

The eSMART project aims to demonstrate benefits for cancer patients using a real-time, mobile phone based remote patient monitoring system, the Advanced Symptom Management System (ASyMS). It is anticipated to greatly improve patient outcomes and delivery of care both during and after chemotherapy treatment. [+ Find out more](#)

## eSMART IN CONGRESS

At page two find reports from conferences where eSMART project was presented:

- Professor Nora Kearney: "eSMART: mHealth in cancer supportive care" at ECPC Annual General Meeting 2015
- Jana Pelouchova, "eSMART project from the Patient Perspective" at MASCC/ISOO Annual Meeting 2015 on Supportive Care in Cancer
- Dr Annegret Schneider: "eSMART: Utilising ASyMS technology to improve outcomes for patients with cancer " at The King's Fund's Digital Health and Care Congress 2015

## eSMART PARTNERS



## PREVIOUS ISSUES

The eSMART Newsletter is a monthly way to share the latest news and information about eSMART project.

Each edition provides updates regarding study's progress, meetings & publications and up-coming events. It also includes a focus on a specific clinical site, introducing key people and sharing patients' experiences and "clinical pearls".

Each issue reaches inboxes on the beginning of the month.

If you wish to receive the eSMART Newsletter automatically every month, please provide us your email address.

You can also find previous issues of eSMART Newsletter [here](#).

## THE NEWSLETTER TEAM

Prof Elisabeth Patiraki, Editor  
Prof Christine Miaskowski  
Dr Stylianos Katsaragakis  
Dr Annegret Schneider  
Mr Francesco Florindi

## YOUR FEEDBACK

We value your opinion and invite you to share your thoughts about the eSMART newsletter with us: [esmart@surrey.ac.uk](mailto:esmart@surrey.ac.uk)

## WELCOME

Welcome to the double July/August issue of our eSMART newsletter. The newsletter you're reading right now was created from the cooperative and productive work of two of eSMART partners, the University of Surrey and European Cancer Patient Coalition (ECPC). In this issue you will find how ASyMS was developed, how patients are involved as co-researchers in cancer research and reports from recent congresses where eSMART project was presented.

## eSMART NEWS

### The History of ASyMS



Dr Morven Miller  
University of Surrey

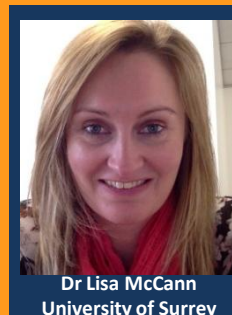
ASyMS evolved from WISECARE and WISECARE+, two multi-centre European cancer nursing studies conducted between 1997-2003. These studies used innovative IT approaches alongside patient reported symptom experiences to improve patient outcomes during chemotherapy. However, they were limited as they utilised patients' retrospective symptom information from paper questionnaires to improve future symptom experiences. With rapidly advancing technology, it soon became possible to remotely assess and transfer patients' symptom information in *real time* to clinical sites and ASyMS (the Advanced Symptom Monitoring System) was developed.

A team of researchers (clinical, academic and computing) then developed the key components of

ASyMS: a real time symptom assessment which could be remotely sent to the clinical site; a risk algorithm to identify symptoms that were deemed out with expected 'norms' and an alerting system for clinicians, allowing them to respond, as necessary, to patients' symptom reports. Following a small scale feasibility study involving patients and health professionals, ASyMS was then evaluated in an RCT of patients receiving chemotherapy for lung, breast or colorectal cancer. Evaluation of patients' symptoms demonstrated that ASyMS was effective in supporting symptom management, while patients' and nurses' perceptions and experiences of ASyMS during this study were also extremely positive.

As a result, ASyMS went on to further evaluation in a range of (English speaking) patient populations and clinical settings including young people with cancer receiving chemotherapy, people with lung cancer receiving radiotherapy, people with palliative care needs, people with haematological cancer and people with breast or colorectal cancer.

eSMART has grown out of these studies and presents the additional challenges of implementing ASyMS in a variety of languages as well as across a range of healthcare systems. It is also the first study in which all data collection will be paperless, with patient recruitment, patient reported outcome measures (PROMs), casenote reviews and the eCRF all recorded electronically. Data collection will begin in the next few months across all the clinical sites and we are looking forward to adding to the evidence that demonstrates the impact of ASyMS on patients' chemotherapy-related symptoms across a number of European countries.



Dr Lisa McCann  
University of Surrey

### Patients as Co-Researchers: A New Reality

During the last few years, we see a steadily increasing number of patients that are involved in various ways in cancer research: as participants, e.g. objects of research in a clinical trial, as respondents to questionnaires and interviews informing research and more recently as co-researchers.

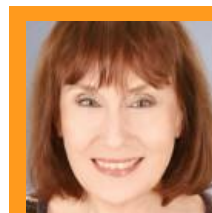
Patients as co-researchers are patients who are members of the research team on equal terms, as the researchers, bringing into the project their lived experience and knowledge to all phases of the project. However, this role is still not common, as patients traditionally have the role of the object of research and not that of the partner. Despite patient participation in clinical trials, till recently their influence on setting the research priorities, the undertaking of research and the interpretation and dissemination of research results was negligible.

The situation has changed considerably during the last ten years with the access to internet and to mobile broadband of vast segments of populations. The internet and social media have enabled patients and families to educate themselves about their disease, to connect to other patients to share experiences, to contact physicians and researches outside the physical settings, to facilitate patient movements.

There are already examples from rheumatoid arthritis, lupus, chronic myeloid leukemia (CML), and other diseases where patients have active roles in research, beyond that of object of research. The experience and knowledge of patients about their particular type of disease can complement that of clinicians and researchers. Patient involvement in identifying and prioritizing topics for research may contribute to make clinical practice and policy more relevant to patient and consumer needs. They may also lead to outcomes that assure a better patient experience and satisfaction as well as improvements in treatment.

There are already various formats of patient education and support for participation in research, including among others medicines development, approval and pricing, clinical trials, ethical issues, health care policy advocacy, but there is still a lot to be done to educate and empower patients for efficiently participating in research and clinical trials. "Patients as partners in research" has become a topic of research with several scientific papers published already, examining various aspects of patient involvement.

eSMART, an innovative research project in mHealth in cancer supportive care, has embraced the participation of patients as co-researchers from its inception. Due to the scope of the project, patients in eSMART have more than one role: they participate as research project partners, through ECPC, the European Cancer Patient Coalition, in Dissemination and Exploitation and as co-researchers in shaping the project, reviewing key project methodologies, ethics, protocol documents and participating in the project management. They also participate as objects of research, through cancer patients recruited at the five locations of eSMART across Europe, who will use the project smartphones to register their chemotherapy symptoms and get real-time advice and support to foster coping. Their insights during chemotherapy time and one year after will help inform the trial about the efficiency of mHealth support during chemotherapy. It is estimated that, if the initial findings of smaller scale prior trials of eSMART are confirmed, the clinical practice of cancer supportive care will change for better.



Dr Kathi Apostolidis  
Vice President of ECPC



## eSMART AT CONFERENCE



Prof Nora Kearney  
University of Surrey

### [ECPC Annual General Meeting 2015](#) : “eSMART: mHealth in cancer supportive care”

The European Cancer Patients Coalition held its 2015 Annual General Meeting from 19-21<sup>st</sup> June in Brussels along with its annual conference. There were 140 delegates from 26 countries with inspirational talks ranging from immuno-oncology to the use of social media to engage patients and their families. I chaired the session on Clinical Trials and had the opportunity to present eSMART which received a very positive response from both patients and professionals working in both clinical care and the technology industry. The conference highlighted the importance of ensuring people affected by cancer are at the heart of innovation in cancer care with a key quote from the conference noting that

“The patient needs from the health system more than prescriptions and waiting lists.” The take home message for me and I think for all of us involved in eSMART was to ensure the trial is a success so that we can play our part in improving both the experience and outcomes for patients with cancer.



Jana Pelouchova, Secretary &  
Prof Francesco de Lorenzo, President of ECPC

[Photos](#)

[eSMARTproject.eu](http://eSMARTproject.eu)

[@eSMART\\_EU](https://twitter.com/eSMART_EU)

[esmart@surrey.ac.uk](mailto:esmart@surrey.ac.uk)

### Report from the MASCC/ISOO Annual Meeting on Supportive Care in Cancer – “eSMART project from the Patient Perspective”



Jana Pelouchova  
Secretary of ECPC

At the [Annual Meeting on Supportive Care in Cancer MASCC/ISOO](#) held at the Bella Center in Copenhagen, from the 25<sup>th</sup> to the 27<sup>th</sup> June, 2015, a session was dedicated to e-health, covering the perspectives of a clinician, nurse, patient and caregiver in separate presentations.

Patients demand for information on cancer, its impact on the patient-doctor relationship, tracing and assembling medical evidence by electronic devices, examples of patient involvement in

projects using technology and last, but not least, the importance of patient networks were the pillars of presentation given by Jana Pelouchova, President of the Leukemia Patient Advocates Foundation, Secretary of the European Cancer Patient Coalition (ECPC).

Besides the current use of mobile devices as means of cost-effective information flow (educative videos, online surveys and mobile applications enhancing adherence to therapies) the importance of using mobile technology in patient supportive care can at best be illustrated by the eSMART project.

ECPC, the largest European cancer patient organisation, as an eSMART research partner ensures the patient centrality of the project design. Monitoring patients with breast, colorectal and haematological cancers during their chemotherapy treatment by means of a specially designed mobile device will give patients the confidence of having an oncology nurse advice/or assistance in hospital depending on their actual state of health. The intervention will be timely and accurately performed depending on the grade of side effects, reducing the burden of unnecessary travels to hospitals or, on the other hand, patients potentially under-estimating adverse events with serious consequences. A question on patient ability to actually use mobile technologies, raised from the audience during the discussion, aimed at the technology “literacy” of the elderly patients. From the position of a patient advocate, we see many cases of patients using mobile devices and enjoying not only skyping with their grand-children, but as a valuable means of overcoming the information vacuum and social isolation and, as in the case of eSMART monitoring, a novel approach to improving cancer supportive care.



### eSMART at the King's Fund Digital Health and Care Congress 2015



Dr Annegret Schneider  
University of Surrey

The King's Fund Digital Health and Care Congress, taking place at the charity's London headquarters from 16<sup>th</sup> to 17<sup>th</sup> June 2015, featured a multifaceted programme, focused around enabling patient-centred care through information and technology. Key players from eHealth/mHealth research, policy, health care institutions, patient advocacy and industry discussed the future of health and care services in the UK and explored how the innovative use of technology is supporting improvements in service provision.

Best practice examples were highlighted in a number of break-out sessions, with eSMART being one of them. I had the chance to present the eSMART study to a wide audience in the session ‘Self-care apps’, in particular focusing on the achievements to date and lessons we have learnt over the past months. My presentation introduced the Advanced Symptom Management System (ASyMS) and how it works, explained the development of risk algorithms to manage side effects of chemotherapy and the symptom response standardisation across European sites, the technical integration of the system and how we prepared our clinical sites for the upcoming trial. I stressed the significance of communication with and support of the clinical sites, when introducing a new, innovative eHealth intervention like ASyMS, as well as the engagement of all stakeholders, including patients and clinicians.

eSMART was well received by delegates, who saw the potential of our intervention to transform cancer care through the use of technology, offering on demand support to patients while reducing costs for the health care system. Clinicians liked ASyMS so much, that some of them approached me after the presentation, enquiring if we are still looking for sites to participate, as they were keen to adopt our technology.

Opinions differed regarding whether a randomised control trial was the best evaluation strategy for eHealth interventions due to the length of time it takes to run them and alternative strategies were discussed, such as service evaluations. Either way, it became clear from talks and discussions at this congress that, despite good ideas for eHealth/mHealth interventions, impact evaluations are challenging and a rarity at the moment. Too often effectiveness is only tested watching website traffic or via small case studies, highlighting the importance of large scale systematic investigation such as eSMART.

The overall consensus at the congress was that health care providers are lacking behind other industries in utilising technology and access services and that this needs to change. More effort and research is required in this field to improve the situation and we are making good progress towards this goal with our project. For more information about this event, visit the [conference website](#), where you can find clips of the keynotes and presentations from the ‘Digital Health and Care Congress 2015’.

