



# Research Strategy South Western Sydney Local Health District

## *Paper No 1: Issues*

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## Executive Summary

In October 2011, the Research and Teaching Committee of the Board of South Western Sydney Local Health District (SWSLHD) requested the development of research strategic plan to embed a research ethos across LHD activities, with longer term (10 year) and shorter term (5 year) strategies.

The planning process initiated within the District occurs within the context of considerable change in the way in which health services are managed, structured and funded and at a local level, demographic changes in the size and age structure of the population. It builds on considerable work nationally and within NSW to achieve a strategic and more focused approach to health research and improve the way it is coordinated and leveraged. It also builds on the growing depth of expertise in health research within South Western Sydney, the establishment of new health researcher units within the District including the Ingham Institute of Applied Medical Research and the opportunities created through new and emerging partnerships with universities and other groups.

Over a four month period, consultation occurred with a range of groups including senior researchers, senior university leaders, clinical leaders and senior managers, consumers, staff and other interested groups about the issues facing health researchers within this District and potential strategies which could be implemented to improve research activity.

Two papers have been developed which summarise the results of this consultation. These papers have been developed to encourage further discussion and to assist in clarifying the potential directions that SWSLHD could take in enhancing health research. The first paper (this paper) addresses the issues faced by local health researchers. This includes concerns with leadership and direction, priority setting and innovation, the need to build research capability including workforce capacity, and the need to focus on infrastructure enablers that support a flourishing research environment.

The second paper considers each of these strategic issues and outlines the potential strategic areas for development. The directions outlined focus on: strengthening health research leadership; developing priorities and innovation for research; building research capability and workforce capacity to undertake health research; increasing community interest and participation in health research; strengthening research infrastructure enablers; and improving monitoring of performance and implementation.

Following further consultation, the Research Strategy will be finalised.

## Introduction

In October 2011, the Research and Teaching Committee of the Board of South Western Sydney Local Health District (SWSLHD) requested that a research strategic plan was developed to embed a research ethos across LHD activities, with longer term (10 year) and shorter term (5 year) strategies. The major aims of the SWSLHD Research Strategy would be to:

- Support and further develop the capacity for research across the SWSLHD.
- Enhance the profile of current research in the SWSLHD.
- Strengthen the quality and quantity of research in the SWSLHD.
- Encourage new researchers, including junior staff, and, sustain the commitment to research of SWSLHD personnel in management, support and research roles.
- Identify the resourcing required to implement the strategies in the Plan and identify potential sources of funding.
- Develop governance arrangements which ensure accountability and responsibility for research conducted according to ethical principles, scientific, regulatory and professional standards and the principles of risk management
- Ensure structures support creativity and lead to research which improves health and health service provision.

This is one of two papers that have been developed to help support the development of the strategy. This first paper provides the policy context for research and then focuses on the health research strengths and strategic concerns and issues that have been identified by District researchers, managers, staff, community and research partners. The second paper focuses on potential strategic directions and actions that can be undertaken to strengthen health research in this District.

## Policy Context

The Council of Australian Governments (COAG) in 2010 signed the final National Health Reform Agreement developed in response to **A National Health and Hospitals Network for Australia's Future**. The agreement establishes a National Health Funding Pool and introduces Activity Based Funding (ABF) to fund hospitals for activity using a nationally agreed price. Under this agreement a new framework for teaching and research will be developed. The lack of standard methods for classifying, counting and allocating costs for teaching and research has been identifying as a significant issue in achieving this end.

The **Strategic Roadmap for Australian Research Infrastructure (2011)** has identified national priority research infrastructure areas. Targeted capability areas include population health, translating health research, urban settlements, integrated biological discovery, eResearch and digitisation infrastructure. The Australian Government has also initiated a **Strategic Review of Health and National Research in Australia** focused on optimising Australia's capacity to produce world class research. The outcomes of this review are expected in late 2012 but a driver has been the structural change occurring through COAG.

The **NSW Health and Medical Research Strategic Review** commenced in July 2011 with a final report expected to be released in mid 2012. The review focuses on NSW health and medical research performance and how the sector can be improved, better coordinated and leveraged; and proposes ways for supporting NSW health needs, clinical trials and commercialisation capacity.

The Discussion Paper from this Review (released October 2011) has identified issues which inhibit the research effort in NSW. Under the vision “NSW will have a global reputation as a centre of excellence for health and medical research that supports a high quality health system and generates social and economic benefits”, the paper proposes to: develop strategic leadership, identification of research priorities and a strategic investment approach; encourage and support research hubs, and include collaboration and translation performance measures into research funding agreements; increase health services innovation by providing clinicians with time and support, training and expertise and by monitoring processes, programs and outcomes; develop systems which encourage clinical trials; leverage research in policy and practice; focus on intellectual property and support early stage venture capital; strengthen the research workforce through programs such as an elite researcher scheme, research fellowships and scholarships; improve research infrastructure support/funding and build research assets; leverage all investment sources; and improve health research administration.

To capitalise on Australian and NSW government directions, the SWSLHD Research Strategy needs to consider the policy context as outlined above. In particular there is a need to further strengthen leadership, innovation and workforce capacity as well as core research activities such as clinical trials and translational research. The implications from these policy directions have been incorporated into this Paper.

## **The South Western Sydney Population and its Health**

South Western Sydney is the fastest growing local health district in NSW with the population projected to grow from its current eight hundred and twenty thousand people to 1.058 million residents by 2021. The most significant growth will occur in Camden, Campbelltown and Liverpool local government areas.

In addition to its size, the population’s characteristics, health profile and the way in which it is changing offer opportunities and challenges for researchers.

Health conditions such as lung cancer, diabetes, cardiovascular disease, hepatitis B and perinatal mortality are all significantly higher in this District than the NSW average. A precursor to these conditions is the relationship between life style behaviours such as smoking, inadequate exercise and poor diet with socio-economic status, environment and culture.

There are approximately 11,200 people who identify as Aboriginal people or Torres Strait Islanders, with large communities in Campbelltown and Liverpool. The health of Aboriginal people is significantly poorer than the general population. For example, Aboriginal people are more likely to die at a younger age, infant mortality is almost twice the rate for NSW babies overall and Aboriginal people are more than three times as likely as non-Aboriginal people to die as a result of diabetes.

South Western Sydney is marked by its culturally diverse communities with Arabic, Vietnamese, Spanish and Cantonese some of the major languages other than English (LOTE) spoken and a large refugee population. This diversity is greatest in Fairfield LGA where 71% of residents use a LOTE at home. There are specific health issues in some communities including overweight and obesity and diabetes in Middle Eastern and Pacific Islander communities, and extremely high rates of hepatitis B in people born in Asian and Middle Eastern countries.

In addition to biological, ageing and lifestyle, social factors such as income, job and education also determine health outcomes. SWSLHD has some of the poorest communities in

NSW with nine suburbs ranked among the fifteen most disadvantaged suburbs in metropolitan Sydney (Australian Bureau of Statistics 2006).

## Consultation Process

As part of the process to develop the Research Strategy, consultation occurred with a broad cross-section of stakeholders. This consultation included:

- interviews with SWSLHD senior health researchers and District Executive and key research partners such as universities
- written submissions (via questionnaire) from SWSLHD Clinical Stream Directors and General Managers
- targeted meetings on specific issues or with specific groups e.g. Aboriginal people, people from culturally and linguistically diverse (CALD) backgrounds, Consumer and Community Council and networks, and clinical trial nurses/coordinators
- discussions with managers of SWSLHD support services
- an on-line survey for staff (completed by two hundred and forty two staff).

The comments from the consultation have been themed to identify the strategic issues and concerns that required consideration in the Research Strategy.

## Leadership and Direction

### 1. SWSLHD Research Leadership, Profile and Research Ethos

Research leadership within South Western Sydney has grown from the teaching hospital status of Bankstown-Lidcombe and Liverpool hospitals. It gained considerable momentum in the 1990's with collaborative partnerships with the University of New South Wales (UNSW) which funded research units such as the Centre for Health Equity Training Research and Evaluation (CHETRE) and University of Western Sydney (UWS) that funded the Centre for Applied Nursing Research (CANR); the commitment of local clinicians; and the commitment and financial support of local companies and communities.

The *Research Strategy for SSWAHS (Western Zone) 2006 to 2011* set the broad strategic research direction for the last five years with its focus on increasing research capacity, strengthening performance, creating an enhanced profile, and sustaining commitment of managers, clinicians and other personnel to the research effort. Major successes of the Strategy have been:

- The establishment of the Ingham Institute for Applied Medical Research, one of the NSW Government's biomedical research hubs. It has a functioning Board and committee structure and was the recipient of \$49 million for the development of research facilities. It attracts significant community support and the on-going support of the Ingham family and there is an active partnership with UNSW and UWS.
- The development of the Ingham Institute Building, a Clinical Skills and Simulation Centre and Research Radiation Oncology Bunker with its MRI coupled linear accelerator (due for completion in 2012), funded through grants from the Australian Government, UNSW, the Radiotherapy Trust Fund and UWS.
- The appointment of a Director of Clinical Trials funded through the Ingham Institute to increase capabilities in the conduct of clinical trials for the entire District.
- An expansion of research design and analysis capacity through the appointment of a biostatistician.
- The creation of an internal grants program with four infrastructure grants of \$200,000 each provided to encourage collaborations into stronger more competitive research enterprises. Four collaborations have been funded: the Allied Health group at Bankstown; Cardiology at Liverpool Hospital; Early Years researchers; and community health researchers working with CHETRE. In addition, a Grant Preparation Scheme was established to provide small grants to assist those who submit NHMRC applications.
- Development of the seven research streams of Cancer, Cardiovascular Disease, Community & Population Health, Early Years, Infectious & Inflammatory Diseases, Injury and Mental Health. These streams reflect the broad priorities of District research.
- Appointment of a Research Director for the Ingham Institute and SWSLHD who provides oversight and direction to the research effort in SWSLHD and ensures strategic directions are achieved.
- In the last three years, increased funding and grants for research projects (excluding capital grants) and over the last five years a strengthening of innovative and essential research in fields such as Aboriginal early years, cancer, and environmental health.



- Annual and targeted research forums which provide opportunities for showcasing local health research, networking and discussing new findings.

The achievements in leadership place SWSLHD in a strategic position to capitalise on the NSW Research Review recommendations. However the consultations with clinicians, managers and staff identified that there is no consistent message about the importance of research from the Board down. This is reflected by the variability across facilities, services and professions in the amount of research conducted, the financial and other supports provided and expectations for accountability and reporting. For example some services incorporate research and research based practice into the duties of all staff whereas other services see research as outside their role. In addition to the efforts to establish the Ingham Institute, the decision by the SWSLHD Board to establish a Research and Education Subcommittee is an important initiative however the need for ongoing concerted leadership for research from an executive level (Board, Chief Executive, District and Facility and Clinical Leaders) was seen as critical for developing a research culture. Lack of accountability will maintain the existing ethos and for this reason reporting on research performance is also seen to be essential.

The need for the District to develop a strong research profile within NSW, nationally and internationally was seen as essential for attracting and retaining high level researchers. However the deficits in infrastructure (physical assets, systems and people) meant that the Districts research profile was not high. As one researcher expressed it "South Western Sydney is seen as a good source of research participants, however staff are not routinely credited for involvement in externally lead research and without this recognition, our researchers are less likely to be successful in grant applications". Leadership will therefore not only require a clear message but also action.

Some senior medical staff proposed research qualifications/experience as a prerequisite for senior positions. While this may be feasible for medicine particularly as hospitals further develop their teaching role, it may not be easily achievable for nursing and allied health professionals who have not had the same tradition or opportunities for further education.

#### Summary of issues

- LHD needs a strong research profile to attract and retain high quality staff
- Importance of research needs to be consistently recognised in LHD facilities.
- The number of staff with research qualifications needs to be increased.
- More research activity should be initiated or directly involve staff from the LHD

## **2. The Relationship between SWSLHD and the Ingham Institute**

Although originally incorporated under the control of the former Sydney South West Area Health Service (SSWAHS), the Ingham Institute for Applied Medical Research was established as an independent legal entity with its own Board of Directors and Executive management team in late 2008. Despite its independent status, there are numerous interdependencies in the roles and functions of the Institute and SWSLHD.

There was a lack of consensus regarding the future role of the Institute within the District. While some clinicians/researchers argued that the Institute should be the main vehicle for District research and management, others indicated that they could see stronger separation in the longer term. This raises fundamental questions regarding their respective roles and functions in research direction, communication with external bodies, performance monitoring and reporting, and promotion and fund raising. It also raised questions about how



conflicts of interest and ownership of intellectual property should be addressed. The current arrangement is a practical solution in the short - medium term however in the longer term the specific roles of each entity and their relationship require clarification.

Within this context, the future direction of the Institute is an issue. Services which are less medically oriented e.g. population health, nursing and allied health were concerned that the inclusion of “applied medical research” in the Ingham Institute’s name suggested that “non-medical” research would not meet the future mandate of the Institute and would therefore not be funded or supported in the future. The development of new research institutes on other hospital campuses or addressing other health priorities was raised. The viability of establishing new institutes with their underlying infrastructure costs, and reduplication of effort and time within the life of this Research Strategy is questionable.

Summary of issues

- The relationship of the Ingham Institute to research in SWSLHD needs to be better defined

### 3. Advanced Health Research Centres

The NHMRC **Discussion Paper - Developing Advanced Health Research Centres in Australia** (2010) proposes the development of Advanced Health Research Centres (AHRC) where consortia of universities, medical research institutes and hospitals apply formally for recognition of their excellence in research and research translation. AHRC’s seek to promote excellence in health and medical research where clinical care is provided, encourage collaboration between researchers, promote the translation of research into clinical practice, day to day care of patients and training in research for health professionals, develop innovative models of care and ensure efficient use of research facilities. These aims are underpinned by collaborations where there is sharing of infrastructure.

Liverpool Hospital is one of eight identified research hubs in NSW and together with the Ingham Institute and existing relationships with universities (particularly the University of New South Wales and Western Sydney) could develop as an Advanced Health Research Centre. While there was support for building relationships with the universities to improve access to research expertise and resources, there was less support for an AHRC as a priority direction for SWSLHD at this stage. Overseas experience suggests that responsibility and accountability mechanisms need to be clearly established to make it work and without guaranteed additional funding, there is the potential that a focus on an AHRC at this stage may divert attention from other strategic imperatives.

Summary of issues

- Advanced Health Research Centres are in early development and their final form and value are uncertain.

## Priority Setting and Innovation

### 1. Research Streams

Research streams help define broad areas of research that external funders and the community can relate to. Research streams also create an imperative for strategic vision among researchers and should give rise to economies of scale. The development of research streams was seen by many as a significant strength of the District, enabling a

broader cross section of disciplines, research units and services to address collaboratively priority research questions and to provide a base from which workforce capability can be developed. Streams were also seen to provide an environment where research could be embedded into clinical practice. This strength is reflected in the new and innovative research that is being undertaken in the District.

The *NSW Health Review Discussion Paper* (October 2011) has identified that in the future research priorities will need to be clearly identified. Although the research streams reflect the overarching broad District priorities, the research priorities and directions within each stream have not been as clearly articulated. This limits the streams' ability to develop projects with greatest potential to attract funds, impact on the health of the community, change clinical practice and engage with and support new researchers/ clinicians in developing their research skills and expertise. It also limits the ability of the District and Ingham Institute to identify where research support (in the form of direct or indirect funding) is required and which areas of research would provide the greatest benefit to the local community.

Summary of issues

- The function, strategies and relationships of research streams need support and leadership.
- The number of streams should be limited but will not define all of the research undertaken in the LHD or in the Ingham Institute
- The relationship between the Ingham research streams and LHD research and clinical services needs to be defined.
- Should research streams be limited to disease entities or reflect professional groupings such as Allied Health or Nursing?

## 2. Potential Research Priorities

The following indicates some issues critical to potential research directions.

### Health Behaviours and Conditions

A stronger approach to prevention was seen by a number of staff as an area which could be further developed. Currently, population health research is targeting areas such as smoking (particularly in Aboriginal communities), environment and mental health. This work occurs in partnership with other agencies including NSW Departments of Housing, Planning and Education and local councils. In addition, it is planned that SWSLHD will host the new NSW Office of Prevention, providing additional knowledge and expertise locally which can further support research into prevention.

The following are examples of potential areas of research for SWSLHD investment:

- The growth of obesity and overweight nationally, and particularly in South Western Sydney, and its impact on a range of health conditions suggest that there may be benefits in developing a new **and stronger** prevention agenda in overweight and obesity to prevent diabetes and related health problems.
- Injury is a potential area for expansion due to its broad interdisciplinary agenda, the impact of life-time disability and broader base of research funding options.
- Research into models of care in prevention, early intervention and treatment of Hepatitis B and related liver carcinomas is important given the large non-English speaking communities in this District.

- Antibiotic stewardship to ensure cost-effective therapy and improve patient outcomes while containing bacterial resistance.

These areas need funding to build on and develop leadership and attract high level researchers.

#### Summary of issues

- SWSLHD has developed considerable expertise in working in partnership with other agencies to address major health problems. The new Office of Prevention to be located in this District will offer opportunities to build on existing research.
- Emerging health problems such as obesity, Hepatitis B and injury require greater attention.

### Aboriginal People

The policy initiative “Closing the Gap”, adopted by all levels of government, is an important initiative in addressing the poorer health outcomes experienced by Aboriginal People. Those consulted indicated that the District is well placed (via its partnerships) to improve the health of the Aboriginal community, with priority given to prevention, health services and translational research. Building on strong partnerships with the Tharawal Aboriginal Medical Service and Marumali, important research which builds national knowledge is being undertaken by services such as Community Health, Mental Health, Health Promotion and CHETRE in the health and development of Aboriginal children in their early years (in Campbelltown), smoking and diabetes.

Aboriginal people indicated that they were “over-researched”, with poor translation of research into practice and limited impact on health outcomes. If health outcomes are to improve, research to inform models of prevention and health care are urgently required. Further where models of and approaches to care (such as service flexibility, holistic care, working through local GP services, and engaging the community through schools) have been evaluated as improving outcomes for Aboriginal people they are rarely translated into clinical practice by mainstream services. Variable attention to true partnerships which involve Aboriginal people in research identification and design, and limited evaluation and feedback about projects are seen however to inhibit ongoing and future participation in research.

Potential areas for research identified by Aboriginal services and staff include: translational research using models which are shown to improve Aboriginal health; researching service effectiveness and building evaluation of health outcomes for Aboriginal people (rather than just outputs) into all health services; building on GP related research occurring in Aboriginal and non-Aboriginal practices; considering the impact of colonisation and forced separation of families on health; improving care planning; and the contribution of institutional racism and career development (capacity building and structure) to Aboriginal employment and burnout.

#### Summary of issues

- Aboriginal people are “over-researched” with poor translation of research into practice or limited impact on health outcomes.
- Potential areas for research include: translational research using models that are known to improve health outcomes for Aboriginal people; a stronger focus on service

effectiveness; building on GP related research; the impact of colonisation and forced separation of families on health; and care planning.

## **People from Culturally and Linguistically Diverse (CALD) Communities**

There are pockets of CALD research in the District covering research topics such as refugee health, violence, and specific health treatment e.g. orthopaedics. However despite the size of the CALD communities, concerns were expressed that clinical research often excludes people who do not speak English (usually citing interpreter costs), limiting the pool of research candidates and potentially restricting generalisation of findings across all residents. In addition, little attention is given to communities with health problems at rates higher than the NSW average. Inadequate consideration of cultural factors such as literacy, community inexperience with research and concerns about confidentiality further inhibit participation. Belated involvement of multicultural expertise and insufficient consideration of community expectations were also seen to impact on future involvement in research and relationships with service providers.

Health professionals have recognised for decades that health care for people from CALD backgrounds requires additional effort and resourcing. A strategic concern for this District is that activity based funding does not adequately consider these additional costs. It is in the District's interest to undertake health services research to identify how health care to these communities can be provided efficiently into the future.

It also in the District's interest to focus more strongly on those health conditions which are at levels above the state-average given their potential to substantially increase demand for hospital based services. It also creates the potential to develop commercial and population approaches to address specific health problems in countries of origin.

### Summary of issues

- CALD patients need better access to clinical trials
- Research should focus on mitigating health inequalities

## **Significant Socio-Economically Disadvantaged Communities**

Traditionally, clinical research has been undertaken with people who can comply with clinical protocols. Lower educational attainment, poor health literacy (i.e. in understanding complex information and the health system) and reduced capacity to meet the costs of participation in research (e.g. parking, transport, child/respite care and leave from work) can impact negatively on the successful engagement of the community.

Population Health, Mental Health and Community Health (and related research units) have significant expertise in working with disadvantaged communities, usually in collaboration with other government and non-government agencies. A collaborative approach in prevention and service provision in meeting the needs of complex and complicated families is fundamental to NSW government direction. Ensuring that our future research includes these communities and supports targeted research will strengthen research outcomes.

### Summary of issues

- Collaborative research in prevention and intervention with disadvantaged communities and complex families needs to continue

## Age of the population

South Western Sydney has the second largest number of births of any District in NSW and a numerically large child and youth profile. The strong focus on early years research and innovation in paediatric care lends itself to addressing national, state and local priorities.

There is also a significant aged population (approximately 98,089 people in 2011) expected to grow by 48% over the next ten years and by 80% by 2026.

The clinical streams of Maternity and Womens Health, and Aged Care and Rehabilitation Services identified a need for stronger leadership and financial support in developing research capacity. Most clinical specialties will be affected by these burgeoning populations and there are significant opportunities for collaborative research in evaluating new models of care and service programs. With the redevelopment of Liverpool and Campbelltown hospitals, there is also an opportunity to explore the impact of health building design particularly on older people.

### Summary of issues

- Significant growth and ageing in the local population will drive the need for evaluation of and research into existing and new models of care.

## 3. Evolving Partnerships and Developments

The University of NSW has contributed significant investment in academic staff and research on the Liverpool, Bankstown and Fairfield campuses. This is likely to continue with opportunities through the Advanced Health Research Centres to develop common research infrastructure such as tissue banking and biostatistical services. UNSW Grant Management Office provides grant review and management services.

The development of Campbelltown Hospital as a Principle Referral Hospital by 2021 and the principal campus of the University of Western Sydney Clinical School within Macarthur provides a unique opportunity to recruit stronger clinical and research expertise to the District and to develop new areas of research in priority areas e.g. innovative models of maternity and paediatric care, and care partnerships with other agencies.

Over the next ten years it is anticipated that there will be a range of models of care, agency relationships and funding arrangements which will change and develop. Some of these initiatives such as specialist surgical centres have already been identified in NSW Government and Australian Government plans. In other cases the changes may be driven by clinicians and services in South Western Sydney. These developments provide further opportunities for research.

An initiative of the Australian Government has been the establishment of Medicare Locals to replace Divisions of General Practice. The new South Western Sydney Medicare Local (SWSML) will commence operation in June 2012 and will have an expanded responsibility and broader coverage of the private health suppliers than previously. It will also share the same boundaries as the District. The District is working with the new SWSML in developing a more strategic approach to health care. There are significant opportunities for increasing collaboration between primary and secondary care researchers in translational and health services research, building on capacity building work of the simulation centre and in using the electronic Practice Based Research Network (ePBRN) developed by the UNSW/SWSLHN General Practice Unit.

The South West Growth Centre (SWGCG) covering Liverpool, Camden and Campbelltown LGAs is a major NSW urban development with a projected population of 300,000 people by 2025. In collaboration with the local Divisions of General Practice, a model for future health service provision has been identified. The model proposes Team General Practices and Primary Health Care Clinics servicing smaller populations, and Integrated Primary Health and Community Care Centres (with potential to offer a wider range of ambulatory care services) serving very large populations. This model will drive new approaches to primary health and community based care and infrastructure developments in the SWGC.

As a collaboration between SWSLHD, the SWSML and universities, this is an important area for research into developing research culture and ethos, and for evaluating alternative ways of providing, managing, operating and integrating primary and community care.

The new Ingham Institute building will provide a central focus for health research in Sydney's South West. Liverpool Hospital has two other developments of importance. The Research Radiation Oncology Bunker will enable clinical researchers to vastly improve patient treatment in cancer patients treated for tumours and will place Liverpool at the centre of world's best practice for radiation treatment across many different cancer types. The Clinical Skills and Simulation Centre will support the practical interaction between desk and laboratory, clinical practice, and public health policy by providing state of the art training and facilities for clinicians, nurses, allied health professionals and students.

Summary of issues

- Australian and NSW government initiatives such as Medicare Locals, urban development in the South West Growth Centre, redevelopment of Campbelltown Hospital and development of the Ingham Institute offer unique opportunities for new partnerships and areas of research.

## Building Research Capability

### 1. Management of Research

The SWSLHD workforce is hardworking and committed to the community in which they serve. The lack of dedicated time for research (and workload pressures created by population growth, growing service demand and insufficient resources) and other supports (e.g. clerical staff) were identified by senior researchers and staff as the most significant barrier for research. Many reported that research occurred outside normal working hours and/or prevented participation in research. These same pressures also create a culture where research was not supported by managers or by other staff.

Not all staff will have the skills, interest in or desire to lead health research however it is broadly recognised that health services and staff should contribute to research to improve health and health care. Towards this end, there was considerable support for incorporating research into the roles of staff and implementing policies which ensuring that dedicated time was allocated for research.

Summary of issues

- The lack of dedicated time for research and workload pressures
- The lack of research supports such as data management, IT and statistics

- A culture where research was not supported by managers or by other staff
- A lack of skills, interest or desire to do research

## **2. Specialist Research Support**

There is a range of expertise which is fundamental to effective research design, development and evaluation. The District has pockets of research expertise provided by research units such as the General Practice Unit at Fairfield; the Centre for Research, Evidence Management and Surveillance; the Centre for Applied Nursing Research; Centre for Health Equity Training Research and Evaluation; and Centre for Population Mental Health Research. In addition to their research, these units foster and support research initiated or undertaken by staff and students. Local medical libraries also provide advice and support to researchers in literature searches, and in some cases actually undertake a search.

Other research services essential to the conduct of research are either not available or of limited availability. For example, many researchers and staff welcomed the recent appointment through the Ingham Institute of a part-time biostatistician but indicated that the position only partially meets local requirements. There is no expertise in the District for telephone and written survey design and researchers frequently need to outsource their statistical work to universities knowing that this work is not a priority and will take longer.

A number of clinicians, services and staff indicated that there was a need for general research support such as data managers and research coordinators. The provision of small grants in the past was seen by some researchers as a very useful strategy for building research however for others it produced variable outcomes. The recent award of larger infrastructure grants by the Ingham Institute has allowed some clinicians to significantly increase their research capacity. The availability of large scale funding in the future from the Ingham Institute is questionable given ongoing research projects.

A major gap identified is the lack of a single coordination function within the District for providing information and advice about research supports, priorities, expertise and outputs. The Ingham Institute has been fulfilling some of this role e.g. producing an annual report however the broader coordination and information role is outside of its mandate.

### Summary of issues

- The lack of research supports such as data management, IT and statistics
- Funding for small grants, early career research support and support for mid-career researchers
- Need for a single coordination office within LHD to provide advice and report on research activity

## **3. Clinical Trials**

A clinical trial is research in which a therapeutic, preventive or diagnostic intervention is tested on human subjects. Although primarily used in the evaluation of drugs or medical devices, this methodology can also be used in health service delivery evaluation and result in improved health care and population health outcomes and longer term benefits economically. The size and diversity of its population make SWSLHD a prime area for clinical trials and there are an increasing number of services conducting trials (including multicentre



studies) in areas such as COPD, paediatrics, cancer, obstetrics and gynaecology and orthopaedics.

The recent appointment of a part-time Clinical Trials director (and statistician mentioned above) through the Ingham Institute are important actions to strengthen trial leadership and direction in clinical trials. However while clinicians and researchers have the capability to expand trials, the historical gaps in coordination and lack of core infrastructure have hampered this work and require urgent attention. While some of these problems are common to all researchers, some are specific to clinical trials. In addition to the dearth of biostatistical expertise, randomisation services are outsourced; clinical trial pharmacists (and staff and systems for drug invoicing) are unavailable or funded on an adhoc basis; there are no standard operating procedures to manage risk and inform proper practice; and indemnity arrangements do not align with community care arrangements. Induction and mandatory training in Good Clinical Practice (GCP) consistent with the International Conference on Harmonisation (ICH) is also not available and mentorship is adhoc.

The South Western Area Pathology Service (SWAPS) provides pathology services to research on a cost recovery basis (where appropriate). Although the proposed amalgamation of all NSW pathology services into a single NSW entity may support the strategic development of research pathology services. However currently SWAPS has variable capacity, space and equipment to significantly increase its support to research and research pathology arrangements (including cost recovery) require review and updating. An added concern is the lack of research specific policies and systems in tissue sampling, management (including dispatch), cataloguing and long term storage of research samples.

Clinical trials nurses/coordinators face additional barriers with difficulty in gaining approval (and funding) to attend mandatory training, trial meetings and conferences; inadequate salaries associated with inflexible award application; and “red tape” in ensuring practical support to patients e.g. free on-site parking.

Specific issues identified in Ethics governance include delays in processing ethics applications which have resulted in the loss of pharmaceutical industry funding, the lack of clinical trial pharmacy expertise on the Ethics Committee and in site specific assessments; and the increasing workload associated with adverse event reporting requirements.

The potential to undertake health services research, using clinical trials methodology, in areas such as aged care, community care and mental health where the range of models of service are expanding are prime areas of research growth and development.

#### Summary of issues

- Statistics and pharmacy are unavailable or funded on an ad hoc basis
- There are a range of clinical trial policy and processes which require development. This includes research pathology systems and processes
- Clinical trials assistants have difficulty undertaking standard parts of their role requirements such as travel to investigator meetings
- Ethics governance has caused severe delays resulting in the loss of pharmaceutical industry sponsored trials.

## Building Workforce Capacity

### 1. The Research Workforce

Researchers in the District have a wide range of skills and interests and include senior “elite” researchers with internationally recognised research, mid-career researchers and new and emerging researchers. Some concerns were common to researchers at all levels including the limited career and salary structure and lack of permanency.

District research units and some researchers receive financial support from the District in the form of a contribution to salaries and goods and services and services in kind (including the cost of administering research grants applied as an on-cost). The consultation identified variable levels of financial support for existing experienced researchers and limited capacity (and flexibility) to attract new elite researchers into priority areas. There was support for the development of financial and other incentives to attract and retain high level researchers i.e. by targeting recruitment to District research priorities and developing a new pool of funds (and other incentives) to provide researchers with essential support. Examples include a contribution to recurrent costs to cover salaries and wages and/or maintaining relatively low on-cost charges for grant administration.

The need to develop and grow our own researchers in a coordinated and planned manner was identified by most researchers and managers. It was noted that mid-career researchers go overseas to further their research careers due to a lack of positions and other supports. Creation of research fellowships locally was seen as a means to retain emerging expertise.

For those interested in research and new researchers, the support is variable. Medical libraries conduct courses in information retrieval and documentation e.g. CIAP and Endnote and research units such as CANR and CHETRE have a formal role in capacity building. However:

- there are no formal education programs covering basic research or methodology e.g. Good Clinical Practice (GCP), research design, statistical methods, etc. As a result staff attend courses outside the District, often at their own cost.
- Unlike the District’s Management Trainee programs, there is no financial support from the District provided to employees undertaking post-graduate degrees by research. In fact this has been formally discouraged and some employees undertake research degrees in their own time.
- there are no formal broadly based mentoring or supervision programs for new and emerging researchers or ways to enable interested staff to contribute to larger projects.

There was considerable support for developing basic and mandatory research education programs, establishing scholarships to enable staff to complete research based post-graduate degrees and developing mentoring programs. The Centre for Education and Workforce Development (CEWD) plays a pivotal role in developing the skills of staff and could play an important role in coordinating research education programs in partnership with universities and providing guidance around mentoring programs.

There was also support for developing conjoint appointments with affiliated universities as a way of strengthening research networks and improving access to specific resources such as journals and programs available within universities.

## **2. Nursing and Allied Health Research**

In an environment of limited resources, SWSLHD staff work collaboratively across health disciplines (and with other agencies) in developing new and innovative approaches to health care and prevention. Further development of this approach in research could occur through the development stream priorities which included interdisciplinary research and stronger networking arrangements

There is a long history in medicine of academic endeavour (including education and research in clinical settings) which is reflected the medical professional structure and award conditions. In contrast, developments in nursing and allied health university based undergraduate and graduate education and professional awards which recognise research expertise are relatively more recent.

There is one nursing professorial position in the District based within the Centre for Applied Nursing Research (CANR). CANR is seen as a major nursing strength enabling the District and University of Western Sydney to work collaboratively to support nurses and midwives in undertaking clinical and health research. It has a well developed track record in systematic reviews and evidenced based practices, the development of nursing and multidisciplinary policies and clinical guidelines, and building the capacity of nurses to undertake research.

Specific issues for nurses and midwives in research were: the lack of an academic base and research experience which prevents nursing-led research; exclusion of nurses from aspects of interdisciplinary research design, analysis and write-up (and non-recognition of their contribution to research); Clinical Nurse Consultants (CNCs) with clinical expertise but almost no post graduate qualifications in research, reducing their capacity to undertake research or to support others; and difficulty in gaining release from clinical workloads.

Clinical trial nurses have additional hurdles in obtaining funding and release to attend mandatory interstate or overseas research training, investigator led meetings, and conferences. The lack of a career structure and permanency has resulted in some nurses leaving the District.

The issues were slightly different for allied health professionals. Although these staff undertake research in undergraduate courses, there is limited practical support to become research active in the workplace. Funding is somewhat fragmented with a dedicated research position at the Liverpool Hospital Brain Injury Unit and a two year Ingham's Institute Infrastructure Grant at Bankstown-Lidcombe Hospital for allied health research. This funding has netted increased research outputs in targeted areas however long term sustained support for allied health research (such as that provided to CANR) is not funded. There is a paucity of academic career opportunities in Allied Health in the LHD.

Clinical based research by both professions also appears to be less visible and/or is poorly recognised. Further financial support to attend and/or present at conferences is variable. Noting the dominance of medical research, there was considerable support by nursing and allied health researchers for targeted scholarships similar to that available in Queensland. There was also support for a dedicated research position/Chair in Allied Health Research and for structures/networks to support research in nursing and allied health clinical practice.

## Summary of issues

- Nursing
  - the lack of an academic base and research experience;
  - exclusion of nurses from aspects of interdisciplinary research design, analysis and write-up (and non-recognition of their contribution to research);
  - Clinical Nurse Consultants (CNCs) with clinical expertise but almost no post graduate qualifications in research, reducing their capacity to undertake research or to support others; and
  - difficulty in gaining release from clinical workloads.
- Allied Health
  - limited practical support to become research active in the workplace
  - lack of academic leadership.

### **3. Community Engagement**

Engagement of the community in the various forms of research can make or break success in a research project. The size of the South Western Sydney population and its diversity (cultural, linguistic and socio-economic) was identified as a major strength by researchers and staff. Perversely the implications of this diversity for research e.g. poor literacy, limited financial capacity, and lack of previous exposure to research were not always considered in project identification and design or in research participants' support.

Local communities are seen to be "generous ....and want to help others in the same situation" however there were barriers to increasing community engagement in research:

- Poor understanding in all communities of the various types of research and its value
- Literacy levels and the dominance of participant information and forms using complex language and concepts provided only in writing or English. Ethics Committee requirements were perceived to increase these problems.
- Need for greater thought about the impact of participation on the private lives of people by recompensing participation (via movie passes or vouchers or promoting altruistic concepts such as "helping the next generation" ), providing financial support e.g. outreach, free parking, cab charges, food and having streamlined administrative processes (e.g. approvals).
- Lack of attention to people from other cultures starting at project design (refer to Issue 5).
- The pathway into research for consumers i.e. timing and place of recruitment (e.g. preadmission clinics, at discharge or in outpatient, GP or community settings), or precursors e.g. helping in education of students which could lead into research.
- Clinician communication style, language and approach used to engage patients and families in research including issues on side effects, confidentiality and privacy.

- The importance of feedback to individuals and communities i.e. the outcome, benefit to patients and the broader community.

Building on SWSLHD Community/Consumer networks, consumers indicated that there may be benefits in involving them in research design and explaining research to potential participants.

Summary of issues

- There are significant barriers to community participation in research in SWSLHD including research literacy, language and culture.

## **4. Ethics and Research Governance**

The SWSLHD Ethics and Research Governance Office is responsible for administering submissions to the SWSLHD Human Research Ethics Committee and providing advice and information about research ethics and human research governance policies.

Although research volume (i.e. nationally funded studies and clinical trials) in SWSLHD has significantly increased, resourcing of the Office does not reflect demand. Researchers identified considerable delays in processing and following up applications, placing grants, trials and student research at risk. In addition, the new ethics staff have not yet developed the relationships and educational programs essential to support researchers.

In 2007, NSW implemented a system of single ethical & scientific review of multi-centre research to ensure that it is only ethically reviewed once. Under this system, Lead Health Research Ethics Committees (HREC) are accredited to undertake a single review on behalf of all sites in the public health system. Unfortunately, the SWSLHD HREC is not an accredited Lead HREC because it lacked sufficient staff and may only review research undertaken within the District. As a result, SWSLHD applications for large multisite research have to be sent to an external accredited Lead HREC for approval. Site Specific Applications (SSA's) required for all research occurring in SWSLHD are a problem with multiple levels of signoff (by SWSLHD clinical and non-clinical services e.g. medical records) before approval can be given.

Differing expectations, variability in procedures and variation in forms increases confusion, duplication and the likelihood of error or omission and makes the ethical approval process arduous. Differing understanding by managers of their delegation can mean that an SSA may be rejected by a facility on ethical grounds even though approved by a HREC.

The Australian Research Ethics Database (AU RED) is used to manage all National Ethics Application Forms (NEAF) and Site Specific Applications (SSA). Although useful for clinical trials, it does not meet the Ethics Office requirements for other work which require Ethical consideration e.g. quality assurance. Low risk studies are reviewed under the separate low risk framework by subcommittees of the HREC.

There was considerable support for increasing resourcing to the Office and in developing education and training for researchers and the Ethics Committee.

Summary of issues

- The Research and Ethics Office is under resourced to meet the requirements to be a lead ethics committee
- SSA processes are time-consuming and variable.

## Infrastructure Enablers

SWSLHD services such as the Information Management and Technology Division (IMTD), Human Resources, Capital Works and Finance play an important role in providing the systems and infrastructure needed to support research activity. The consultation identified a range of areas where a more concerted focus is required.

### 1. Physical Assets for Research

Research assets such as offices, wet labs, equipment, clinical rooms and research storage areas are located predominantly in Liverpool (e.g. the Clinical Services Building, the main hospital building and Speed Street) and to a lesser extent in other facilities. The new Ingham Institute building, Cancer Research Bunker with MRI and Skills Simulation Centre provide much needed new infrastructure to expand research capability.

Access to clinical space, office and storage for research purposes is an issue in all facilities. Recent capital planning for Liverpool and Campbelltown hospitals has attempted to take into account the needs of research to access clinical rooms however the staged development of these facilities suggests that access (at least in the medium term) may be difficult. Demand created by a growing and ageing population will place additional demands on clinical space and equipment. Adequate accommodation for research activity is required in all major facilities.

### 2. Financial Management

The financial management of research projects is complex with considerable diversity in funding sources (i.e. government, non-government, special purpose and trust (SP&T), pharmaceutical and philanthropic), grants and partnership arrangements, and variability in processes for payment, reporting and accountability.

The District Finance Department is developing new systems and processes such as electronic ordering and timely cost centre reporting to improve financial management. This should address some of the concerns identified in financial management of research however there is also a need for clearer processes for project identification and grant management (including acquittal and end of project management), improved understanding about financial arrangements with research partners and funders and better costing methods for determining the financial viability of research.

### 3. Human Resources

Efficient human resource processes are particularly important for enabling research to meet timeframes and ensuring that experienced staff are recruited and retained. The need for a research career structure with flexibility in employment and pathways to permanency, variable understanding of research requirements by middle and senior management (such as the need for clinical research credentialing), and delays in recruitment and conference leave (and related) approvals were identified as areas which required additional attention.

There are no specific awards applicable to researchers, particularly 'dry' researchers who are often employed as 'Health Service Managers'. This creates difficulties with grading, recruitment and promotion.

## 4. Information Management

The Information Management & Technology Division (IM&TD) provides technical infrastructure which improves information flow and links clinical information. The progressive rollout of the CERNER electronic medical record (eMR) and other functionalities, access to the Health Information Exchange and increased capacity to videoconference are important new developments. Concerns identified by researchers focused on data governance e.g. operation of data bases which do not interface with CERNER, poor use of the eMR research capabilities, the cost of purchasing research statistical software and fire-wall barriers between the District and universities (which restrict communication and access to university resources).

Summary of issues

- Research in SWSLHD requires greater support from infrastructure enablers such as IT, human resources and finance if it is to thrive.

## Implementation and Measuring Progress

As noted in the policy context of this paper, the funding of health research under the COAG agreement is still unclear with lack of agreement about how to measure research performance. The collection of information about performance will be particularly important for Districts such as SWSLHD which have an emerging research role.

Currently information about research affiliated with the Ingham's Institute is collected by the Institute however this excludes research undertaken with other universities or institutes. While some services e.g. Brain Injury Unit collect detailed qualitative and quantitative information about research outputs, there are no performance within performance agreements.

As part of this strategy, it will be important that SWSLHD develops systems for measuring outputs and monitoring and evaluating the effectiveness of strategies.

Summary of issues

- Implementation will need to be monitored and performance indicators developed to assess progress.



## References

Commonwealth of Australia *A National Health and Hospitals Network for Australia's Future*, Canberra 2010

Department of Innovation Industry Science and Research *Strategic Roadmap for Australian Research Infrastructure*, Australian Government Canberra 2011

Commonwealth of Australia *Strategic Review of Health and National Research in Australia*, Website, <http://www.mckeonreview.org.au/> (accessed 24 February 2011)

NSW Ministry of Health *NSW Health and Medical Research Strategic Review Discussion Paper 31 October 2011*, NSW Ministry of Health Sydney 2011

National Health and Medical Research Council *Discussion Paper - Developing Advanced Health Research Centres in Australia*, Australian Government Canberra 2010