

RIM

Research Matters



Autumn 2021

Welcome to our patient newsletter

Welcome to the first issue of Research Matters.

As the Director of Research & Innovation Operations, I believe patient and public involvement is central to all our activities as we strive to achieve research excellence and enhance our reputation as a leading centre for cancer services.

Such involvement is critical to ensure that we are guided by patients and the public to address population needs and are mindful of ethical issues.

Towards this goal, this quarterly newsletter, developed in collaboration with our Patient and Public Involvement (PPI) forum, will not only help with

promoting awareness of research endeavours and achievements but will also provide opportunities for wider engagement, participation and input.

I hope that you find this newsletter both informative and valuable and welcome your thoughts and ideas for content of future issues.

Dr Gillian Heap



Dr Gillian Heap

Director of Research & Innovation Operations

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SPECIAL INTEREST:

- **Patient and Public Involvement Forum established**
- **Training for PPI members**
- **Radiotherapy Research**
- **Psychosocial Oncology Research**



Now that The Clatterbridge Cancer Centre (CCC) is firmly embedded in the Knowledge Quarter of Liverpool, in close proximity to the University of Liverpool, we are already witnessing greater collaboration between academia and NHS healthcare staff within CCC.

Despite the prevailing circumstances, it is encouraging to see how we can all adapt to tackle population needs. This would not be possible without active public and civic participation.

As the Clinical Director of Research, I am committed to ensuring that our dedicated staff – doctors, nurses and allied healthcare professionals – have the opportunities for research and innovation to improve the experience and outcomes of patients with cancer.

It is essential that all research activities are guided by the patients, their carers and the

public to ensure that research has patient benefit and wellbeing at the centre of its focus.

This newsletter is a great initiative to promote such involvement.

Prof Nagesh Kalakonda
Clinical Director for Research



The Patient and Public Involvement (PPI) Forum

CCC has long recognised the importance of patient and public participation in routine and research activities. Patients are invited to participate in clinical trials.

In 2014, NHS England published its Five Year Forward View which proposed a more engaged relationship with patients and carers. For compliance, our directorate of Research & Innovation has sought to extend patients' involvement in its activities.

In 2019-2020, CCC launched a comprehensive Patient Involvement Strategy to ensure that our care and services take into account patient and public experience. In addition, CCC is committed to involving diverse socio-economic groups of patients and public in its research activities. Such involvement provides a wealth of insight, perspectives, expertise and experience. In November 2020, our newly established PPI forum convened for the first time.



"I'm delighted with the formation of the PPI group. Patients are at the heart of what we do and ensuring they have a voice that is heard is of paramount importance to staff in R&I"

Emma Whitby, Head of Research Delivery

Clatterbridge Biobank

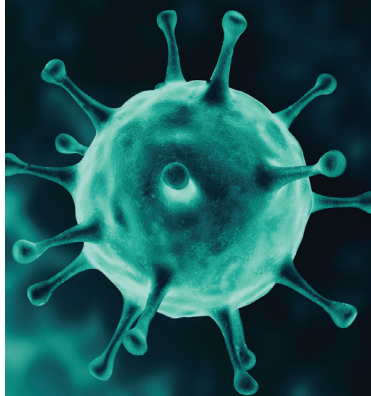
The importance of learning from patient insights and experience to improve research outputs and outcomes cannot be understated. We are grateful to patients who have consented and donated samples for research.

Studies on biological samples is fundamental as they help us address issues such as early detection, optimal and individualised treatments, and to maximise treatment outcomes whilst mitigating treatment toxicities in the short and long term.

Towards this end, CCC has established a unique biobank that systematically collects patient samples to facilitate high-quality research. The biobank also collects samples from healthy volunteers for comparison.

Systematic sample collections during patient treatments also help determine why outcomes in different patients are different. Samples are collected following informed consent from patients. Reviewing how and why the samples are used and outputs of research projects is the responsibility of the Biobank Governance Committee. Two members of our PPI Forum serve on the committee to reflect the patient perspectives and to provide regular feedback.

Effect of COVID-19 on Clinical Trials



Staff within R&I have worked incredibly hard to unpause all the clinical trials which were affected by the COVID-19 pandemic.

In line with national directives on COVID-19, we had to pause recruitment to a number of clinical trials, but all these have been restarted and new ones established.

The R&I Directorate has also been involved in a number of COVID-19 research studies, including one called SIREN that is investigating how prior infection and vaccination affects the risk of catching the virus in UK healthcare workers. About 250 members of staff at Clatterbridge are involved.

The pandemic has been a challenging time for all our staff and patients and it has also affected our ability to meet with patient and public representatives in person due to restricted access to hospital sites.

Nevertheless, we have tried to engage with our PPI group in 'virtual' forums. We sincerely hope that as restrictions are eased we will resume 'normal' working with the group once again.



“My research team are my warriors in my battle against this disease”

Bernadette Ross (Radiotherapy patient)

Training for PPI Forum



We have embraced and adopted the UK standards for public involvement in all research activities as recommended by the National Institute for Health Research (NIHR).

The standards were developed by NIHR INVOLVE and outline the values and principles of public involvement.

These standards encourage approaches and behaviours, such as flexibility, sharing and learning, to promote good and comprehensive public involvement.

Achieving the standards will require careful planning,

establishing timelines and, crucially, the involvement of patients and the public.

The standards include:

- developing a framework PPI in all research activities
- encouraging ‘reflection and learning’

Due to the prevailing circumstances, a planned in-person workshop had to be deferred and members were directed to an online learning portal hosted by NIHR.

Psychosocial Oncology Project



COLLABORATE • DISCOVER • IMPROVE

Liverpool Health Partners (LHP) is a collaborative project between academic and clinical concerns to improve health outcomes within the region.

The embedded LHP-Cancer programme aims to ‘improve cancer outcomes by advancing high-quality collaborative research and embedding it in cancer services across the region’.

The plan is to explore cross-cutting research themes developed by listening to the voices of patients.

The projects address all aspects of the patient journey that cover diagnosis, treatments and survivorship.

A PPI focus group was involved in distilling potential themes and avenues for research prior to approaching suitable funding bodies.



The Clatterbridge Cancer Centre is committed to delivering world class cancer care.

There is a clear recognition and desire to ensure that research and innovation (R&I) is integral to the core business of its activities.

The opening of the new flagship state-of-the-art hospital at the heart of the Knowledge Quarter in Liverpool provides a unique opportunity to re-examine, re-invigorate and refresh the strategic plan for research.

Our guiding principles and priorities reflect views that have emerged from wide consultation within the organisation as well as local and national drivers for clinical and academic research.

We are committed to ensuring that we take into account patient/public views, perceptions and insights as we seek to deliver our research agenda that will ultimately benefit patients.



We aim to have a positive impact on:

- Patient outcomes, experience and journey
- Research culture, ethos and outputs
- Staff engagement and education
- Patient and public involvement.

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Get Involved

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Public and patient involvement is central to all activities of The Clatterbridge Cancer Centre, including research.

There are various organisations that support patients and members of the public to get involved.

A national advisory group (NIHR-INVOLVE) defines public involvement in research as 'research being carried out with or by members of the public rather than to, about or for them'.

Anyone who uses health and social care services can be involved in research –

patients, carers, parents/guardians and the public. Such involvement provides researchers with valuable insights and takes into consideration their views and experiences to influence research direction and outcomes.

This can lead to better research, clearer aims and objectives, and faster uptake of new evidence for better outcomes.

There are various ways that patients and the public can get involved in research, such as participating in a clinical trial, donating samples for research, being actively involved in

the development of research projects and the dissemination of research findings.

If you are interested in joining our PPI Forum, you would be made most welcome and your views would be greatly valued.

If you are interested in becoming a public or patient representative for research at CCC please contact Mary Jordan for more information. Email Mary.jordan3@nhs.net