is about its what impact we have on that patient for that particular time and it might be different 6 months down the line but
- I: It's a dynamic process isn't it. We have an electronic care plan we use within acute services within cancer care and I can save it as a PDF and email it out and we haven't taken that forward step yet to send that out to community pharmacists. But I have a care plan, you have a PCR. Having something that is a little bit more joined up would probably be what we should be lobbying for and having that shared record even moving across. Do you think you would use it differently if you knew it was going to be picked up by the hospital team or the hospital clinicians, you know the medical staff for example or even the nurses using it. What do you think you would do differently if it became that single record?
- P3: That would be really useful.
- I: Do you think you'd use it?
- All agree
- P4: I would check that first before I would check my current PMR against (*inaudible*) and Pharmacy Manager because it would be the most up to date in the time and information and you're not then reliant on letters being sent to GPs and a copy of it going to the patient ...sometimes that's what you're at the mercy of ...sometimes you've got pharmacists in hospital that will contact the community pharmacy and that's great cause you've got that information and you know then to expect a change but we're not always lucky it doesn't always happen you need to have a more seamless approach and if we have it all documented on the PCR and not using 3 different systems...we are using one thing that is already in existence then actually how can we use that to make it a better system it's not a brilliant tool you know the IT's not fabulous but it's what we got just now it wouldn't be something extra that we asking to do people.

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P3: Agree.

P5: Agree.

I: And let's say if you had this what would be your top 3 things you want from the hospital pharmacy in that record when that patient's discharged?

P3: You want to know their condition, their diagnosis, you'd probably want to know the medication they just been discharged on.... I don't know whether there's any other issues.

P5: Any follow up arranged.

P1: Better communication as soon as the patient gets discharged. If the hospital could communicate better with the community pharmacies that the patients with that would be a lot easier than relying on the patient's discharge letter just to find out that they've returned from hospital.
Saying that I think the documentation of the actual discharge letter is actually quite good it is quite informative and sometimes they do tell you if there's been any changes you know but sometimes you find you might have to chase it up sometimes missed out or the dose has been changed for some reason but doesn't actually state why.

P3: Sorry I've just thought about something there when you were mentioning about the PCR and whether you would be different if you knew it was being shared with hospitals. Just thinking about myself and I kind of think it's almost like a chore that you're doing creating these records in community pharmacy. If you know that it's going to be utilised it's going to be shared it's going to be some benefit to the patient you would really be more inclined to actually, this is not a just a chore, this is not just on my to do list, this is something that will actually benefit the patient and right now you find in community pharmacy it's all about chores, getting things done. You know it's going to have an impact on the patient and their family.

I: OK we're opening a very big hospital in the South. So let's say we are discharging, I don't know, 200 patients a day into the locality. So you might be getting several patients coming back to you. How would you prioritise those patients if we wanted you to follow up on all of them. Do you have current systems for prioritising?

P4: We don't have current systems, like within Boots we don't have current systems but it would be very much the patient demographic actually so who is the biggest risk of falling through the net....complex dispensing patients.....patients who are on DDS packs who actually are probably not perhaps as compliant or perhaps have the understanding actually that changes do happen. That would be a huge thing for ourselves.

P1: High risk patient and high risk medicines

P3: I always look at opioids. I'm always having to go out and ask the patient "have you been on this opioid before". I don't even know whether it's something that the doctor has prescribed or what's happened. I have to chase it with another community pharmacy "have you seen this prescription before". That's one of

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my main barriers. So if I knew this is the dose and it's been slowly going up, yes it's alright it's not too bad as I thought. So I would...high risk medication like opioids.

I: What else would you put in the category of high risk medicines? We have a view on high risk medicines within the hospital but (*interrupted*)

P2: Oral anticoagulation, methotrexate, anything with a narrow therapeutic index.

P4: Insulin, lithium.

P2: Yeah.

I: So you can prioritise perhaps with high risk medicines, compliance aids, patients that maybe have complex care needs, is there any IT system or do you think IT could help you prioritise these patients in any way?

P4: That's probably a way to do it but.. laughs....

P2: There's no IT system available. I know in the PCR doing a risk assessment we can flag somebody if they need looked at recently or you know if they are urgency basically to look at but...

I: So could your pharmacy records with medicines prioritise patients because there would be a high risk drug there. Can the system do that just now?

P3: I think so.

P1: Usually when you access the patients file, a specific patient, it usually pops up like as a warning to tell you. I don't know...

P3: Come up methotrexate isn't it? ...that depends on what system you use....I don't know all systems.

P2: I'll be honest, I don't know if this is an issue in community pharmacy you know I think that all members of staff in a pharmacy are aware of what's urgent what's important the order in which we should deal with problems really. I don't think.... it's never a problem I've stumbled upon in my experience in community pharmacy... when we get discharge letters you know we look at it we deal with it right then and there. I think everybody's capable of assessing if the change needs to be made now at this time.

P3: Are you talking about if somebody comes in with a prescription and we don't have a history or we don't really know much about the drug history that something kind of flags up on our computer and sort of says this is opioid patient or this is somebody ...

I: Something like that or if there was maybe gaps in a care record might think that's a patient to invite in because I don't know much about them. You know I wondered if the technology was there...

P4: I think a lot of it comes down to personal development and you asserting yourself to say that's high risk and I think a lot of our teams are quite

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challenged on that and I think we are quite lucky with some of the teams we have but perhaps where there is a training issue but within hospital and community we are SOP driven so high risk SOPs are the ones that at the forefront of your mind all the time.

I: So you already have that kind of high risk category there at the moment. Is that true of all of community pharmacy or just some of the multiples?

P4: I imagine it will be different versions of it but consistent in terms of Boots will do it one way and Lloyds might do it differently.

P2: We as pharmacists, we don't even need an SOP to be able to assess you know what is clinically high risk you know.

P3: But I think it's important to have those kind of procedures for like if it's a CD, how do you deal with that. Do your counter staff know it's a CD. Things like...

P2: That's down to us training our staff you know.

P5: I think it's good in terms of being able to direct you. A lot of it your dispensers deal with so much so much that it gets referred on to you so it's giving them the right training to know that these are the things that need to be referred onto the pharmacist immediately...

I: To triage?

P5: Definitely triage it so that we actually know.

P3: In my role as MacMillan pharmacist I've been out to a lot of the community pharmacies to...I'm doing an audit of the network pharmacies and we found when we asked the question can we see your SOPs, do you have any SOPs to do with palliative care patients there were none. They were all to do with CDs, there were different things about palliative care so that you know, do you have SOPs in place for CDs, do you have any SOPs to be able to identify that a prescription is for a palliative care patient or what do you do if you don't have the drug and it's for a palliative care patient. How would you go about that, would you phone another network pharmacy...there wasn't any kind of formal SOPs and that was one of the things that we found was kind of lacking and that's across a whole load of community pharmacies not just....

P4: I think...I think that must depend on whereabouts you go because within palliative network pharmacies that's reliant upon you as a palliative care pharmacist making sure your team are able to ascertain by looking at a prescription straight away so our team very much they know..

P3: Of course there's...*(stops speaking)*

P4: We've got a process of ascertaining and in the pink leaflet that we just got given out, it's got a process there for if you are a pharmacist, if you are a district nurse, if you are a GP, so that in a sense ... highlights that and you as a pharmacist making sure that we share that information with the team to make sure that they deliver that because at the coalface we can't see

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everybody. You need to re-prioritise our time in terms of, and you are very much a face to face profession now.

I: So do you think there is a training gap there with the high risk medicines, triaging of patients maybe is that something we can feedback that NES could take forward or maybe just on an individual...

P3: I think it's very individual.

P2: For Lloyds no.....I know we've had a focus on it over the last few years. Don't think so.

P4: I think as well with the GPhC inspectorate it doesn't give you any leeway to not have sufficient training particularly for your match fit audits. I doesn't matter what day of the week they come in they expect to see the same standards across there's no grey area and as I suppose we get more competent at taking ourselves through these audits that actually you get everybody to that level.

P3: I think like you say though it depends on what times so trying to get the team trained up and there's always going to be out of hours where you don't have regular staff...when you have a new face... that's when the problems do sometimes occur when you are not aware of a lot of prescriptions and who to turn to, to actually get help from.

P2: See regardless of what member of staffs been involved, see that prescription that comes in that always has to pass a highly qualified member of staff be it us as pharmacist or our ACTs ...so.... I don't think this is an issue because I think the people, pharmacist or ACTs always going to see the prescription, notice it's high risk and act accordingly.

I: OK thinking about what we might be able to do from the hospital side, do you think it would be helpful if there was a system at discharge to highlight priority patients for early review or input to community pharmacists. So we would effectively be doing the work for you. We are obviously trying to get patients out of hospital faster and not necessarily every outstanding care issue has been addressed. So, if we could come up with a system do you think that would be helpful?

P2: What does a priority patient look like?

I: Well I guess perhaps for us that might be somebody who has been started on an inhaler and we might want you to do some follow up, for example a patient who is on maybe a reducing dose of steroids and might be helpful to do....I thinking of some of my own patients that might come through. This is where I guess your high risk and our high risk might not be...I think there are some similarities there obviously with insulin, methotrexate and things like that but it might be something that we could collaborate a little bit on because our view of a priority post-discharge might be something different from your own and do you think it would be helpful if we even had some dialogue about that? A system like that?

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- P4: I think initially starting to get a copy of the discharge letter is all the information we need because on that it's very clear when something's been commenced, something's been discontinued and you would have enough savvy to say well I'll give that person 8 weeks and review their inhaler and be allowed to set our own.... use our own initiative to then say well that's methotrexate that needs a blood within 4 weeks, that's insulin we need to double check for you know for retinopathy and things like that and cross refer but having the information that the persons been admitted first of all and discharged would help us so much never mind being told priority. I think just having the information then allowing you to put that into the care plan would just be amazing cause we don't always have that information.
- P2: We need it fast and we need the doctors to get it fast as well cause often we can get a discharge sheet the doctors still haven't actioned any sort of changes in medication, we're chasing it up, they've not received it, that's where patients become lost or they don't receive the best care that they could so it needs to be fast everybody needs to get it.
- P5: There's points we're getting patients coming in bringing us their discharge letter in, we're taking a copy of it, we're then having to phone the GPs to say have you got this have you got script to a point that happens some of the time I'm faxing them the discharge letter down...
- P2: (*interrupts*) That's actually true.
- P5: ...because they haven't received so they won't action any changes for...and we've had issues with children's prescriptions from the hospitals where they've had a dosage changed. I had a wee girl on Prograf, her dose had changed on it, the surgery refused to action any change on it because they haven't had a direct contact but I had all the information from the mother and this wee girl's dose had changed and she had nothing left at all and the surgery refused to issue a prescription so I had to contact Yorkhill direct to get the information to issue an emergency of it until they could get somebody to directly speak to the GP and if that was more seamless that wouldn't have been an issue, I had to make that professional decision to give a supply of a drug that I couldn't guarantee they would give a me prescription for so it's a hard situation when you are sitting there going you've got somebody who could be having rejection if I don't give this.
- P2: Can I just ask, see discharge letters, are they still sent via post and there's not an electronic message?
- I: They are electronic to GPs
- P2: Electronic to the GPs?
- I: That requires it happening at ward level and I can't say how quick that button is pressed.
- P1: I just want to confirm though like sometimes the health centres don't actually get the discharge letter or the surgeries don't actually get it... obviously we don't actually get it... usually we are normally the last people that know

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anything about it as well so I think communication there at that level would really help..just so that providing that care for the patient faster.

- I: So I think we need to improve the discharge process. How we get the information to you that the patient's in hospital, thinking about the number of admissions that come through and they may be in for a short period of time. How do you want that sent to you if we were able to do it because we don't always know who their community pharmacist is. Is a phone call the best way?
- P2: A phone call's fine but see ideally, there'd be a national network, there would, and you'd just log into this, one programme, you'd put in the patient's name and get up to date information.
- P3: That would be brilliant.
- P1: Agree. That would save so much time.
- P2: As I said, this could done through the PCR this isn't hard nowadays. They tried to do this about a dozen years ago with N3, I think they called it and it failed but now we've got ipads and everything, we're becoming more IT literate, you know things have moved on.
- P3: The District Nurses use apps and things why can't we (laughs)
- P5: Even if there was a basic system in place that kind of even if just you went on and it flagged up x-patient has been admitted and then x-patient is discharged and it flags it to you what pharmacy, community pharmacy they use so ideally yep we'd have all the information with their discharge information but at least you'd know they'd been discharged so you can chase up what's happened with them that would be a very basic system.
- P3: Yeah. It would just make care so seamless
- P5: Whether you had all the information at that point, if you just knew they were in hospital and when they were discharged you can then do something with it.
- P4: Touching on Prescription for Excellence and it's a bit of a contentious point, but is one of the points not where patients would opt and be registered with a community pharmacist. That part I totally don't agree with but to register with a community pharmacy that provides current care, surely that would be a good tool to allow that rather than looking at it like well Dorothy-Jane you're my pharmacist, I don't necessarily think that's the way we should probably be going because of patients (inaudible) we've got to be careful with in case you did anything but as part of that would be that if you are registering I suppose like CMS you would then have a registered community pharmacy that you would be attending and that would then link into, well it would just be like an alert basis rather than actually sharing initial lots of information, cause we appreciate as well how busy hospitals are but touching on what you've said, it's just admitted and discharged that you would then notify that yourselves.
- I: P3, you mentioned patient, or you mentioned apps, and I'm doing some work, very early stages on a cancer app for patients. What do you think just round the table about patients having apps for supporting their own self

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management. We are calling this My Wellness App. Do you know of anything out there? If patients come to you what ...

- P3: I mean the only thing I see with patients is if they've got a lithium card, if they've got some kind of card and that's a wee bit of information. If they had something, and it's an app that showed all their kind of history of admissions, you know drugs on discharge and so on that's be great, be great but then would there be problems with consent? Who can see it, what staff can see it and so on.
- I: We are working through the governance is making this slow but you know, you are right, having it more electronic rather than bits of paper, cards held.
- P4: So touching on discharge as well, sometimes if we get a discharge letter quite often from hospitals because we do have the issue of confidentiality with a fax then if we do get, are lucky enough to get a fax, then sometimes what you get is a fax of a discharge slip with all the patient details blanked out which...
- P4: I can appreciate the difficulty that we are in but as well we need to look at the risk of that and actually could that be mis-transposed to someone else particularly if we are looking at DDS patients who quite commonly might all be all similar types of drugs or you know anticoagulants or things like that, as well.
- P3: I just think it's a way forward to get away from all that and go and use this new technology.
- P4: And show that actually we're capable of using the information accordingly and not being distrustful with information as well. We want to do the right thing for the patient. That's why we need the information... it's not to be nosy or to know what's going on ... it's about having up to date every minute information that you can make competent and confident decisions about your care.
- P5: We are professionals, why would we misuse the information? I don't really see why people have a real big issue with giving the community pharmacist information. We're not there to cause a problem.
- P1: Yeah, easier access to all the information would be really helpful.
- I: Thinking now just specifically about Prescription for Excellence, one of the key aims is a single medications record. So you've currently, we've slightly touched on this which electronic systems or forms you currently have access to. So it's your PCR, and you don't have direct access to ECS or KIS. See for your care record, your pharmacy care record, do you use that for selected groups of patients, would you have one for all of your patients, would that just be asking too much?
- P4: If you've got the person's consent you are able to create a PCR for anybody. So I suppose looking at locally enhanced schemes that how we documented a lot of the issues. If we got audited that's the proof actually that we deal with 400 or so patients on that but not everybody that you would create a PCR for is necessarily registered for CMS because you would close the active care

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issue. But if you record something is a care issue then you need to put in when you next review them depending on their level of priority and you would set that date.

I: So it's selected patients, patients yes.....

P1: The time it takes to transfer all the information details into the PMR, PCR for every patient, it does take time you know..

I: Ok, so there's quite a bit of transcribing from one system into another

P1: Yeah, yeah

P4: Within Boots, our care home patients run off a different systems to what walk-in patients run on and because the care home patients run off a system it's not necessarily completely electronic we can't actually drag that information over, we manually input it and the point of PCR is to make sure that you import that medication each time you dispense that, that necessarily wouldn't be feasible but you could create a care issue for something like bisphosphonates or if you were doing the asthma scheme from that point of view...

I: Do you think an integrated care record then would help you monitor adverse effects of medicines then and outcomes of therapy. Are you going to bring patients back to see how they're doing on a new treatment, has it been effective, that type of thing. Do you get much involvement..

P3: Yeah

P4: Nod

P3: You're often kept out of the loop a wee bit about what is going on and so you don't necessarily know that you need to follow them up....but if you've got access to this and you know they've been started on a new drug, or it's gone up or their symptoms have worsened you know to follow that up and maybe ask to see then again, or, I don't know whether you'd have a consultation with them or actually visit them but that's something that would be beneficial

P5: To an extent it's a bit patient reliant, you rely on your patients telling you that they're going for this investigation or something's happening so that when they then come back you can check in with them or see changes. So kind of inhalers and things are relatively straightforward cause you see a new one come through, and you speak to them and you can sort of just now we are doing the asthma scheme that you can address that, but there's so many things that people will especially if they don't always stick to the same community pharmacy... you don't know that it's not, they've not been on it for 6 months and just have had it dispensed elsewhere. So I think it would be quite good if there was a way that you could actually see that they've had this 4 or 5 times before but has anybody checked in with them at least it's a way of being able to. I kind of routinely when I give out scripts, kind of check you know is any of this new to you? Do you need any kind of assistance with them? That's the only way at the moment we've really got of obviously identifying....

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All nod

P3: Or, or you see a prescription for an asthma patient and its using too much salbutamolthen you can think to ask whereas you are.....it's all about guess work...

P1 : I personally normally if a new prescription comes in I usually check the patient's file and it's usually quite up to date ...it's like your main source of information so I always check that and also usually flags up if it's a new prescription item and that's would be like your time to kind of intervene and actually speak to the patient on that day, so it's like on a day to day basis sort of thing so...

P4: So within different systems as well you've got key people that you're relying on them transferring that information then to then allow you to make the appropriate clinical check rather than us staring a computer all day, our patients aren't going to benefit from that but from talking to them and having proper consultations with them can really help to reduce like duplications of therapy and things like that as well so there's obviously a big drive about clopidogrel just now and the number of duplications that we are seeing coming through it's from probably poor transposing of discharge letters at surgery level and then patients being left on it for a period of time that wouldn't be suitable or having aspirin and clopidogrel things like that because they've not been reviewed and I suppose a lot of that comes down to accurate transposing of discharge letters. The GPs aren't doing it themselves they're relying on other people giving that information as well....

I: Certainly the prescribing errors at the transfer of care is well recognised and that is where errors often occur. You've just used a good example there of clopidogrel. Within chemotherapy we certainly try and deal with the predictable side effects. We build up the chemotherapy prescriptions to include supportive medicines like anti-sickness medicines, skin preparations and things like that. So we're trying to manage the most predictable ones. We can't deal with the very unpredictable and that's one of the things that we workas hospital pharmacists....

So an integrated care record then you would be able to see everything, the medicines record and I suppose thinking about predictable problems, they would be able to be addressed almost at the point of prescribing. Are any of you prescribers?

All indicated No.

I: So, are you hoping to do the prescribing course or become prescribers?

P3: Yes

P4: Love to

P2: It's of no interest to me. Laughs.

P3: I'll be doing it this summer...this summer.....looking forward to it.

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- I: So to prescribe safely then you really are needing to have that integrated medicines record thenyes, yes.. so do you have some thoughts on how that might affect your ability as a prescriber...
- P2: At the moment prescribing pharmacists tend to be based with, in a GP surgery, healthcare, sorry health centre so they've got access to probably the most up to date patient record so that isn't an issue. If the pharmacist were ever to prescribe from branch then everything's going to be via word of mouth and...
- P3: They will need access. I know of cases of pharmacists actually just being next door to a health centre so they can maybe do half a day clinic so they are able to go into the GP surgery and have access to all the records and they run asthma, respiratory clinics so that's quite useful. But there would have to be a way of accessing records in a community pharmacy you know if you were to run a clinic in community pharmacy
- P2: And of course the Prescription for Excellence is set out one of its objectives for all us to be prescribing pharmacists within 10yrs. How they do it I don't know but..
- P3: and also..
- P2: Where are we going to be based if we can all prescribe ..
- P3: The other issue in a community pharmacy we just don't have enough computers sometimes it's just all used up. While we are going to our dispensary might have a dispenser dispensing from one computer or doing care homes while on the other one busy with walk-in prescriptions. How do you actually sit down.... you would need another computer in another room to actually see patients and have consultations and that's a big issue
- P4: I think even though we are not independent prescribers we probably need to look at the minor ailments services cause in our own right we all are prescribers whether or not you are selling something over the counter or whether or not you are providing a minor ailments prescription for it. We should have the same amount of information making those decisions as what we would have if we were independent prescribers...
- P3: I agree, laughs
- P4: ...so a lot of it is establishing that communication with the person or with whoever' s in for that person because if they've got a good rapport with you you're more likely to get the information out of them and a wee bit of what we were talking about as well, quite often particularly with the multiples you tend to move about quite a lot. People like to see familiar faces, they like you to remember their name and that carries a long way with it as well. You see how it works with GPs. I think CMS has shown that quite often community pharmacies get more information out of patients cause they'll be more truthful with you about what current reality is as opposed to GP level because they know they might get a slap on the wrist or they are maybe not doing what they should be doing and quite often they'll know that but I suppose it's about as pharmacists how do we support them so they get the biggest benefit from

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their care that they've got just now to have then an impact on their compliance, and concordance as well...

P3 : If you come across, you mentioned minor ailments there, at the weekend somebody comes in and they've got constipation you can so easily just give senna but then you find out they are on opioids and then you start worrying is it bowel obstruction? Am I competent enough to just give a laxative and you do worry about those things and maybe for ease of mind if we just had access to *they were discharged from hospital and yes they were on this and they were already prescribed lactulose or senna*, it's OK for me to give that out or you know sometimes you kind of hesitate and you get a wee bit worried when it's a cancer label especially.

P2: Yeah

I: Do you have any anxieties about recording your care issues, your input to care, if that was going to be visible say across the whole Health Board, for any clinician looking at it if that was a shared record that became a permanent electronic record?

P3: I would want to receive some training, I would want to, just to get an overview so that we're all doing the same thing and you know who's going to see it and whether it's going to have any legal implications. You'd want to know that information first, but will we get into trouble.....

P4: Having said that you would record something in a PMR without having appropriate training...you do.

P3: That's true..

P4: I think the patient is at the forefront of your mind and actually if you think you're doing the right thing for the patient and your profession you will only document what's necessary for that person to get the best outcome from their treatment and you do it in a professional manner the same as you would be doing anything else and making sure that the level of information you're given is appropriate for the GP so I think initially when CMS came in you would were more likely to see aspirin with or after food, that doesn't mean anything, that's not going to benefit that patient, that's about, it's not a tick box exercise and that's not how we should be looking at it. It's about, I think pharmacies looking at themselves as well and changing the way pharmacists used to work we're not lickers & stickers we've got a professional mind and we've got a clinical ability and we need to as a whole cohort to be able to deliver that, I think as well within community.

P2: Just touching on that subject of anxiety, PCR's etc, I think one of the things about the CMS is it's a great idea in theory. We've actually been bombarded with you know a number of registrations to achieve whether you're a multiple or an independent because of the way the funding is, you're really got to have a high amount of patients. So at the moment, say if you've got about 800 or 900 patients registered to CMS, see creating PCR records for them, even if you can get yourself a lot of time it's very very hard to do, make time for that number of patients.

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P3: Yeah..

P2: So that would have to be looked at, it would, because I'm not striped of my dispensary. I can get out and about no problem but it's still too many patients. So I think that's where the only anxiety would ever be, the volume.

I: So do you think there's some core information that should be recorded.... do you think you're recording additional information that's not that relevant to your delivery of care? Or do you think that all the fields are necessary?

P2: Is that with PCR you're talking about here? No I think everything is relevant. Everything.....because health, everything impacts on health so, see to have that big broad picture and it's amazing what you can drive from that be it lifestyle, be it medication, anything so I think everything there is relevant. You could add on more yet.

P3: And I think the public will gain confidence if you've got all that information and you can actually give advice on lifestyle and things and they'll think that the pharmacist is actually taking time to actually talk to me, not just giving out a bag of medicines. That makes an impact as well...

P4: I agree with you in terms of, community pharmacy was always based on volume previously and actually people who are in community pharmacy now don't really want to be based on volume but that's still, we still have two systems that are not quite met in the middle yet, so while you still have the volume on what your reimbursements from that, but there's this whole aspect of we want to be clinical and we want to be doing what we should be doing but trying to deliver, all your plates spinning, that can be a task which can be more intense in some stores in comparison to other stores making sure your support level's right with your dispensing staff and having them trained to the level that's necessary I think can be a challenge because there's a cost implication with that as well, we've all got a budget to hit at the end of the day.

P1: And we only have so much time to do everything so you know, there's a lot of time constraints as well so we need to consider that you know, we are offering all these different services, you know, while we're doing all these different things.

I: So how do you currently prioritise what you do then, is it....what kind of systems or thought processes do you do to prioritise your patients through your day?

P1: We have like a routine, well we have a routine you know when patient's medication is about to be up, we know when it needs to be ordered so we do things in advance, maybe the day before or the week before so if there's any errors we can chase that up, it gives us enough time to get all the medication that a patient needs on time, so you know so to get all the meds, to get the best care that they can possibly get and we identify any issues as well so we usually do things a week in advance or we might do some sort (inaudible) on certain days because it's generally a bit more quiet on those days we have more time to see the patient, to speak to the patient, you know, so I think that the stores I work in, in Asda, we do that as well, we do that on specific days, might provide the (inaudible) service on Saturday or Monday; you know and

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also it depends who is kind of qualified if you're working with locums, you might not be able to provide certain services as well so..

P3: I've found my work has changed with the dispensers now becoming ACTs and they're now able to check things it has changed the way I work. I've got a little bit of extra time I can actually talk to patients now, so it might change the way you work in day as well and that has certainly helped and that's probably the way forward too to up skill all staff....

I: Yes, it's higher level activities performed by the pharmacist, you are the expert.

P2: Believe it or not we are spinning more plates now than we were, right, however, I actually feel I've got more time now than I've ever had, you know and we've got off site dispensing. We've got ACTs and it's coming to fruition....

P3: It's time to become a prescriber.

P2: Aside from that yeah. But I think it comes down to us, you know, we've got to know how to manage our time, how to organise our day, what's urgent, what's important, what order we deal with things. You know some things computers aren't going to help us with.

I: If you had access to the e-PR, this is what we call Clinical Portal within the health board and I am lobbying hard on your behalf to get it but there's a few things that are stalling this. Currently I can go into a patient record pull up with their CHI number and I can see everything that has happened for that patient. I can see all the admissions and discharges, all their letters, all their scans, all their reports and it's all there. I don't need to see it all and I don't look at it all, and the same way you guys would, but if we were able to get, through putting in the CHI number of a patient registered with you, to see something within that record, and there were certain fields, certain categories, lab tests and various letters from clinic to GP, that type of thing, what do you think you would need to see if we can then advise the EPR teams that for community pharmacy to come into the service we could open up certain categories, certain services that are indexed within that electronic record. It's an electronic version of a paper record effectively. What do you think you would want immediate access to see?

P3: The blood tests, U&Es and if somebody's on insulin.....have access to the sugar reading, Hb1c, that kind of, it's sort of basic stuff isn't it but if we had access to that and we were seeing some patients, diabetic patients, or COPD patients and we had access to FEV1, those kind of readings, that would be really really useful and I think if we're having a bit more time now and if our staff are being up skilled then surely we should be going down that route...

P2: yep.

P3: If we can manage our time and maybe have time for consultations that a selected, selected sort of patient group.

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- P2: The patient journey, it's quite good to see that as well, you know so, we can see when they've been to their GP, when they've been in hospital, you know, what new medications have been put on when, I mean it's all...
- I: The new version of the Portal actually has a patient timeline, graphs episodes, it's coming.
- P3: OK
- P4: That alone would be enough to let us...
- P3: Does that let know if they've been to the GP surgery, if they've been to hospital, does it show you everything on that graph?
- I: The GP consults I'm not sure because I don't know if the GPs will feed that appointment data but every inpatient and outpatient consultation will be on that graph so at least if it's out with a visit to the GP or the DN coming out, that gives you admission and discharge, the IDL is on there as well...
- P2: That would be very helpful...
- P3: That would be brilliant just to show us where they've been, who they've been to.
- P4: That alone would allow us to ascertain who we need to speak to because quite often when we're seeing different patients, quite often when patients are diagnosed with cancer their whole life is taken over by appointments and being told where to be, when to be there and quite often actually when we start to see them is when that's finished, and they are quite lost because nobody's now telling them and nobody's guiding them through, we're going to see you in 2 weeks, we're going to...they come up and theyalmost lose track of time because of the whole kind of cycle of their chemo and radiation is defined for them and actually when that finishes, on you go, you're fine now and that's actually when we start to see them cause they get back out, they're a wee bit lost, they've lost their confidence and for us to be able to look at that to see current information on last appointment, next appointment, current medication that would be enough for us to then ascertain what's the GP we need to speak to, no actually they are going back to see the consultant on this day and actually that's maybe when your medication will change that tells us a lot about..
- P2: Yeah
- P3: I know you touched before how some patients, we are not going to misuse the information that we've got, well it's funny cause sometimes the patients have an expectation that we actually do know (laughs)....they'll come in and they "did the GP not tell you that I saw so-and-so" and, I'm like, no I don't know, I don't know sorry, I can't even contact the GP surgery today so I don't know.
- All nod
- P2: Half of them think we generate the repeat scripts.

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P3: So they do, they have that expectation that we have got shared information and we don't and if they've got that expectation it should be met, we should have access to it.

P4: Can I just say something as well that quite often the patient has a diagnosis of cancer or something very severe, they attend hospital appointments with somebody so quite often that person's with them, they're taking that information in and then relaying it so when we then get them in community, that's when they're there themselves and quite often that's where the freedom of information can be quite different cause their understanding is maybe different because it's being relayed by someone else. Perhaps t the point in time you can imagine that they're there but they're probably not taking all the information in and quite often that's where the difficulty can then arise they maybe can't quite remember what order what's happening in, or what the change has perhaps been and you get them when they are in themselves and they don't have that support team with them that's taking the information in.

All nod.

P3: And I find it difficult to have a conversation with them in a community pharmacy if there's other patients there, I need to take them to the side. They might start crying, they might start, you don't know what's going to happen if you start asking why did you go to the hospital and I'm trying to get out of them what it is and it's very difficult for me to do that.

I: So you wouldn't know if your patient's having chemotherapy.....

P3: Unless they told me, yeah, I wouldn't know

P2: I think that's a major failing. We are acting on information given to us from a patient...

P3: It is terrible.

P2: ...and the quality of the information....

P3: It is terrible.

P4: So, had someone the other day that I had no idea they were getting chemo but I had phoned the GP to say I was concerned that they've not been picking up their DDS pack , and they were like "oh it'll be ok, they've been in and out of hospital , they wouldn't give us the information and I managed to find the daughters number on her care record and we phoned and the first time I knew about it was when I got a prescription for a heparin flush. And that's when I was like, something's obviously going on here. and they were all "oh yeah he's got a line put in he's getting chemo" I was like now it makes sense, but for us not to chase that up, if something was to happen, you're the one's that's accountable for that as we've not ascertained why that person's not picking it up.

P5: Nods.

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- I: So if we, within the hospital gave the patient some information if they were happy to then hand it in to their community pharmacy, we've got treatment protocols and they can go to a number of pages. They're very detailed, takes information from the Summary of Product Characteristics and brings it all together. Would that be of any use do you think to at least tell you that. It tells you the medicines, it tells you how often, it tells you common side effects, toxicities, toxicity management.
- P3: It would explain why they wanted something from the minor ailments, yes that makes sense, I know now the side effects of their chemo and it would make you a bit more confident talking to them knowing all that background.
- P1: Especially if they are on a lot of medication it would be really helpful.
- P2: Are you saying paper though?
- I: Currently yes, until I can get my patient App doing everything for me ...

(all laugh)

- I: ..but it can be PDF'd and emailed.
- P4: Even if just one pager to say, you know, within community pharmacy we are able to use the internet to get access to the SPC so we're able to look that up and you could stab a guess at what side effects you think are going to be the most prevalent for them. But just to have the information that actually that's when they get it, that's when they're next going to be reviewed, their next treatment cycle because they might be well after their first one but it's maybe kind of subsequent, 2nd or 3rd one that we start to see them decline a wee bit and they start coming to me, and it's not maybe appropriate to be doing minor ailments and then maybe we could liaise with their XXX that this patient's not doing very well, can you maybe look at this, or record it so a one pager would..

All nod

- P5: Even having contacts, who do you get in touch with if this patient is having an issue, who is their consultant, who is their port of call cause a lot of the time, with cancer patients particularly, it's not their GP, it's the consultant that manages everything for them. They don't have... so if we don't know who that is then, a lot of the time the patient's not in the right frame of mind to be able to say this is who it is, here's their phone number, that's who you need to get in touch with. Because they don't a lot of the time necessarily, they might have it written down in a book somewhere with their information that they keep on their treatments. But if they were having some sort of major issue out in community and their next appointment wasn't for 3 weeks is there a protocol for us to refer in?
- I: So maybe some signposting information for what to do..... who in the team to contact...
- P1: Who to contact.

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- I: So maybe building on this and to bring it to a conclusion.... Any changes to the hospital delivery of services that we can improve on, to make medicines safe out in the community so, probably at the moment a 1 page summary of the patient's started chemotherapy, this is what it is, these are my contact details, anything more?
- P1: More of a summary sort of a thing...then if there's any problems that we've found we can either contact you or chase it up, just so that we know, you know what's happened.
- P4: Even just to know when the treatment cycles are, maybe then predict actually they might need a delivery that week or they might not you know, it would allow you to do some small basic things that might make their life a little bit easier.
- I: One of the difficulties we sometime have is identifying which pharmacy, so it's the one on Dumbarton Road and it's a heart sink you know it's a very very long road. Can, do you have anything you can give to patients that have your contact details, like a pharmacy card that you could hand over and say "if in hospital they ask you who your community pharmacy is can you give then this card, or this App, or thisWithin my electronic care plans I have a drop down option of all the community pharmacies in GG&C but unless I know it's Paisley Road West or Dumbarton Road and which number, or the description of where the pharmacy is often means nothing to me unless I've locumed in that shop. If they say it's half way along Dumbarton Road by the bus stop I don't know where that is.
- P5: I know for us, my store is based on Kirkintilloch Road which is actually in Lenzie but we get a lot of discharges sent to ourselves for Kirkintilloch patients who are actually at the Regent Centre so I know I can send them straight onto the other store.
- I: Even thinking of the number of Glasgow Roads that there are within Glasgow...
- P5: The number of phone calls I get that are not for me....
- I: What do you think, is there anything that we can be smarter about, what about you giving something to the patients, almost like an alert card. Going electronic is the ideal thing but not every patient will have a Smartphone or know how to use it.
- P3: Especially the elderly patients....
- P4: I don't think there's anything available just now. I suppose relationship is the big thing and perhaps going forward, Prescription for Excellence, is that why they are then wanting to have a named pharmacy.
- P2: Well see Lloyds, we actually have some really good things with regards to that. We've all got business cards for the branch, on it states speak to this person, so you could have my name on it, it's got our hours that we're opened and contact details so it's got our phone number, telephone, address, it's a

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simple wee card that slots in. We've also got like customer charter leaflets, our service leaflets..

P3: We don't have something with the word you are saying so

I: I'm thinking something credit card sized that can be slotted into a purse or a wallet so that, often what we are doing is that we asking for do you have medicines there and we can see the label if they haven't brought their meds in with them or they brought them in then they've been taken back home by the relatives then we can sometimes, you know it can sometimes take an extraordinary long time to find..

P3: Gosh.

P2: I'm using these wee cards and they are great. I give them out all the time, you know, just as a good way to follow up with patients to call into us, I know the phone numbers on the label but still it means the patient is going to carry it about with them.

P4: I'll quite often say that's our direct number and that's my name but I wouldn't be doing it, oh you're going into hospital, here's my details you know.

P3: It's something to think about.

P1: I think business cards is a good way to go but...

P3: A card, kind of wallet sized is a good idea, yeah.

P1: To give out to every patient you see.

P3: I'm actually going to feed that back to our team, it's actually a really good idea.

I: It's really good idea for the two way sharing, we would have the communication details hopefully of us and it is helpful if we need to make that phone call, you know we are going to put your patient onto LMWH because they're on chemo and that have to come off warfarin, you know these things that are important.

P4: With PCR you are identifiable from that cause your contractor code's on it and on the first page you can put additional information and I always put the telephone number of the pharmacy there but you've got to put your name as to who's completing it. If you've started using something like PCR and everybody used that one system then that information would be there.

P1: If you could access PCR, you could put all the patient's details, like what pharmacy they are in, like you just access the PCR to get that information as well so I think from the hospital side it would be a lot easier and would benefit both parties.

P5: I suppose going down the route of the app that you talked about it would be quite good if on an app it could state that this is my GP, this is the pharmacy I use.

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P2: Yeah.

P5: If they've got consultants, this is my consultant at the Beatson...

All agree

P5: It's a quick, look there you go it's on the phone, there's all my details.

P1: Just here when you need it.

P5: Put an emergency contact on it.

P2: It does, it sounds great but the challenge is then input of data, who's going to put it in, is it going to be up to date, how are we going to maintain it that sort of thing, especially between all the different disciplines, IT systems, and PCR, it's not the fastest.

P4 It's not the best tool but it's what we've got.

I: It's what you've got and again it might provide a building block for the next iteration of it in whatever shape or form it looks like. Is there anything else you want to say with regard to technology, communication and seamless care or we can call this to a close?

P4: I suppose just that community pharmacy we want to know the information so that we can help the patient and having that helps us do that to best of our ability. We might not always get it right first time but the more used we get to actually using it then we get familiar with it we can only benefit patients and not just those going through cancer but any type of admission or change in medicine actually it would be so useful.

I: Splendid. Thank you, thank you all very much. I really really appreciate your openness.

Focus group concluded.

Time 10.57am

Appendix 16

Health app specification for University of Strathclyde

Proposal for a patient/clinician cancer App for NHS Greater Glasgow & Clyde

Fiona MacLean, Lead Clinical Pharmacist (Cancer/Neurosciences)

Background

Systemic anticancer therapy is prescribed on ChemoCare, an electronic system used across the West of Scotland. This system is only accessible to cancer specialist staff and consequently, medicines reconciliation at the point of discharge cannot be completed by junior staff creating gaps in the information communicated to GPs.

Aim

An app for smartphone/tablet devices is desirable to bring together the complete list of medicines that patients receiving complex chemotherapy will receive. A dual function app for both clinician and patient is the preferred option whereby the clinician and the patient are permitted to enter different details, for example:

- Controlled clinician entry of medication (name, reason for use, duration, dose, where to obtain further supplies), appointments, “do’s and don’ts”, contact details
- Patient-driven entry of primary care interactions (e.g. GP visit), symptoms, appointments, side effects, chemotherapy toxicity

Challenges

- Creation of a patient-friendly App that will serve the dual functions noted above
- Creation of an interactive patient diary to record medications/appointments/lab tests
- Functionality to upload information for both patients and clinicians on cancer medicines and management of toxicity
- Functionality to signpost patients to other support services e.g. Macmillan

August 2014

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App evaluation tool



	Questions (Usability) ¹		1	2	3	4	5		N/A
1	It was easy to learn how to use the system	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
2	I believe the system may be more productive than a paper based alternative	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
3	I believe the help/information pop ups were helpful	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
4	It was easy to record my side effects	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
5	It was easy to record my appointments	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
6	The layout and organisation of the system was clear	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
7	Overall, I am satisfied with this system	Strongly disagree	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Strong agree	<input type="checkbox"/>
System Capabilities ²									
8	General system speed e.g. Starting up and general use	Slow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Fast Enough	
9	Viewing all information I entered was	Difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Easy	
10	Designed for all levels of users	Never	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Always	

Notes:

^{1,2} Some questions taken and adapted from <http://hcibib.org/perlman/question.cgi?form=QUIS>

Questions 1-7: scoring was 1 to 5; Questions 8-10: scoring was 1, 2 or 3. Total score possible was 38.

Appendix 18

App evaluation consent form



CONSENT FORM – Please Sign		
1	I confirm I have read and understand the information sheet provided and I am happy to take part in the evaluation.	
2	I understand that taking part is voluntary and that I can stop at any point	
3	I understand that my data will be held securely and treated confidentially and that only anonymised data will be used in reports or publications.	
4	I understand that after My Wellness Track project team has used by data it will be anonymized and held within Strathclyde University for analysing within future research projects.	
5	I understand my information will be stored for additional future research and I will not be able to be identified from any analyses performed by approved researchers.	
	I have read points 1-5 above and agree to take part in this research	----- --
	I would like to provide my demographics for research purposes (provide below)	----- --

Age: -----
 Gender: -----

Appendix 19

Ethics approval for patient interviews for App evaluation

Ethics Approval

You are Liam McCann (SE2010 - 201147749)

Home Application ID: 200 Title of research: My Wellness Tracker - Evaluation

Summary of research: Interview NHS patients via/within the presence of Fiona MacLean (NHS Pharmacist) with regards to applications suggestions and application feedback. The interview is about the actual and perceived usability and usefulness of the Cancer Care app to the user in self managing their condition. No questions will be asked specifically about their health – only about how they manage it and how the app may or may not help with this.

Example of the types of questions we will ask include:

Q1. How easy to find the application to use?

Q2 Is there anything within the application that you find difficult to use? If so how could we improve this?

Q3 How can we improve the overall application

How will participants be recruited?

Volunteers on the day of clinics. They will be recruited via NHS clinician Fiona MacLean.

How will consent be demonstrated?

Participants will be sent an information sheet and consent form at least 24 hours before being invited to take part. During the session they will be asked to read the info sheet and sign the consent form.

They will be reminded that their responses are confidential and anonymous and that their participation is voluntary. A copy of the signed consent forms will be held in a locked filing cabinet by the project supervisor Dr Marilyn Lennon at University of Strathclyde.

What will the participants be told about the conduct of the research?

They will be told the following

- What the research is for
- What application is been made
- When the application will be ready
- Where and how to obtain it
- How to provide further suggestions/feedback if required

What will participants be expected to do?

With permission to the NHS clinic runners attend the clinics under Fiona MacLean's supervision. Users will be given a brief introduction to the project (all done via the clinical lead Fiona MacLean) and then asked to sign a consent form. They will then be given a walkthrough of various features of the app and asked to give feedback on the perceived ease of use, and usefulness of the various features of the system.

How will data be stored?

The interviews/focus groups will be recorded using a digital audio recorder.

2/18/2015 Ethics Approval

<https://local.cis.strath.ac.uk/local/ethics/index.php?view=200> 2/2

Appendix 20

Presentations and publications

Presentations

British Oncology Pharmacy Association Annual Symposium

2017

Poster presentation

Investigation of community pharmacists' input to the pharmaceutical care of patients prescribed systemic anticancer therapy. Results of a focus group and questionnaire.

2016

Oral presentation and poster presentation

Patients experiences of anticancer therapy and opportunities for community pharmacists to support patients with cancer.

2015

Oral presentation and poster presentation

Design and evaluation of an App for patients with cancer: the Wellness Tracker.

Poster presentation

A retrospective analysis of a cohort of lung cancer patients: co-morbidities, toxicities, pharmaceutical care issues and unscheduled care. Do we really know our patient population?

Publications

Abstract will be published in the *Journal of Oncology Pharmacy Practice* in 2017:

Investigation of community pharmacists' input to the pharmaceutical care of patients prescribed systemic anticancer therapy. Results of a focus group and questionnaire.