

Sydney Partnership for Health, Education, Research and Enterprise (SPHERE)

# SPHERE Report 2019



**Australian Government** 

National Health and Medical Research Council



NHMRC accredited Advanced Health Research and Translation Centre

# Question 1: Better Care

What health services (e.g., procedures, preventative measures, treatments or devices) has the centre developed, tested, implemented and scaled-up, or eliminated, to deliver better care for patients?

# Part A: Short answer (maximum ½ page)

#### Please explain:

- your strategy to address this issue and progress to date
- what measures/metrics (a maximum of five) you will use to determine if you have succeeded
- where you are on the impact pathway.

## Strategy to address this issue and progress to date

The Sydney Partnership for Health, Education, Research and Enterprise (SPHERE) is developing a variety of initiatives across its platforms and programs that aim to deliver better care for patients. The partnership has initiated a comparative effectiveness research initiative termed "Supporting Leading Better Value Care" (SLBVC). This program is designed to identify more effective systems, models of care and treatments not only aiming to improve quality but also to reduce the cost of health care across the SPHERE population. A call was made in October 2018 for SLBVC grants. Two \$150,000 grants have been awarded to support research projects over two years. In addition to this focused comparative effectiveness SLBVC initiative, the strategy for all the SPHERE partnership clinical academic groups (CAGs) is to invest in a variety of clinically co-designed projects that are aiming to improve healthcare outcomes initially within the catchment population for the project and then to scale up across the partnership.

What measures/metrics (a maximum of five) you will use to determine if you have succeeded 1. SLBVC projects

- Number of health service partners that have adopted and implemented specific evidencebased care in SLBVC projects.
- Number of partners that have implemented a specific process, procedure or treatment in SLBVC projects.
- Number of processes, procedures, treatments streamlined or eliminated in SLBVC projects.

## 2. CAG projects and the CAG performance management framework

All CAG project activities undergo annual performance review where the categories of assessment, the assessment criteria and success metrics have purposely been developed to drive translation of best evidence practice towards achieving impact in healthcare practice and all policy. The performance management framework categories of assessment criteria and metrics are included in the appendix *(Table 1).* 

## Where you are on the impact pathway - specific examples from the SLBVC initiative

Project 1 - Additive diagnostic value of Prostate-specific membrane antigen (PSMA) to multiparametric MRI (mpMRI) in the diagnostic setting: Ability to reduce unnecessary prostate biopsies in men being investigated for prostate cancer. PRIMARY Trial: This project will investigate the effectiveness of novel diagnostics leading to reductions in the number of unnecessary invasive procedures in patients being investigated for prostate cancer.
Project 2 - Raising the bar in hip fracture care - a win for everyone: This project aims to streamline processes (models of care) to prevent surgical treatment delays for hip fractures.
The projects funded by the SLBVC Grants Scheme are ongoing and preliminary results are due Feb2020. SPHERE's impact pathway for Better Care is illustrated in *Table 2*.

# Part B: Case study (maximum 1 page): Chief Investigator - Professor Afaf Girgis

In your case study, please explain the:

- challenge/problem
- approach/response
- significance
- reach.

## Patient Reported Outcome Measures for Personalised Treatment and Care (PROMPT-Care): Improving care for cancer patients

## Challenge

Patient reported outcome measures (PROMs) are increasingly important measures of quality of healthcare delivery. However, integration of PROMs into clinical practice, and in particular, a "real time" clinical decision aid, remains challenging.

Cancer care is one of the nation's highest volume services with more than 43,000 new cases of cancer diagnosed in NSW in 2014<sub>(1)</sub> and 140,000 in Australia in 2018<sub>(2)</sub>. With improving five-year survival rates, more than 3.5% of our population are cancer survivors<sub>(3)</sub>. When systematically and fully implemented as part of routine care in all cancer centres in Australia, PROMs have the potential to:

a) improve cancer patient outcomes and improve health service utilisation efficiency;

b) reduce costs to patients and the health care system by tailoring cancer follow-up based on patients' PROMs;

c) enhance participation in clinical trials by reducing patient burden through utilisation of routinely collected PROMs data for evaluation of clinical trials; and,

d) identify gaps and variations in cancer care and provide benchmarking reports to help improve the performance of individual cancer centres.

# Approach

A ground-breaking new model of care for cancer patients has been successfully trialled in the SPHERE partnership. Researchers have developed an innovative electronic feedback system to capture patients' views on their psychosocial wellbeing as well as their physical symptoms and to provide this information to their clinical care team in real-time. This project, called the Patient Reported Qutcome Measures for Personalised Treatment and Care (PROMPT-Care) involves cancer patients completing a 10 to 15 minute online survey at regular intervals during their treatment and follow up. The results are summarised for the clinical care team at each consultation with recommendations to address issues of concern. At the same time, the patients receive feedback with links to support services, lifestyle information and self-management tools.

## Significance

Led by Professor Girgis AM (a member of SPHERE's Cancer CAG), PROMPT-Care facilitates early intervention and holistic patient management. It increases the efficiency of health services by identifying patients in need of more urgent and personalised intervention while ensuring others are not recalled for appointments that are not necessary. In addition, this information is directly integrated into patients' electronic health records for long term follow up. PROMPT-Care gives emphasis to the importance of psychosocial wellbeing as a driver of high-quality health outcomes and allows the delivery of care to be adapted to the individual patient's needs. In addition, it delivers efficiency benefits by reducing emergency department presentations, saving time and reducing unnecessary intervention.

## Reach

PROMPT-Care will now be implemented as routine care in all cancer centres in South Western Sydney and Illawarra Shoalhaven Local Health Districts in NSW. The system has potential to be rolled out nationally and also has potential for benefit in other chronic disease conditions. The pathway to impact for this case study is demonstrated in *Table 2*.

<sup>1.</sup> Cancer Institute NSW, February 2019 Cancer Registry Report https://www.cancer.nsw.gov.au/cancer-data-pages

<sup>2.</sup> Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW.

<sup>3.</sup> Australian Institute of Health and Welfare 2012. Cancer survival and prevalence in Australia: period estimates from 1982 to 2010. Cancer Series no. 69. Cat. no. CAN 65. Canberra: AIHW.

# **Question 2: Platforms and Systems**

What platforms or systems has the centre developed to support improved health services?

## Part A: Short answer (maximum ½ page)

#### Please explain:

- your strategy to address this issue and progress to date
- what measures/metrics (a maximum of five) you will use to determine if you have succeeded
- where you are on the impact pathway.

## Your strategy to address this issue and progress to date

SPHERE's Strategic Plan is organised under three portfolio areas: (CAGs; Strategic Programs and Research-enabling Platforms; and National Systems Level Initiatives (NSLIs) (managed in part with the Australian Health Research Alliance [AHRA]). In November 2018 and guided by our five key goals [health and economic (deliver improved health outcomes); research translation: research knowledge creation and innovation: education (professional development and workforce capacity/capability) and partnership (listen and engage)], SPHERE developed the Strategic Outcomes Map depicted in *Figure 2*. The platforms were established in early 2018 and their activities are underway. The CAGs were formed in 2017. They have developed key performance indicators and are progressing implementation of projects across 16 important health priorities. The strategic programs and research-enabling platforms - Implementation Science (IS), Knowledge Translation (KT), Clinical Trials Support and Enablement, Clinical Workforce Development, and Innovation - are designed to support the CAGs to deliver transformational projects that will have impact on local healthcare practice and policy. Specific examples of initiatives implemented are: two SLBVC grants, six Researching Important Clinical Questions to Improve Health (RICH) Outcomes workshops and three Translational Research Fellowships (TRF) which enable and resource CAG projects and engage academics, clinicians and researchers to address important clinical research questions to improve systems of care. Platform and Systems measures

- Number of implemented and scaled up models of care across SPHERE's ecosystem and beyond.
- Number of completed projects that were developed from RICH Outcomes projects.
- Number of processes, procedures, treatments or devices streamlined or eliminated.
- Number of partners that have implemented the (specific) process, procedure, treatment.

## Where you are on the impact pathway

All SPHERE's platforms and systems have invested in and are at different stages along the impact pathway to support improved health services. CAG projects are designed and then assessed using the "translation to impact" framework (see *Table 1*) and have timeframes for implementation and impact ranging from one to five years with some projects already demonstrating impact in vulnerable groups and improved models of care. The formation of networks, including a Translation Committee, the CAGs, Steering Committees, and a KT and IS "Academy of Experts" bring together academics, researchers, health professionals and consumers to identify and develop translational research projects aimed to provide a more effective dissemination of information towards achieving improved healthcare systems that are locally embedded. SPHERE's impact pathway for Platforms and Systems is illustrated in *Table 2*.

#### Part B: Case study (maximum 1 page): Chief Investigator - Dr Geraldine Hassett In your case study, please explain the:

- challenge/problem
- approach/response
- significance
- reach.

## Challenge

Primary care is a rich environment for Clinical Trial research within Australia that could be better exploited through establishing a national general practice-based research network. The South

Western Sydney Diabetes Quality Network (SWSDQN) was developed through consultation with South Western Sydney General Practitioners to develop a local diabetes clinical trial network.

The SWSDQN has been developed to stimulate primary care based clinical trials by

- fostering collaboration
- stimulating a focus on quality (which includes research)
- promoting the do-ability of practice-based research
- creating an ability to identify trial-eligible patients
- providing organisational/trial expertise.

The SWSDQN includes the representation and support from South Western Sydney Local Health District (SWSLHD) and South Western Sydney Primary Health Network (SWSPHN).

# Approach

The SWSDQN utilises Electronic Decision Support Tools to assist Primary Care Practitioners within the SWSLHD to audit their practice data and facilitate their participation in Clinical Trials. The program assists the Primary Care team to prepare their practice to partake in research through undertaking a rigorous process of data cleaning, this will enable a General Practice's future participation and leadership in clinical trials.

The SWSDQN aims to facilitate Primary Care participation in clinical trials through moving each practice through a pyramid of quality, that encompasses:

- Clinical Audit and Data Cleansing;
- Active QI involvement to improve clinical care;
- Participation in Clinical Trials; and
- Proactive engagement in, and development of, Clinical Trials.

The SWSDQN is underpinned by the utilisation of SWISHcare a clinical audit, benchmarking and decision support tool that supports each practice to review their clinical records and identify gaps in current records. SWISHCare supports practices to identify at risk patients and connect with relevant specialists.

Participating practise receive the:

- support from a Project Officer (0.3 FTE) to assist the practice review their practice data to ensure that practices record required patient information, develop disease registers, implement a recall reminder system and broaden patient information programs;
- support from a Clinical Trial Manager (0.3FTE) who will be tasked with promoting participation in clinical trials, the overall efficient day-to-day management of the trial and establishment of procedures to ensure adherence to trial protocols and administrative requirements; and
- participation in quarterly Network meetings that are utilised to provide education to Primary Care teams in regard to participating in clinical trials and to provide a forum for General Practitioners to identify/negotiate the trials that they will participate in.

## Significance

The SWSDQN comprises representation from eight General Practices that encompass representation from all 7 Local Health Districts within the SWSLHD. The SWSDQN provides a model for engaging General Practices in clinical trials and supporting the primary care team in participating in clinical trials.

## Reach

The SWSDQN is supporting Primary Care sites within South Western Sydney to engage and participate in clinical trials. The model that is being utilised through this network can be used to inform future clinical trial networks across the SPHERE catchment. The pathway to impact for this case study is demonstrated in *Table 2*.

# Question 3: Meeting Catchment Needs

How is the centre meeting the needs of its population, including vulnerable groups?

## Part A: Short answer (maximum ½ page)

#### Please explain:

- your strategy to address this issue and progress to date
- what measures/metrics (a maximum of five) you will use to determine if you have succeeded
- where you are on the impact pathway.

#### Your strategy to address this issue and progress to date

The program of work in SPHERE's strategic plan (*Figure 2*) was designed to meet MRFF priorities 2016-2020 including 'Improving the health of vulnerable groups, those with chronic comorbidities, those towards the end of life, along with disadvantaged, ethnic and indigenous groups'. This focus is evident in CAG projects, the Workforce and Development Translational Research Fellowships and in SPHERE's alignment and collaboration with the Australian Health Research Alliance (AHRA) National System Level Initiatives (NSLIs) and National Networks (e.g. Aged care and Wound Care). SPHERE's 16 CAGs have developed portfolios of work that address important health issues and focus on meeting the needs of various vulnerable groups (refer *Figure 1*). *What measures/metrics (a maximum of five) you will use to determine if you have succeeded* 

- Number of initiatives that engage Aboriginal and Torres Strait Islander community and consumers or other vulnerable groups to inform research priorities and translation activities.
- Number of consumers and members of vulnerable groups that attend forums for research priorities, planning and translation activities.
- Number of projects that have a focus on vulnerable groups.

#### Where you are on the impact pathway

A variety of CAG projects and our Translational Research Fellowships, each focussing on health care unmet needs and vulnerable groups, are underway and are at various stages of activity/completion. The case study below describes one of these projects in South Western Sydney. In addition to this and a number of other internally focused projects, SPHERE's membership of AHRA has enabled a coordinated broader state and national approach when engaging with Government on health priorities, particularly for indigenous communities but also for other vulnerable groups. In the area of indigenous health, a first for the NSW academic sector has been the joint appointment across SPHERE and Sydney Health Partners of Sydney-wide, co-funded program manager who will be working to identify opportunities for the two partnerships to work together on strategic initiatives. SPHERE's impact pathway for Meeting Catchment Needs is illustrated in *Table 2*.

Part B: Case study (maximum 1 page): Chief Investigator - Professor David Simmons In your case study, please explain the:

- challenge/problem
- approach/response
- significance
- reach.

## Challenge

Australia, and in particular Greater Western Sydney (GWS), has a large Pacific Islander migrant population(1). Pasifika communities have some of the highest rates of obesity and type 2 diabetes (T2D) globally, along with high rates of diabetes complications, such as nephropathy and cardiovascular disease(2). Insufficient physical activity and poor nutrition interacting with preexisting inherited predisposition are amplifying obesity and diabetes rates(3). While progression from impaired glucose tolerance (a form of pre-diabetes) to diabetes can be prevented/delayed, there is limited evidence of successful intervention to prevent progression from normoglycaemia to prediabetes, or from other forms of prediabetes to diabetes. Preventing diabetes complications includes optimising glycaemia (measured by HbA1c), blood pressure and lifestyle(4).

# Approach

South Western Sydney (SWS), Le Taeao Afua (The New Dawn; LTA), a pilot, theory based, lifestyle program, based upon New Zealand programs, was introduced at the request of the local Samoan community. The program was implemented over 3-6 months, across 4 SWS Samoan Churches.

The project was governed at all stages by a Samoan community representative reference group. As the prevention projects have developed, the group has expanded to include representation from other Pacific communities from across Sydney.

Baseline data showed high prevalences of overweight/obesity (96%) and diabetes (32.8%, including 13% undiagnosed) across the program's participants. The intervention included 12 lifestyle messages delivered by volunteer peer support facilitators (PSFs) supported by employed community activators (CAs). LTA demonstrated high participation, lifestyle changes, a reduced HbA1c and church-wide changes in the content of public feasts.

LTA intervention had a train-the-trainer approach and utilised PSFs to deliver peer support to the wider community. A CA trained and supported the PSFs. GP attendance was promoted in parallel to this community approach through eg referral letters for those with abnormal results.

Twelve healthy lifestyle and 10 diabetes management content messages remained central and consistent to all intervention sessions that were delivered using multiple methods across three main settings (church, community public spaces and homes). Churches selected the message they wished to focus on during each week of the intervention. The messages were translated into Samoan and each message had associated evidence-based materials, including visuals, and tools to assist individuals in making healthy lifestyle choices (e.g. Australian government published physical activity guideline booklets, pedometers, water bottles).

## Significance

LTA confirmed that recruitment and delivery of the intervention via churches is feasible. Of a total available sample of 159 Samoan adults aged ≥18yrs, 75% consented to participate in LTA and 67% had baseline data collected. Twenty individuals completed training to become a PSF. During the 12-month period, over 110 intervention activities were delivered across the three churches.

Churches are well attended by Pacific communities in Australia and thus act as useful organisations to work with this population. Our LTA intervention, involving CAs (comparable to community health workers), PSFs and structured material, was associated with widespread community engagement. Church feast content changed radically. Pre-post evaluation showed an overall HbA1c reduction of 0.4% (p<0.001: including a reduction of 0.7% in those with known diabetes), a diastolic blood pressure reduction of 2 mm Hg (p=0.08, ns), near doubling of self-reported total physical activity (p=0.019, particularly in those without diabetes 134 vs 335 mins/week, p<0.001) and increases in low fat choices, such as cutting the fat off chicken (15% to 24% of the sample, p=0.029

## Reach

The program benefited the local Samoan community of South Western Sydney. The Pacific Reference Group who manages the program have asked for the program to be extended across GWS. The next step is to extend the project across 48 Sydney Pacific Churches across Sydney. The pathway to impact for this case study is demonstrated in *Table 2*.

Hawley, N.L. and S.T. McGarvey, Obesity and diabetes in Pacific Islanders: the current burden and the need for urgent action. Curr Diab Rep, 2015. 15(5): p. 29.

<sup>2)</sup> Ackermann, R.T., From Programs to Policy and Back Again: The Push and Pull of Realizing Type 2 Diabetes Prevention on a National Scale. Diabetes Care, 2017. 40(10): p. 1298-1301.

<sup>3)</sup> International Diabetes Federation. IDF Diabetes Atlas. 2017 (http://www.diabetesatlas.org).

<sup>4)</sup> Davies, M.J., et al., Management of hyperglycaemia in type 2 diabetes, 2018. A consensus report by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). Diabetologia, 2018. 61(12): p. 2461-2498.

# Question 4: End User Involvement

How are end-users, particularly consumers and clinicians, setting research directions or otherwise actively involved in closing the loop between clinical practice and research?

# Part A: Short answer (maximum ½ page)

Please explain:

- your strategy to address this issue and progress to date
- what measures/metrics (a maximum of five) you will use to determine if you have succeeded
- where you are on the impact pathway.

## Your strategy to address this issue and progress to date

Central to the SPHERE strategic plan is the health service translation goal (identified by health service managers responsible for consumer and patient engagement, health service delivery and primary health networks). SPHERE has engaged a high-profile Consumer and Community Engagement Leader, to develop an overarching consumer and community engagement and involvement framework to be implemented across SPHERE platforms and programs that aligns with this goal. The CAGs are clinician led, with consumers and clinicians represented within CAG leadership committees, working groups, planning, consumer events and annual performance assessments. SPHERE's Clinical Research Workforce Development and Innovation platforms further support the involvement of consumers and clinicians. For example, the RICH Outcomes Workshop Program brings together a multidisciplinary team of clinicians, researchers and users of research evidence to build scientifically robust and socially relevant research projects. These workshops increase knowledge and have high applicability in a clinical setting through research translation.

## What measures/metrics (a maximum of five) you will use to determine if you have succeeded

- Number of clinicians and healthcare professionals involved in research (co-design, undertaking and leading) in the CAGs and RICH Outcomes workshops.
- Number of collaborative forums across SPHERE's ecosystem and beyond that bring together academic, health service, education and consumers.
- Number of consumers and members of vulnerable groups that attend forums for research priorities, planning and translation activities.

#### Where you are on the impact pathway

Clinician and consumer involvement within CAGs in SPHERE have led to inclusive participation and built strong partnerships with diverse communities and vulnerable groups empowering them to collaborate in clinical research projects aimed at closing the loop between clinical practice and research. Over the next 12 months, SPHERE will develop an overarching framework for Consumer and Community Involvement in Research that we will align with the AHRA Community and Consumer Involvement and Engagement National framework. The SPHERE framework will guide consumer involvement and engagement in the CAG and Strategic Program/Platform activities. Four RICH Outcomes Workshops conducted by the Respiratory, Sleep, Environment and Occupational Health CAG have led to the formation of projects and working groups to address important research questions to be implemented over 24 months. The SWSLHD Allied Health RICH Outcomes Workshop also engaged clinicians and healthcare professionals working across all allied health disciplines in SWSLHD who would like to build their capability in research. Two research projects focusing on innovative models of care were developed at this workshop and are currently underway. SPHERE's impact pathway for End User Involvement is illustrated in *Table 2*.

#### Part B: Case study (maximum 1 page): Chief Investigator - Professor David Simmons In your case study, please explain the:

- challenge/problem
- approach/response
- significance
- reach.

# Challenge

The challenge was to create an environment in which researchers engaged with consumers to ensure that there was a community and consumer voice in all stages of research.

# Approach

To ensure that consumers are genuinely engaged in research, the Musculoskeletal Clinical Academic group (MSK CAG) set up a Consumer Community Council (CCC).

Setting up a Consumer and Community Council (CCC)

- Advertise for consumer representatives
- Interview respondents
- Organise training with Health Consumers NSW (Cost is approximately \$3500 for up to 20 consumers.
- Project officer (PO) then organised a meet and greet consumer forum for consumer reps and clinicians and researchers who belonged to the MSK CAG.
- PO organised bi- monthly meetings for the council members selected through the interview process.
- CCC and PO developed templates for consumer review of specific research projects and research grants

Once established, the CCC members worked with researchers to design tools (templates) to simplify the review of research materials and look at the research from each side's perspective. Having these tools made it easier for researchers and consumers to work together. The tools were important to enhance communication between the researchers and the community and consumer groups. This interaction was facilitated through the PO for the MSK CAG who acted as the link between the CCC members and the researchers.

## Consumer Engagement within the MSK CAG

The CCC has been established for 12 months. The establishment of this CCC was led by an individual now appointed to an overarching leadership role as the SPHERE leader in community and consumer involvement and engagement. Members of the CCC have reviewed protocols, codesigned research questions, given feedback on a number of grants and provided valuable feedback in the interpretation of study results. Members of the CCC have also been invited to be assistant investigators on a number of research projects.

## Significance - Benefits of consumer engagement in research

- Involving consumers with a lived experience of what's being studied ensures the research is relevant to the end user and the community which supports the end user.
- Connecting researchers with consumers allows both groups to see the value in the perspective of the other. Consumers understand the importance and complexity of research. Similarly, researchers appreciate how consumers can bring a better perspective to what they're looking to achieve in the first place.
- Having consumer input in research can also lead to better-informed research that has a more meaningful outcome. Consumers can bring information to researchers that may avoid problems (such as myths which may be present in the public domain but unknown to the researchers).

#### Reach

Establishment of the CCC has enabled an environment in which researchers engage with consumers to ensure that there is a community and consumer voice in all stages of MSK research across SPHERE partners. The pathway to impact for this case study is demonstrated in *Table 2*.

## Question 5: Workforce

How is the centre building workforce capacity and capabilities in research and translation to ensure health professionals have access to evidence-based education and training and are contributing to health research?

# Short answer (maximum ½ page)

#### Strategy to address this issue and progress to date

The Clinical Research and Research Translation Workforce Development Program aims to build a clinician workforce skilled in research, research translation, implementation and improvement. Addressing our healthcare partner's needs, the program encourages and supports healthcare professionals across all disciplines to engage in research training, thereby driving the conduct of high quality, clinically relevant research; but importantly, also focuses on development of skills (including leadership skills) necessary to support implementation (developing the healthcare "implementers") and ongoing healthcare improvement (developing the healthcare "improvers"). Stage I of this program is the SPHERE Translational Research Fellowship Scheme (TRFS) which supports healthcare professionals/clinicians employed within research active units to conduct translational research whilst undertaking formal research training (e.g. PhD, MD) by funding protected time for research activities. The TRFS supports and promotes excellence in health and medical research by encouraging collaboration between academic and health services. The program is building a workforce skilled in research and translation by encouraging and supporting healthcare professionals and clinicians across all disciplines to increase their research activity and fulfil the ultimate aim of this program.

#### Measures and metrics

- 1. Number of health professionals formally trained in research conduct and build competencies and capabilities through the SPHERE TRFS.
- 2. Number of health professionals who develop translation and implementation competencies.
- 3. Number of clinicians involved in research through SPHERE's TRFS projects.
- 4. Number of mentorship initiatives and activities delivered by the SPHERE TRFS.

#### Where you are on the impact pathway

Three inaugural SPHERE TRFS Fellows (Round 1 2019-2021) commenced their three-year fellowship terms in February 2019. Two Fellows have enrolled in higher degree research programs (PhD candidates) at partner universities. A formal mentoring program with senior clinical academics was established for supervision and mentoring of emerging healthcare professional/clinician researchers. SPHERE's impact pathway for Workforce is illustrated in *Table 2.* 

## **Question 6: Partner Contribution**

How are the partners of the centre contributing to its operation?

#### Short answer (maximum ½ page)

SPHERE is a nationally unique partnership bringing together expertise to undertake and translate research into solutions to improve the health of the communities in the South Eastern and South Western Sydney regions. SPHERE aims to drive improvements in healthcare through research and innovation, education and engagement with industry. It comprises 14 financially committed partners: SWSHLD; SESLHD; St Vincent's Health Network, Sydney (SVHN); Sydney Children's Hospitals Network (SCHN); The University of Technology, Sydney (UTS); UNSW Sydney (UNSW); Western Sydney University (WSU); Children's Cancer Institute; Centre for Eye Health; Victor Chang Cardiac Research Institute (VCCRI); Neuroscience Research Australia (NeuRA); Garvan Institute of Medical Research (GIMR); Ingham Institute for Applied Medical Research and the Black Dog Institute.

SPHERE's Governance and Organisational Structure is illustrated in *Figure 3*. SPHERE's Council comprises 21 representatives from the partners. Partner members also advise on SPHERE's two Sub-committees of Council, the Strategy and Performance Sub-committee and the Finance, Audit and Risk Sub-committee. The partnership is currently operating under a Memorandum of Understanding between the founding Members executed in December 2016. The Partners have agreed to commit significant funding (0.05% of total annual income) over 5 years (~\$4m per annum). This investment has been critical to the establishment of strategic programs and leveraging funding. This large-scale investment has allowed relatively rapid scale-up of program activities and commencement of a local level of translation and cooperation between academia and healthcare. Partner members are represented in Executive and Steering Committees and diverse working groups to guide the implementation and delivery of project activities across all SPHERE's platforms and programs. The CAGs are led by clinicians from different geographical locations and different health service partners. Each partner has enabled access and facilitated participation for SPHERE initiatives. SPHERE's Translation Committee includes the CAG Leadership. University Research Development Managers, Consumer & Community representatives, Health Service Research Directors and the SPHERE Management Team. This group contributes to the strategic development of the SPHERE ecosystem via engagement within their organisations.

# **Question 7: Clinical Trials**

Have you improved processes (e.g. ethics and/or governance arrangements) so that your patients can access clinical trials more easily and/or sooner?

#### Short answer (maximum ½ page)

The aims of SPHERE's strategic plan for Clinical Trials Support and Enhanced Clinician, Patient and Public Involvement in Clinical Research are to improve the access to, recruitment into, effectiveness and impact of clinical trials for our communities and achieve growth, financial return and sustainability in the clinical trials sector for SPHERE partners and other key stakeholders. Three Steering Committees, each focussed on different aspects of clinical trials (CT) support and enablement, have been established to guide further development and implementation of the Plan.

1. <u>CT Design and Oversight</u>. An environmental scan of clinical trials activity, processes, capacity and resources across SPHERE is currently underway. Informed by the environmental scan, we will then focus on opportunities to: share resources and improve access to expertise in CT design; create and share tools; create networks; enable access to training and create formal opportunities for mentorship and capacity building for trialists and staff at all levels.

2. <u>CT Research Ethics and Governance.</u> Two priority-setting workshops were held in 2018. The highest ranked priorities and current activities are: GCP Training - SPHERE is supporting GCP Train the Trainer training for relevant staff; Training of HREC members - HREC training workshops are being planned; Standardisation of Procedures - SOPs, guidelines, trial budget costing tools etc; Auditing and monitoring of clinical trials - Training to be provided to selected staff; Honorary appointments - research passport/clinical credentialing - feasibility being examined; CT Sponsor Responsibilities - planning for a Workshop on Sponsor Responsibilities has commenced; and information and resources are being collated to be made available on the SPHERE website. A Gap Analysis on human research ethics and governance policies and procedures in relation to clinical trials conduct has been completed for three of the four health service partners in SPHERE (SESLHD, SWSLHD, and SVHN, Sydney).

3. CT Conduct and Enhanced Recruitment Performance - Clinician, Public & Patient Involvement: Priority focus areas are: Professional development & educational material; Consumer & Community engagement and involvement; and a Proactive focus on Primary Care. Specific initiatives currently being progressed include: collation of CT educational resources with a package of training options being developed; planning for a Consumer-Researcher Workshop as a first step towards building a framework for practical co-development of research with health consumers; and development of the GP Diabetes Clinical Trial Network - *The South Western Sydney Diabetes Quality Network* - which aims to facilitate General Practitioner participation in clinical trials.

# APPENDICES

Table 1 - SPHERE CAG Performance Management Framework

Categories under Assessment	Weighting %
Leadership	20
Research & Innovation	25
Education and Training	15
Translation into Policy and/or Practice that delivers Impact	35
Collaboration and Partnership extension across AHRA	5
Total	100

Assessment Category			
Highly achieved	Partial achievement	Limited achievement to date	
Leadership of the Clinical Academic Group (Score out of 10)			
Descriptors for a score 10 - 8	Descriptors for a score 7 - 4	Descriptors for a score of 0-4	
Internal Stakeholders	Internal stakeholders	Internal Stakeholders	
<ul> <li>Internal Stakeholders</li> <li>Evidence of:</li> <li>Developing Participation: High attendance at executive meetings; Conduct of at least one larger scale meetings engaging the entire CAG membership;</li> <li>Inclusiveness: All or near all SPHERE Partners represented at both Executive and membership level. Regular consumer engagement in priority setting and decision- making.</li> <li>Partnership: strong strategic alignment of purpose between CAG and Partner plans</li> <li>Communication: clear evidence of inclusive leadership and shared</li> </ul>			
decision making across stakeholder groups (including public and patients <b>External Stakeholders</b> • High CAG "visibility" across SPHERE including cross-CAG	<ul> <li>Limited CAG "visibility" outside SPHERE including CAG activities and collaborations state-wide and national</li> </ul>		

• Developing CAG "visibility"		
outside SPHERE including CAG		
activities and collaborations		
state-wide and national		
Research & Innovation – Delivery	on milestones and outcomes acco	rding to Plan (Score out of 10)
<ul> <li>Descriptors for a score 10 - 8</li> <li>Evidence of:</li> <li>High Effectiveness: evidence of very good prioritisation and performance delivering the vast majority of what was planned</li> <li>An operational plan that has achieved substantial healthcare or policy impact</li> </ul>	<ul> <li>Descriptors for a score</li> <li>between 7 - 5</li> <li>Evidence of: <ul> <li>Reasonable Effectiveness:</li> <li>sound prioritisation and</li> <li>performance delivering a</li> <li>reasonable proportion of</li> <li>what was planned</li> </ul> </li> <li>An operational plan that <ul> <li>has achieved some</li> </ul> </li> </ul>	<ul> <li>Descriptors for a score between 4</li> <li>-0</li> <li>Evidence of:</li> <li>Limited Effectiveness: limited evidence of prioritisation and performance delivering a relatively low proportion of what was planned</li> <li>An operational plan with few achievements as yet</li> </ul>
relative to timeframe/opportunity	important outcomes but not as yet made any clear impact on healthcare improvement	cally, State or Nationally (Score out
of 10)		
Descriptors for a score 10 - 8	Descriptors for a score	Descriptors for a score between 4
Evidence of:	between 7 - 5	-0
All CAG projects having	Evidence of:	Evidence of:
alignment with healthcare	Most major CAG projects	Limited alignment between
partner priorities for	having alignment with	CAG projects and healthcare
improving service delivery	healthcare partner priority	partners priorities
and/or patient outcomes	areas	No evident health service
and/or new policy	Some health service	management executive
development	management executive	sponsorship of key projects
Extensive executive	sponsorship of projects	Predominantly researcher led
sponsorship by senior Health	Some co-leadership of	projects with limited Health
Service Management of key projects	projects involving Health	Service Staff (Clinicians,
	Service Staff (Clinicians,	Managers, Frontline)
• A high proportion of CAG projects and other activities	Managers, Chairs of Health committees)	involvement
being co-led by Senior Health	<ul> <li>Some Community, Patient,</li> </ul>	No Community, Patient,     Consumer and/or Family
Service Staff (Clinicians,	Consumer and/or Family	involvement in co-design,
Managers, Chairs of Health	involvement in co-design,	conduct, delivery
committees)	conduct, delivery	<ul> <li>Limited or no participation of</li> </ul>
Significant Community,	<ul> <li>Developing participation of</li> </ul>	the CAG
Patient, Consumer and/or	the CAG	leadership/membership and
Family involvement in co-	leadership/membership	important NSW or national
design, conduct, delivery of	and important NSW or	agencies such as NHMRC, ACI
		-
	national agencies such as	and CEC
projects	national agencies such as NHMRC, ACI and CEC	<ul><li>and CEC</li><li>Limited or no CAG leadership</li></ul>
<ul><li><i>projects</i></li><li><i>Extensive participation of the</i></li></ul>	NHMRC, ACI and CEC	• Limited or no CAG leadership
<ul> <li>projects</li> <li>Extensive participation of the CAG leadership/membership</li> </ul>	NHMRC, ACI and CEC <ul> <li>Some CAG leadership or</li> </ul>	• Limited or no CAG leadership or membership involvement in
<ul><li><i>projects</i></li><li><i>Extensive participation of the</i></li></ul>	<ul> <li>NHMRC, ACI and CEC</li> <li>Some CAG leadership or membership involvement in</li> </ul>	• Limited or no CAG leadership or membership involvement ir local, state or national clinical
<ul> <li>projects</li> <li>Extensive participation of the CAG leadership/membership in NSW or national agencies</li> </ul>	NHMRC, ACI and CEC <ul> <li>Some CAG leadership or</li> </ul>	
<ul> <li>projects</li> <li>Extensive participation of the CAG leadership/membership in NSW or national agencies such as NHMRC, ACI and CEC</li> </ul>	<ul> <li>NHMRC, ACI and CEC</li> <li>Some CAG leadership or membership involvement in local, state or national</li> </ul>	• Limited or no CAG leadership or membership involvement in local, state or national clinical practice guideline writing,

<ul> <li>national clinical practice guideline writing, state or national quality of care standards development</li> <li>Increased involvement of LHD/Ns policy and senior healthcare management staff in the CAG &amp; SPHERE activities</li> <li>Increased awareness and understanding across the broader CAG membership of how to design and conduct health research within a healthcare setting using implementation science and knowledge translation methodology</li> <li>An understanding and the development of processes within the CAGs for working in partnership for uptake of new knowledge and best evidence into clinical practice</li> </ul>	<ul> <li>quality of care standards development</li> <li>Increased awareness by policy staff of CAG and SPHERE activities</li> <li>Increased awareness and understanding of how to conduct translation health research within healthcare settings and use fit for purpose methods to enable translation</li> <li>Increased understanding and uptake of new knowledge and some efforts to develop communication processes for discipline related best evidence</li> </ul>	<ul> <li>Limited involvement of local health management and policy staff in the CAG activities</li> <li>Limited awareness and understanding within the CAG membership of how to conduct translational health research and embed it within a healthcare organisation</li> <li>Limited understanding of how to use the CAG for knowledge dissemination and to promote the uptake of new knowledge or best-evidence practice.</li> </ul>
Descriptors for a score 10 - 5	Score between 4 -3	Score between 2 -0
Evidence of:	Evidence of:	Evidence of:
<ul> <li>Leadership of SPHERE wide education and training activities</li> <li>Significant member participation in education and training programs offer by other CAGs</li> </ul>	<ul> <li>Significant member participation in education and training programs offer by other CAGs</li> </ul>	<ul> <li>No member participation in education and training programs offer by other CAGs</li> </ul>
Collaboration and Partnership exte	ension across AHRA (Score out of	10)
Descriptors for a score 10 – 5	Score between 4 – 3	Score between 2 - 0
Evidence of:	Evidence of:	Evidence of:
Involvement of 5 or more     NHMRC accredited     Centres	Involvement of 3 or more     NHMRC accredited Centres	Involvement of less than 3     NHMRC accredited Centres

PATHWAY TO IMPACT	1 - Better care	2 - Platforms and Systems	3 - Meeting catchment needs	4 - End User Involvement	5 - Workforce
Start (year)	2017	2017	2017	2018	2018
Activities	Δ	ΔΒ	Δ	Δ	
Outputs				□ <b>D</b>	
Impact	□ <b>A</b>		□ <b>C</b>		
Scaled and sustained					
Measures/Metrics for success*	1,2,3	4,5,6,7	8,9,10	11,12,13	14,15,16,17

Table 2 - SPHERE's pathway to impact measures/metrics

\* See Measures/Metrics for details in Table 3

 $\Delta \text{ Overall SPHERE}$ 

□ Individual projects

A Question 1 case study

B Question 2 case study

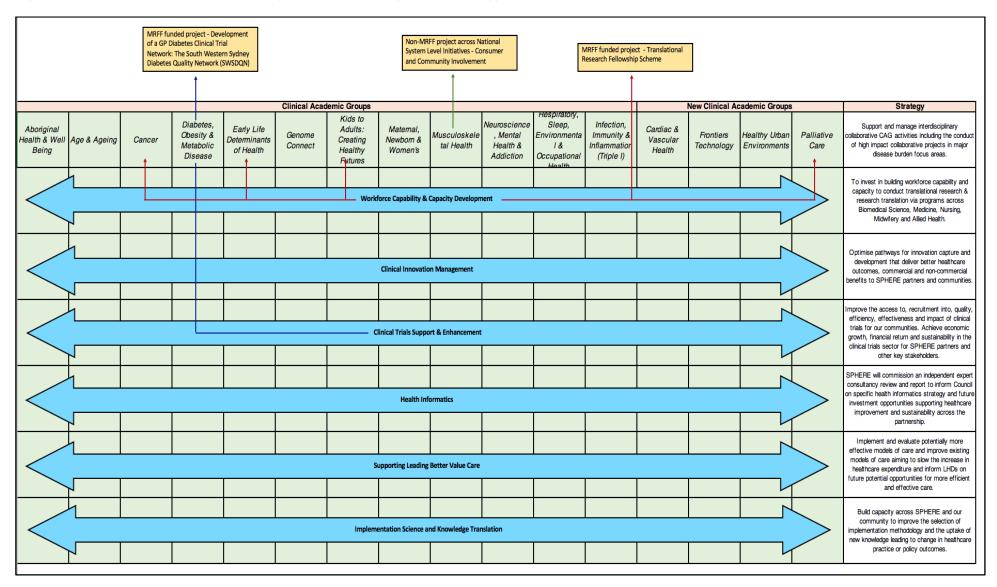
C Question 3 case study

D Question 4 case study

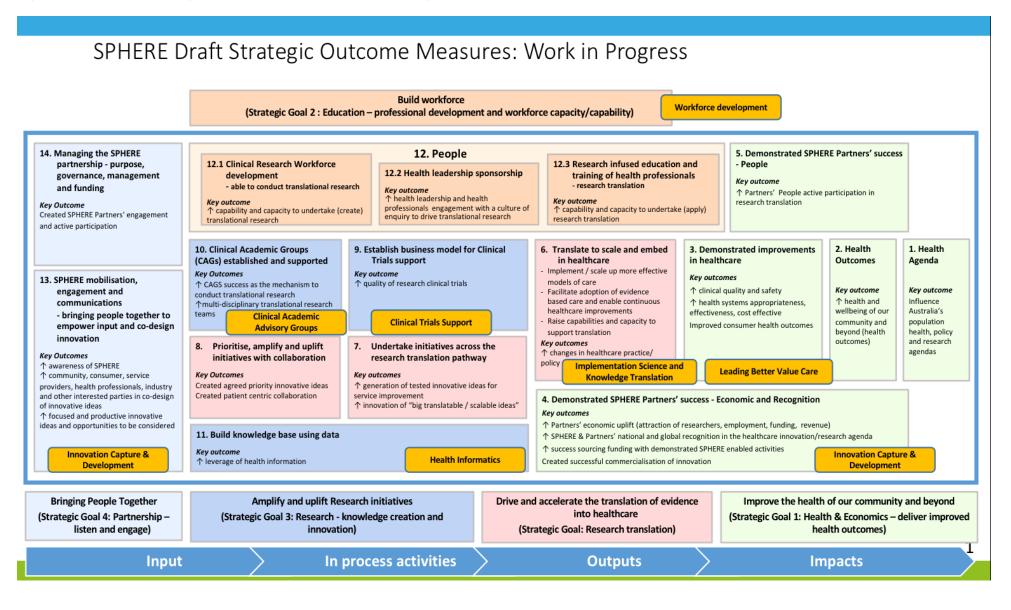
Table 3 - SPHERE's measures & metrics

Metric/Measure	SPHERE Measure/metric	NHMRC Question
Number 1	Number of health service partners that have adopted and implemented specific evidence-based care in SLBVC projects.	Better Care
2	Number of partners that have implemented a specific process, procedure or treatment in SLBVC projects.	Better Care
3	Number of processes, procedures, treatments streamlined or eliminated in SLBVC projects.	Better Care
4	Number of implemented and scaled up models of care across SPHERE's ecosystem and beyond.	Platforms and Systems
5	Number of completed projects that were developed from RICH Outcomes workshops.	Platforms and Systems
6	Number of processes, procedures, treatments or devices streamlined or eliminated.	Platforms and Systems
7	Number of partners that have implemented the (specific) process, procedure, treatment.	Platforms and Systems
8	Number of initiatives that engage Aboriginal and Torres Strait Islander community and consumers or other vulnerable groups to inform research priorities and translation activities.	Meeting Catchment Needs
9	Number of consumers and members of vulnerable groups that attend forums for research priorities, planning and translation activities.	Meeting Catchment Needs
10	Number of projects that have a focus on vulnerable groups.	Meeting Catchment Needs
11	Number of clinicians and healthcare professionals involved in research (co-design, undertaking and leading) in the CAGs and RICH Outcomes workshops.	End User Involvement
12	Number of collaborative forums across SPHERE's ecosystem and beyond that bring together academic, health service, education and consumers.	End User Involvement
13	Number of consumers and members of vulnerable groups that attend forums for research priorities, planning and translation activities.	End User Involvement
14	Number of health professionals formally trained in research conduct and build competencies and capabilities through the SPHERE TRFS.	Workforce
15	Number of health professionals who develop translation and implementation competencies.	Workforce
16	Number of clinicians involved in research through SPHERE TRFS projects.	Workforce
17	Number of mentorship initiatives and activities delivered by the SPHERE TRFS.	Workforce

## Figure 1 - SPHERE's CAGs and Enabling and Support Programs - Strategy



# Figure 2 - SPHERE Strategic Outcome Measures - Work in Progress



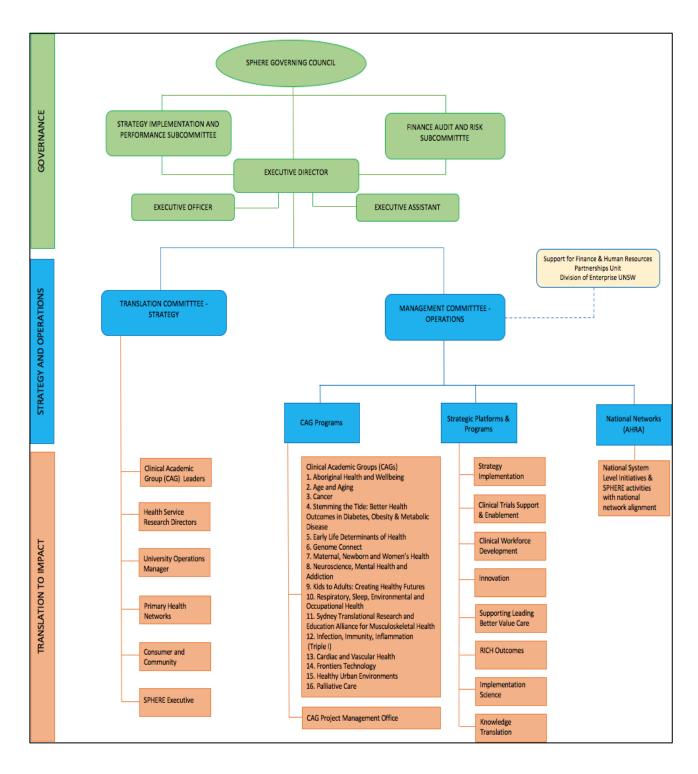


Figure 3 - SPHERE Governance and Organisational Structure