Wednesday, 13 June 2018

**SPHERE: Announcement of $6Million Investment to Continue Clinical Innovation and Deliver Improved Healthcare**

.

The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE) has announced the Australian Government’s new Medical Research Future Fund (MRFF) will provide funds of $6million over three years for SPHERE and the other National Health and Medical Research Council (NHMRC) Accredited Centres.

Professor Ian Jacobs, President and Vice-Chancellor of the University of New South Wales and inaugural Chair of SPHERE said “This funding enables us to extend our work and go beyond to deliver more impactful, focused outcomes for patients and health services. We are delighted to accept this new funding from the Australian Federal Government to continue our research to reshape the way we approach important health issues through innovation and translation to deliver practical solutions”

### SPHERE is a partnership between 14 leading organisations in health, research and education sectors and aims to develop new and innovative ways to deliver better healthcare for communities in NSW. It was officially launched as a NHMRC accredited Advanced Health Research and Translation Centres (AHRTCs) in Sydney in April,2017.

Since then and over the past 12 months, using substantial and nationally-unique partner investment of $4million per annum, SPHERE activities have been gaining momentum through the establishment of 12 Foundation Clinical Academic Groups (CAGs) and key strategic programs.

The co-investment and support by NSW Health and the MRFF’s first distribution has contributed to the development of other programs such as the Clinical Trials Program and co-leading the National Systems Level Initiative of Health Systems Improvement and Sustainability across all 9 accredited AHRTCs.

In just over 12 months, SPHERE has already made some significant breakthroughs and advancements that reflect the power of bringing together people who were previously in unconnected groups, to focus on real world consumer and community-driven issues and outcomes. These achievements also reflect the focus of SPHERE’s partners in both the academic and healthcare worlds on the “research translation to impact” agenda that is an important piece in Australia’s health and medical research policy.

The *Genome Connect* CAG is one of these impressive developments. Based on a clear and pressing need, led by Professor Tony Rosciolli, *Genome Connect* has a focus on translating the complex landscape of genomic testing into clinical practice. *Genome Connect* has pioneered the establishment of new models of multidisciplinary care using both face-to-face clinics and telehealth to integrate best-practice clinical genomics and genetic counselling with the latest laboratory genomics testing.

This SPHERE project is already making a difference to patients and families, for instance by providing answers to questions around diagnosis for families with a child with disability and through removing the need for invasive pregnancy testing around these issues.

Many families who have a child with a severe disability often struggle to find an answer as to why or how it happened. The members of *Genome Connect* have, through SPHERE, worked together to provide state-of-the-art genomic testing to help provide answers to these questions as well as avenues for treatment.

An example of this is that a specific alteration (gene mutation) was identified in an affected child in a family in a gene known to cause intellectual disability. This gene had only been identified recently and it was through the professional connections and up-to-date analysis systems that *Genome Connect* was able to identify this as the cause of the learning disability. No other type of test would have been successful.

The impact for the family was immense. They learnt that, this was a new gene mutation which was present only in their affected son and which was not present in either the mother or father, which meant that the chance of it occurring again was low. The family was also able to properly access the NDIS and connect with another family with a son with the same disability, providing them with resources and support which they did not have previously.

Modeled on successful academic health science alliances in the UK and the US, SPHERE has already highlighted a range of state and national health challenges as key priorities, including cancer treatment, mental health, diabetes and childhood illnesses.

Professor Chris Levi, Executive Director of SPHERE said, “One of the key goals of the partnership is to accelerate the path of promising and potentially lifesaving research into clinical practice. This investment will allow us to continue to harness the expertise, knowledge and innovation of Australia’s leading minds in health, education and research to deliver solutions to major health challenges.”

Another revolutionary program being driven by SPHERE, is the *Cancer* CAG led by Professor Michael Barton. Working in collaboration with the Cancer Institute NSW, and, under the leadership of Professor Afaf Girgis, they have developed a novel patient-reported outcome measurement system, the Patient-Reported Outcome Measures for Personalised Treatment and Care (PROMPT-Care).

Patient reported outcomes (PROs) are increasingly important in patient-centred healthcare. However, despite accumulating evidence that collecting PROs and transferring results to the treating health professional in real-time has the potential to improve patient well-being, cancer outcomes and the efficiency of the use of the medical system, the practice of routinely collecting patient-reported outcomes is not widespread. The integration of PROs into clinical practice remains challenging.

To overcome these challenges, PROMPT-Care was developed; the first eHealth system in Australia that is fully integrated in hospital oncology information systems (OIS), enabling routine collection of PROs. PROs are collected electronically from patients approximately monthly and presented as summary reports which are accessed in real-time and used by medical staff during appointments to address issues highlighted by the report. To support and empower patients to self-manage, patients are also emailed resources specifically targeting their reported outcomes.

It has been demonstrated that PROMPT-Care is highly acceptable to and manageable for patients and oncology staff, and it has informed the care of more than 440 patients to date in South Western Sydney Local Health District (SWSLHD) and Illawarra Shoalhaven LHD (ISLHD).

PROMPT-Care is the first fully integrated eHealth system of its kind in Australia. The key feature distinguishing PROMPT-Care from previous oncology-based eHealth systems is its total integration into the hospital’s OIS, which has not been achieved in other projects to date.

It is informing the state-wide patient-reported measures initiatives of both the NSW Health Agency for Clinical Innovation (ACI) and the Cancer Institute NSW (CINSW). The electronic tool can be adapted to other clinical groups very easily which means there is significant potential for this method of electronic data collection to become the way of the future in health care.

-ENDS-

**About SPHERE:** <https://youtu.be/lJg5R5kJa54>

**Media Contact:** for more information, contact Momentum2

Lyn Tuit via (02) 9212 2000 | 0405 160 275; or ltuit@momentum2.com.au or Emily Donelly edonnelly@momentum2.com.au

