

Issue January,
10 2016

Newsletter



eSMARTproject.eu
[@eSMART_EU](https://twitter.com/eSMART_EU)
esmart@surrey.ac.uk

eSMART: Randomised controlled trial to evaluate electronic Symptom Management using the Advanced Symptom Management System (ASyMS) Remote Technology for patients with cancer

A warm welcome to the first eSMART Newsletter of 2016, which was prepared by the eSMART team of King's College. Reading January's issue you can learn about King's College actions regarding the training of the involved clinicians, the recruitment in the PILOT phase, upcoming eSMART events, as well as ECPC activities on mHealth.

WELCOME

Happy New Year from all of us in London, we are now feeling the cold after record warm temperatures leading up to Christmas! Jenny and I have been busy finalising contracts, while Katy has been working out the logistics of the alert handling process and rolling out training to the clinicians. We are now delighted to say we have started recruitment for the feasibility at Guy's.

We have had help in identifying patients from the respective tumour group Clinical Nurse Specialists and Katy and Jenny have been occupied with working out the optimum recruitment process, doing the randomisation, enrolment and ensuring completion of the PROMs, while at the same time keeping patients engaged! So far we have had some great feedback and constructive comments from both patients and clinicians involved and we are looking forward to commencing recruitment to the main RCT.



Katy Cheevers, Joe Arms, Jenny Harris

In terms of the other London sites, Mount Vernon opened in December and are now part way through their recruitment for the feasibility and St Georges are due to start recruitment in the coming weeks.

It feels great to have started and hopefully we are gaining valuable experience to meet (or beat!) our monthly target of 8 patients; wishing you all the best with your recruitment at your clinical sites.

Upcoming Events

- **24-25 February 2016:**
3rd eSMART Consortium Face to Face Meeting to be hosted by Sykehuset Innlandet Hospital, Lillehammer, Norway.
Representatives from the 11 eSMART partners are going to have a productive meeting about the study.

- **25 February 2016:**
eSMART Public Seminar: "Mobile Technology to support cancer patients in chemotherapy" to be held at Sykehuset Innlandet Hospital, Lillehammer, Norway [+ Find out more](#)



Work Package 3: One-year chemotherapy follow-up



Jenny Harris,
King's College

At King's we are delighted to be leading Work Package 3; the one-year follow-up of patients. As researchers with a particular interest in survivorship, we think this work is really exciting as there is currently such a lack of research into the sustainability of the effects of eHealth interventions and eSMART will provide the first longer-term assessment of the ASyMS technology. Our team has lots of experience in undertaking prospective studies and so over the coming months, as we commence the RCT, we will be in contact with further information and advice about ways in which we can all try to encourage patient's continued involvement long after their active treatment has ceased. If you have any questions, suggestions or concerns about the follow-up please do get in touch with us, we'd love to hear from you!

The Newsletter Team



Prof Elisabeth Patiraki
University of Athens
Editor



Prof Christine Miaskowski
University of California, San Francisco



Dr Stylianos Katsaragakis
University of Peloponnese



Dr Annegret Schneider
University of Surrey



Mr Francesco Florindi
ECPC



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement number 602289

New Cancer Centre at Guy's opening April 2016, by Katy Cheevers



Katy Cheevers
Research Nurse

I am the research nurse working with Jenny and Jo on the eSMART trial and I am mainly based at Guy's. In September I will start my MSc dissertation looking at the difference in patient perspectives on the impact of the environment on patients experience of receiving chemotherapy treatment as a day case using phenomenological methods. I will compare patient experiences before and after the move to the new cancer centre building. I have a good opportunity to

new centre as other clinical sites might be interested in how the Centre aims to improve cancer service provision at [Guy's & St Thomas'.](#)

Construction has been underway since September 2013 with plans to complete and open by April 2016. Patient groups have been consulted in all areas of the building design with the main aims being to inspire and ensure patients are receiving the most up to date care. The patient pathway has been seriously considered; current services mean some patients have care provided at 13 different clinical areas split over two hospital sites- Guy's and St Thomas'. The new centre will allow this to happen all under one roof split into different 'villages' one for radiotherapy, chemotherapy, research and a 'welcome' village including a rehab gym, Dimbleby Care and Support Services centre and relaxation areas with a café and shop.

Waiting times came up as a big factor for patients. This is being combated by the initiative of 'No unnecessary Waits', in which patients will know exact waiting times and queue lengths and clinicians will move around

the building to reduce these.

Another key theme identified by the patient groups was the negative connotations surrounding radiotherapy taking place underground, which patients described as 'an airless dungeon'. The new cancer centre has the radiotherapy department situated on the second floor with lots of natural light.

A lot of consideration has been given to the appearance of the building, with patients also involved in selecting three artists to ensure light, functionality and longevity are prevalent throughout.

As well as providing fantastic care the new centre will be able to treat many more people from the South East London area, 6,500 patients will be treated yearly. The number of radiotherapy treatments will be able to rise from 47,500 currently to 80,000 yearly. £15,000,000 is still needed in donation for the centre so a few of us are doing the Guy's triathlon challenge to fund raise- that's a 2.4km run, 15k cycle and 10k of Guy's tower (29 floors!!!) if you'd like to sponsor please email me!

[+ find out more](#)



New Cancer Centre Building
Guy's Hospital
South East London

eSMART PARTNERS



Partner	Clinical Site	Partner	Clinical Site
Vienna	Medical University Vienna	Athens	Agiou Anargiri Cancer Hospital
Dublin	St James's Hospital		Metropolitan Private Hospital
	Waterford Regional Hospital		Air Force General Hospital
	St Vincent's University Hospital	Oslo	Innlandet Hospital Trust
	St Vincent's Private Hospital	London	Mount Vernon Cancer Centre
Surrey	Clatterbridge CancerCentre		Guy's and St Thomas'
	Royal Surrey County Hospital		St George's London



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement number 602289

Interview with Michael Flynn, Clinical Nurse Consultant and Principle Investigator of eSMART at Guy's hospital, has over 10 years' experience in Oncology nursing



Michael Flynn
Clinical Nurse Consultant,
Principle Investigator of
eSMART at Guy's hospital

Can you explain your background in Cancer Care?

I did my training in Brisbane, Australia which is the capital city of Queensland. Became a registered nurse in 1988, started in Oncology in 1989. It was a 17 bedded ward with a day unit attached. I've noticed a real change over the years from inpatient to more ambulatory care focusing the majority of care in an outpatient setting.

the tools available to do so. eHealth will improve patients symptom reporting so we can intervene before adverse events take place. At the cancer centre touch screens and call forward systems will hopefully modernise patient pathway through the building.

What are the challenges of setting up a trial like eSMART?

The biggest challenge with any trial is embedding a new process. We all know what the standard of care is because we've been doing it, in some instances, for 10 years so to actually change a process can be difficult. For staff and the general public, at times, technology needs to be sold to them. Even younger patients do not always embrace this whole heartedly. Whilst a large number of our patients are also from a pre-mobile phone era.

How do you think trials like eSMART will affect or change the role of some health professionals?

It will help us to become more proactive rather than reactive, gives a better understanding of what patients are actually going through I'm hoping it will stop the chemotherapy day unit becoming factory like and only noticing the patients while they are in the clinic this way more contact will be kept when patients are at their most vulnerable.

Great stuff, and when you're not at work what do you enjoy doing?

I enjoy playing hockey and spend a large amount of time either providing a taxi service for my two children or in Sainsbury's super-market.

Can please explain your current role as a Clinical Nurse Consultant?

The role of clinical nurse consultant as I see it is someone who is an expert in their clinical field and is looking to move the field forward through service development, research and role modelling for the rest of the profession.

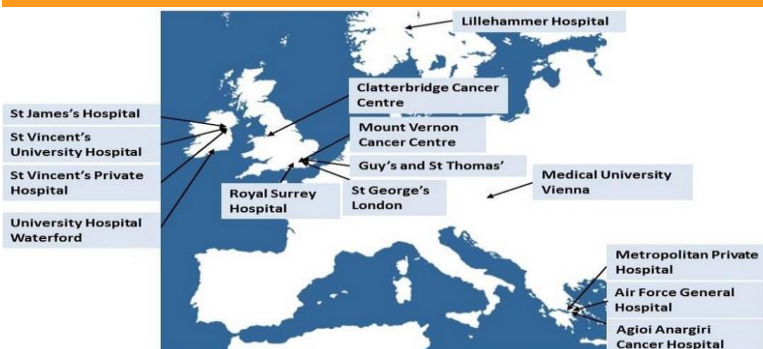
Thinking of the new Cancer Centre being built at Guy's how do you think eHealth is going to improve patient experience?

In the community it is left to patients own responsibility to monitor symptoms, sometimes without the preparation, understanding or

Location of eSMART Partners map



Location of eSMART Clinical Sites



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement number 602289



EUROPEAN
CANCER
PATIENT
COALITION

Established in 2003, the European Cancer Patient Coalition (ECPC) is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the major to the rarer cancers. ECPC was established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to exchange information and share best practice experience. [+ find out more](#)

ECPC, Member of the European Commission Working Group on mHealth Assessment Guidelines

ECPC is among the organizations selected to become a member of the European Commission Working Group on mHealth assessment guidelines.

Mrs. Kathi Apostolidis, ECPC Vice-President, will be representing ECPC within the group due to her experience in e-health and m-health integration in healthcare policy. The European Commission had launched a call for expression of interest to appoint organisations as members. The mandate of the group is to develop guidelines (common quality criteria and assessment methodologies) for assessing the validity and reliability of the data that health apps collect and process. The guidelines developed are expected to build on existing initiatives and best practices in Europe.

ECPC expressed a strong interest in joining this initiative since mHealth apps are becoming increasingly popular among the cancer patient community. The guidelines are expected to be published by the end of this year.

Privacy Code of Conduct mHealth apps - ECPC Position

The Code is a much needed tool to increase the trust of users into mHealth apps, which have the potential to enhance patients' access to quality healthcare and to increase their quality of life. The objective of the Privacy Code of Conduct is to foster citizens' trust in mHealth apps, raise awareness of and facilitate compliance with EU data protection rules for app developers. Overall, ECPC supports the purpose of the Code, and believes the draft generally complies with the needs of cancer patients' and their carers in respect to privacy.

Regarding privacy, ECPC's understanding is that the only exemption to the consent for using personal health data is the one granted by the General Data Protection Regulation to the collection of data for historical, statistical or scientific purposes. Therefore, ECPC suggests to inform users any time their data is anonymised by the developer for uses other than historical, statistical or scientific purposes.

ECPC is however concerned regarding the implementation of the Code, in particular regarding the governance and adherence structures. The efforts of the Code writing group must be met with equal efforts to put together a reliable governing structure to ensure that the burden of the risk cannot lay on the end user.

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](#).

YOUR FEEDBACK

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



This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement number 602289