

# SCHN Strategic Planning Process

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A strategic plan for research is being developed that will accelerate SCHN towards becoming a world leading translational research organisation by;

- building on existing excellence
- realising/investing in new opportunities and
- maximising our collaborations and partnerships.

The process has been informed by;

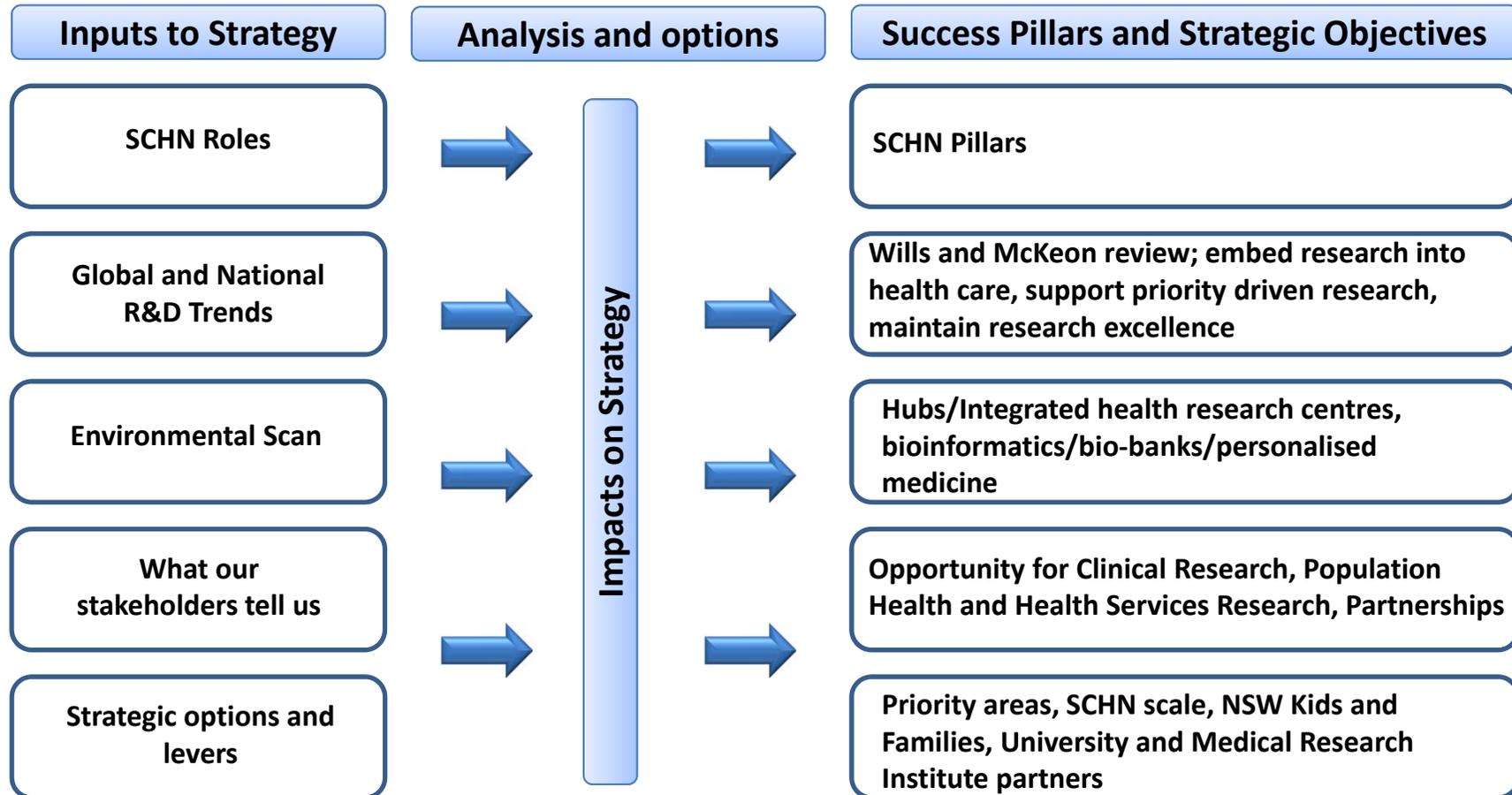
- considerable input from staff on strategies/models to best support people, provide infrastructure, improve communications and priorities for future investments
- Information from each of the research focused sessions, with the help of local champions has been collated and considered/incorporated into the overall strategy
- current health and medical research reviews at university, state and national level
- SCHN strategy

Jack Steele and Tom McGinness from the CSIRO Strategy Team have facilitated the sessions.

The strategy has taken a high level collective approach in developing and prioritising each of the Objectives, Goals and Actions.



# Building the Strategy



National Health Priorities

NHMRC Strategic Plan 2013-15 [http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/nh160\\_nhmrc\\_strat\\_plan\\_201315.pdf](http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/nh160_nhmrc_strat_plan_201315.pdf)

National Priority	SCHN Research Impact
<ol style="list-style-type: none"> <li>1. Arthritis and Musculoskeletal Conditions</li> <li>2. Asthma</li> <li>3. Cancer Control</li> <li>4. Cardiovascular Health and Stroke</li> <li>5. Dementia</li> <li>6. Diabetes Mellitus</li> <li>7. Injury Prevention and Control</li> <li>8. Mental Health (with a focus on depression)</li> <li>9. Obesity</li> </ol>	<p style="text-align: center;">√√ √ √√√ √  √√√ √√ √ √√</p>
Improve the health of Aboriginal peoples and Torres Strait Islanders through the support of health research and its translation	√√√
Preparing Australia for the 'omics' revolution in health care	√√√
Primary health care; helping practitioners and patients to gain value from research evidence, especially in areas of health inequalities	√
Improving care of patients with multiple and complex chronic disease	√√
Healthy start for a healthy life	√√
Claiming benefits for human health not based on evidence	
New and emerging health threats – infectious diseases, environmental hazards, changes in the human environment	√√√
Health and research in our region	√

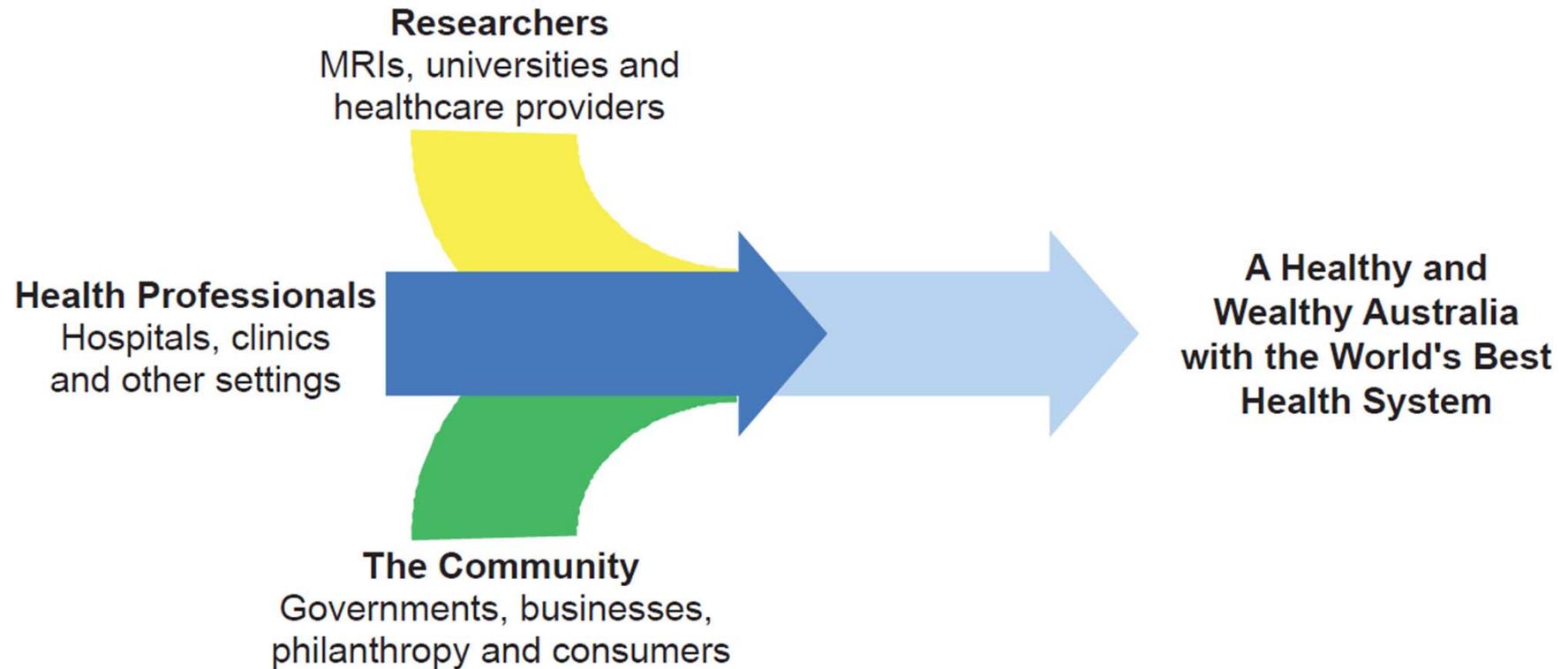
Rankings above are based on SCHN's research impact assessed by the following criteria:

- **Excellence:** Research that has been a recipient of sustained CIA Tier 1 funding in the last 2-4 years
- **Capacity:** >20 researchers focused on a research area
- **National Profile/Impact:** Recognised as a national leaders in research area
- **SCHN Research Activity:** Collaborative research activity across CHW and SCH

# Partnerships and Collaborations

McKeon Review of Health and Medical Research, February 2013

## Delivery Through Partnerships



**'Better Health Through Research'**

# Strategic Options: *Potential movements in our positioning for selected indicators*

	Choice	
<b>Impact</b>		
<b>Science Health</b>		
<b>Infrastructure and Financials</b>		
<b>People</b>	<p><i>Internal Operations</i></p>	<p><i>Use of Resources</i></p>
<b>Research Focus</b>		

**Legends:** assessment of current balance; potential change in indicator

# SCHN Research Strategy 2013-2017

To ensure SCHN Research retains strategic intent and clear direction over time, this plan aligns closely with the overall SCHN Strategic Plan 2012-2017 <http://www.schn.health.nsw.gov.au/resources/SCHN-Strategic-Plan-2011-2016.pdf>

## Our Vision

To be a world leader in translational research for children and young people

## Our purpose

SCHN Research is committed to discovering and implementing new ways to help improve the health of children and young people by:

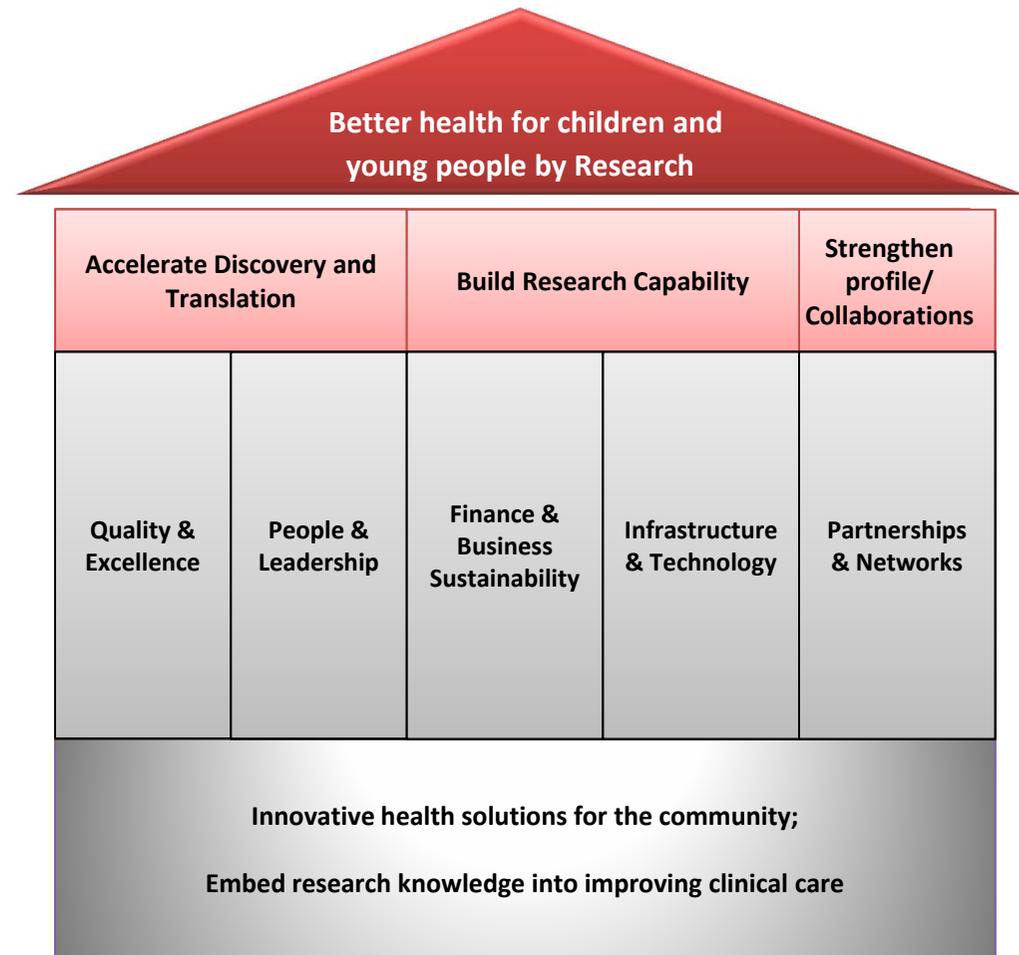
- Discovering new insights into how diseases work, diagnostic methods and treatments
- Translating research outcomes into clinical practice and disease prevention within the community
- Determining which treatments are safe and effective
- Working collaboratively locally, nationally and internationally
- Being a trusted scientific and policy advisor and partner

## Our Mission

To drive excellence in health research leading to improved health outcomes for children

## Health Values

Collaboration  
Openness  
Respect  
Empowerment



# SCHN Research

***“Better health for children and young people by Research”***



Research Support Services and Enablers	
Site Specific	SCHN
<ul style="list-style-type: none"> <li>• Fundraising</li> <li>• Laboratory / Imaging</li> <li>• Animal Facility</li> <li>• Grants &amp; Scholarships</li> </ul>	<ul style="list-style-type: none"> <li>• Executive</li> <li>• Corporate Governance</li> <li>• Ethics and Research Governance</li> <li>• Finance</li> </ul>

## Research Strategic Plan 2013-2017

Success Pillars	Quality and Excellence	People and Leadership	Financial & Business Sustainability	Infrastructure and Technology	Partnerships and Networks
<b>Strategic Objective</b>	SCHN Research will encourage innovative approaches to drive and achieve research excellence and to become a leader in paediatric health and medical research.	SCHN Research will lead the delivery of paediatric research and advocacy through a highly-skilled and professional workforce.	SCHN Research will ensure financial sustainability and will support growth to meet increasing demands and advances in technology.	SCHN Research will invest in infrastructure that supports and enables excellence in research.	SCHN Research will work to enhance the health of children and young people across a diversity of settings and systems.
<b>Strategic Goals</b>	1.1 To be a leading paediatric research centre in Cancer, Rare Disorders, Infectious Disease, Indigenous Health and Chronic Disease.	2.1 Promote and further develop pathways to support the professional development of researchers and research support staff.	3.1 Develop income streams to ensure the ongoing financial viability, sustainability and growth of research activities.	4.1 Provide virtual and tangible world class resources and facilities that enable efficient research, information sharing and collaboration.	5.1 Implement formal relationships with hub research partners and other affiliated research entities for the purpose of collaboration, efficiencies through economies of scale and potential improved funding opportunities.
	1.2 Build capacity in and capitalise on existing excellence in population based health by developing the SCHN Population Health Research Collaborative.	2.2 Implement strategies which facilitate the development and transfer of knowledge and skills.	3.2 Enhance our knowledge of capital requirements for asset replacement and planned growth.	4.2 Foster a culture of interdisciplinary research at SCHN.	5.2 Improve mechanisms across SCHN to enable efficient collaboration for translational research.
	1.3 Implement research integrity framework that supports the conduct of high quality research at SCHN and protects research participants at the highest level.	2.3 Ensure SCHN and employees interests are protected when entering into formal relationships with third parties.	3.3 Improve support for Research Grant Activity and Management.	4.3 Facilitate translational research through a common bio-banking strategy, embedded within patient management streams, centred within pathology and routine across the SCHN.	5.3 Work with Government, academic and health service partners to build research networks that enhance health care through the translation of research into patient care.
	1.4 Build Capacity in Health Services Research .	2.4	3.4 Develop and implement a robust impact measurement framework that defines success of translational research at SCHN.	4.4 Provide optimal operating systems and practices which enhance the capability to deliver high quality research.	5.4 Grow strategic research partnerships with leading national and international peers in fields where we seek to build profile.
	1.5 Support research in existing/emerging areas of opportunity for State and National impact.	2.5	3.5 Research space is allocated equitably based on appointment and performance	4.5	5.5 Develop and implement a systematic program of engagement with leaders in government, industry and the community.
<b>We will not</b>	Support unstructured research that does not achieve tangible outcomes.	Invest in resources and expertise that are not aligned with our strategy.	Seek or accept revenue that is not aligned with our strategy.	Compromise our values or the health and safety of our staff, children and families.	Compromise our values or credibility as an advisor in search of revenue.

## Research Action Plan 2013-2017

**Quality and Excellence: SCHN Research will encourage innovative approaches to achieve and maintain research excellence and to become a leader in paediatric health and medical research.**

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs and Impact):
No:	Summary				
1.1	To be a leading paediatric research centre in Cancer, Rare Disorders, Infectious Disease, Indigenous Health and Chronic Disease.	Leverage existing relationships with Kids Cancer Alliance initiative to establish a national translational cancer research collaborative.	M	Jun 2014	Meet with existing and potential stakeholders to draft concept for national infrastructure funding for cancer research.
		Develop concept plan for centre for Rare Disorders research. See appendix A.	H	Nov 2013	Collaborative structure and plan developed for funding opportunities;  Project Officer appointed.
		Scope new concepts for building and supporting centres of research excellence at SCHN in indigenous health, chronic diseases and in infectious diseases.	M	Jun 2014	Establish relationship / partnerships with Universities as part of their strategic initiatives in this area.
1.2	Build capacity in and capitalise on existing excellence in population based health by developing the SCHN Population Health Research Collaborative (PHRC).	Implement a Population Health Research Collaborative (PHRC) Governance and Management structure for SCHN.	H	Aug 2013	SCHN PHRC Management Committee meeting regularly.
		Implement a Population Health Research Collaborative (PHRC) Steering Committee that brings together internal and external stakeholders including Sax institute and NSW Kids and Families.	M	Dec 2013	SCHN PHRC Steering Committee meeting twice/year.
		Appoint a part-time Project Officer to assist in building a profile and facilitate funding applications.	H	Oct 2013	Raise awareness for Population Health Research for young people at SCHN and in NSW.
		To undertake new collaborative research projects that would focus on priority populations consistent with strategic objectives developed by collaborative.	M	Jun 2014	At least one new collaborative cross discipline projects initiated;  Improved understanding and management of injury, disability and illness prevention in young people.

## Research Action Plan 2013-2017

Cont. Quality and Excellence: SCHN Research will encourage innovative approaches to achieve and maintain research excellence and to become a leader in paediatric health and medical research.

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs and Impact):
No:	Summary				
1.3	Implement research integrity framework that supports the conduct of high quality research at SCHN and protects research participants at the highest level.	Complete a gap analysis and develop an SCHN Framework based on the NHMRC Australian Code for the Responsible Conduct of Research.	H	Apr 2014	Overarching SCHN Framework and plan for implementation completed.
		Provide support to researchers through improved Ethical and Governance Review.	H	Dec 2013	Timeframe for Ethical and Governance Review are in line with or better than State benchmarks.
		Develop an Audit and Monitoring Framework to ensure compliance with Good Clinical Practice (GCP) and National guidelines.	H	Jun 2014	Audit >2 high risk research studies in which SCHN is a study sponsor.
1.4	Build Capacity in Health Services and Health Effectiveness Research.	Develop a collaboration that could apply for Tier 1 funding for Health Services Research.	M	Dec 2014	Implement a support program for Health Services Research .
		Build partner relationships to assist SCHN in evaluating our investments in information technology.	M	Oct 2013	
1.5	Support research in existing/emerging areas of opportunity for State and National impact.	Support the development of Centre for Children's Bone Health Research. See Appendix B.  Adolescent and Psychological Medicine – to be developed.	M	Feb 2014	Seed funded projects.

## Research Action Plan 2013-2017

**People and Leadership: SCHN Research will lead the delivery of paediatric research and advocacy through a highly-skilled and professional workforce.**

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
2.1	Promote and further develop pathways to support the professional development of researchers and research support staff.	Work with partners to further develop a range of options to support professional development for Early/Mid-Career staff.	H	Jun 2014	Promote and further develop pathways to support the professional development of researchers and research support staff across the Network.
		Introduce and manage an internal Travel / Small grant scheme for Early/Mid-Career Researchers to apply for and use as seed funding and/or to support travel associated with their research.	M	Dec 2013	There will be four travel / small grants awarded annually.
		Support and encourage SCHN researchers to undertake training in Media Communications.	M	Jul 2014	1-2 Research Media Communication sessions/training per year.
		Promote training and educational opportunities in good clinical practice and research governance.	M	On-going	>1 GCP courses per year;  Up-to-date information on Research Intranet/s of education and training available (refer to 4.1);  Annual Research Leadership Seminar series.
2.2	Implement strategies which facilitate the development and transfer of knowledge and skills	Implement a series of Manager/Administration Forums to ensure staff are up to date with management/administration processes within SCHN.	L	Sept 2013	Improved information sharing of SCHN /NSW Health Management and Administration.
2.3	Ensure SCHN and employees interests are protected when entering into formal relationships with third parties.	Develop a SCHN procedure for the efficient review of all research related agreements and contracts.	M	Oct 2013	SCHN Procedure for Research Contract Review is implemented.  Contract review turnaround at benchmark.  Education Forums for research contract review and execution twice annually.

## Research Action Plan 2013-2017

**Financial and Business Sustainability: SCHN Research will ensure financial sustainability and support growth to meet increasing demands and advances in technology.**

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
3.1	Develop income streams to ensure the ongoing financial viability, sustainability and growth of research activities.	Investigate pathways for funding and advocate for State and Federal support that align with recommendations from recent Health and Medical Research reviews.	H	Jul 2014	Increase University / Public Funding by 20% year on year;  Eligibility for MRSP funding.
		Develop and implement a Fundraising (Westmead & Randwick) strategy to support both infrastructure and direct research cost needs.	H	Jul 2014	Increase Fundraising Revenue by 30% year on year.
		Develop a funding mechanism to help cover the 'real' costs of a Tier 1 competitive research grant.	M	Jul 2014	Complete a full analysis of financial support required (funding gap) to cover the full costs of research;  Develop / seek options for support.
		Support the allocation of secure protected research time for clinician researchers based on performance and strategic opportunity.	M	Jul 2014	Nominate 5-6 senior clinicians to lead/ scope the project;  Options for support submitted to SCHN Research Executive.
		Educate and advocate Intellectual Property and Commercialisation at SCHN.	M	Feb 2014	>2 Education Information Forums with SCHN staff;  Research intranet/s up to date.
		Review processes for management of Intellectual Property and Commercialisation.	M	Dec 2013	Transparent criteria for filing and managing IP and Commercialisation;  IP register that will manage all associated costs;  Funding model submitted to the SCHN Public Contribution Fund Committee for consideration.

## Research Action Plan 2013-2017

**Cont. Financial and Business Sustainability: Financial and Business Sustainability: SCHN Research will ensure financial sustainability and support growth to meet increasing demands and advances in technology.**

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
3.2	Enhance our knowledge of capital requirements for asset replacement and planned growth.	Develop a master plan for capital and infrastructure research needs.	H	Dec 2013	Asset replacement strategy budgeted for annually.
		Identify the opportunities for expansion of the Randwick research footprint.	H	Jul 2014	Capital plan presented to CE and SCHN Capital Planning Committee.
		Develop business plan for clinical research facility at Westmead.	H	Dec 2013	Capital plan presented to SCHN Capital Planning Committee.
		Ensure financial sustainability of the KRI Small Animal Facility.	H	Jun 2014	Business Plan presented to the SCHN Executive for consideration.
3.3	Improve support for Research Grant Activity and Management.	Promote and ensure all relevant funding opportunities are available to researchers.	M	Dec 2013	Increased number of competitively funded grant applications by 20% by 2015.
		Document the current level of competitively funded research activities via an approved Grant Management Process and recorded on a grant register.	H	Sept 2013	>95% of registered grants are reconciled with general ledger.
		Working with partners, assist and provide advice for development of peer review grants.	M	Dec 2014	Refer to 2.4 - Tier 1 Grant success rate > national average.
		Provide assistance and education to researchers to manage cost centre budgets.	M	Dec 2013	Researchers to participate in budget planning for financial years.

## Research Action Plan 2013-2017

**Cont. Financial and Business Sustainability: Financial and Business Sustainability: SCHN Research will ensure financial sustainability and support growth to meet increasing demands and advances in technology.**

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
3.4	Develop and implement a robust impact measurement framework that measures success of translational research at SCHN.	Develop a performance assessment that tracks the progress of research activity e.g. IP/Commercialisation, Publications, Grants, Income, students, National and International Collaborations.	M	Nov 2013	Report performance on an annual basis to SCHN Executive, research community and stakeholders as required.
		Identify Sponsored and Investigator led Clinical Trials activity and Participants.	M	Oct 2013	Number of trials and participants/trial.
3.5	Research space is allocated equitably based on appointment and productivity/performance	Develop criteria for allocation of office/desk and laboratory areas	M	Jun 2014	Develop a policy for research space allocation to ensure transparency.

## Research Action Plan 2013-2017

### Infrastructure and Technology: SCHN Research will invest in infrastructure that supports and enables excellence in research

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
4.1	Provide virtual and tangible world class resources and facilities that enable efficient research, information sharing and collaboration.	Working with partners, increase the speed and access to internet for research context sites.	H	Jul 2014	Internet access speed increased >500%.
		Enhance Tele-link / Video communications between sites.	H	Oct 2013	Lync availability in >2 research rooms at each site.
		Working with partners, increase easily accessible offsite research data storage capacity.	H	Nov 2013	Offsite storage increased by >100%.
		Enhance Internal and external communications.	M	Sept 2014	2 <sup>nd</sup> monthly communiqué;  Appoint Communications Officer.
4.2	Foster a culture of interdisciplinary research at SCHN.	Share and raise awareness of research activity at SCHN by convening research seminars where researchers/research groups will be called upon to present.	M	Jan 2014	Conduct 1 seminar per year;  Research presentations at Hospital Grand Rounds.
		Evaluate online and social media, and its impact on how scientific information is sourced and distributed in the context of profiling our research.	L	Jun 2014	Identify and use safe mechanisms for profiling research via social media.
4.3	Facilitate translational research through a common bio-banking strategy, embedded within patient management streams, centred within pathology and routine across the SCHN.	Aggregate and strengthen bioinformatics expertise.	M	May 2014	Identify senior positions in bio-informatics in SCHN and/or partners.
		Develop working group to discuss strategic opportunities. See Appendix C.	M	Jun 2014	Scope internal and external resources and services;  >1 new position to support biobanking and/or bioinformatics.

## Research Action Plan 2013-2017

**Cont. Infrastructure and Technology:** SCHN Research will invest in infrastructure that supports and enables excellence in research

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
4.4	Provide optimal operating systems and practices which enhance the capability to deliver high quality research.	Enhance operational support at SCHN Research including bio-statistics, Pathology, Clinical Trials, Genomics.	M	Jun 2014	Complete a full needs analysis of resources required at SCHN.

## Research Action Plan 2013-2017

Partnerships and Networks: SCHN Research will work to enhance the health of children and young people across a diversity of settings and systems.

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
5.1	Provide research infrastructure support by efficiencies through economies of scale and potentially improved funding opportunities.	Implement formal relationships with Hub Research Partners and other affiliated research entities for the purpose of collaboration.	M	Nov 2014	Hub partnership agreements at Westmead and Randwick;  Collaborative agreement between SCHN, CMRI and CCIA.
		Scope costing model(s) for participation in WRH core facilities.	M	Dec 2014	1 core facility agreement.
5.2	Improve mechanisms across SCHN to enable efficient collaboration for translational research.	Implement support framework (including human resource) across the Network which supports translational research along its life cycle.	H	Oct 2013	Integrated coordinated SCHN Clinical Research Centre with sites at Randwick and Westmead.
		Develop SCHN Research Advisory Committee to oversee translational research at SCHN.	H	Dec 2013	Formal Research Advisory Committee formed with SCHN Research Executive membership as well as stakeholders and independent representation.
		Develop and Implement a comprehensive Clinical Research education program across the Network with streams for Investigators and Study Coordinators/Nurses.	M	Jan 2014	Increased Clinical Research Activity at both SCH and CHW;  Low level Clinical Research Audit Findings on inspection.
		Implement various communication tools to advocate and inform both internally and externally the success of translational research conducted within SCHN.	M	May 2014	Increased Collaboration opportunities measured by research activity reports.

## Research Action Plan 2013-2017

Cont. Partnerships and Networks: SCHN Research will work to enhance the health of children and young people across a diversity of settings and systems.

Strategic Goals		Actions	Urgency	Timeframe	Our success will be demonstrated by (KPIs):
No:	Summary				
5.3	Work with Government, academic and health service partners to build research networks that enhance health care through the translation of research into patient care.	Implement Paediatric Trials Network Australia (PTNA)	H	Dec 2013	Funded agreements with at least 5 partners.
		Strengthen relationships with NSW Kids and Families and ACI	M	Jul 2014	Funded partnerships.
		Map and review SCHN Research participation at key state and national committees to ensure that SCHN translational perspectives are represented	L	Dec 2014	Mapped representation of SCHN staff on key state, national and international committees, advisory boards.
5.4	Grow strategic research partnerships with leading national and international peers in fields where we seek to build profile.	Strengthen existing and review opportunities for strategic national and international collaborations in high priority areas.	M	Dec 2014	>1 MoU in place with international research organisation(s).
		Working with partners, scope the options for integrated Health Research Centres.	L	Sept 2014	Agreed model(s).
		Support the identification of joint clinical-academic appointments with closely affiliated Universities to promote clinical translational research programs.	M	Dec 2014	Creation of new joint clinical academic appointments.
5.5	Develop and implement a systematic program of engagement with leaders in government, industry and the community.	Through a planned communication strategy, develop an engagement model with appropriate Industry, Government and community stakeholders to enable collaboration which enhances SCHN Research Communities ability to deliver its strategic goals	M	July 2014	Approved and active Communication Strategy for SCHN Research.

# Characteristics of leading research centres

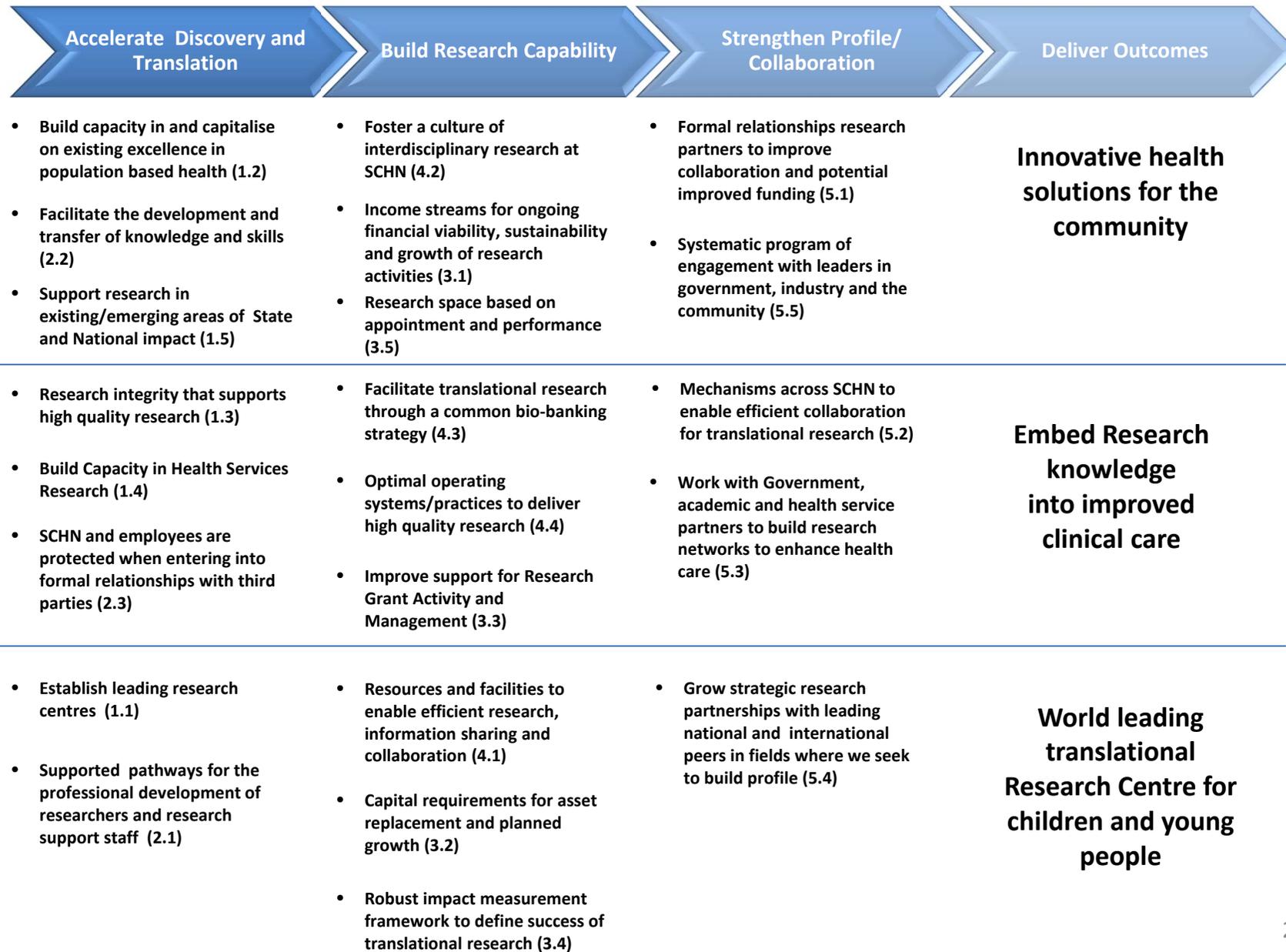
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- **Excellence:** Research that has a strong track record of sustained CIA Tier 1 funding in last 2-4 years
- **Capacity:** >20 researchers focused on a research area\*
- **National Profile/Impact:** Recognised as national leaders in research area
- **Multidisciplinary:** Across different disciplines
- **SCHN Research Activity:** Collaborative activity across CHW and SCH

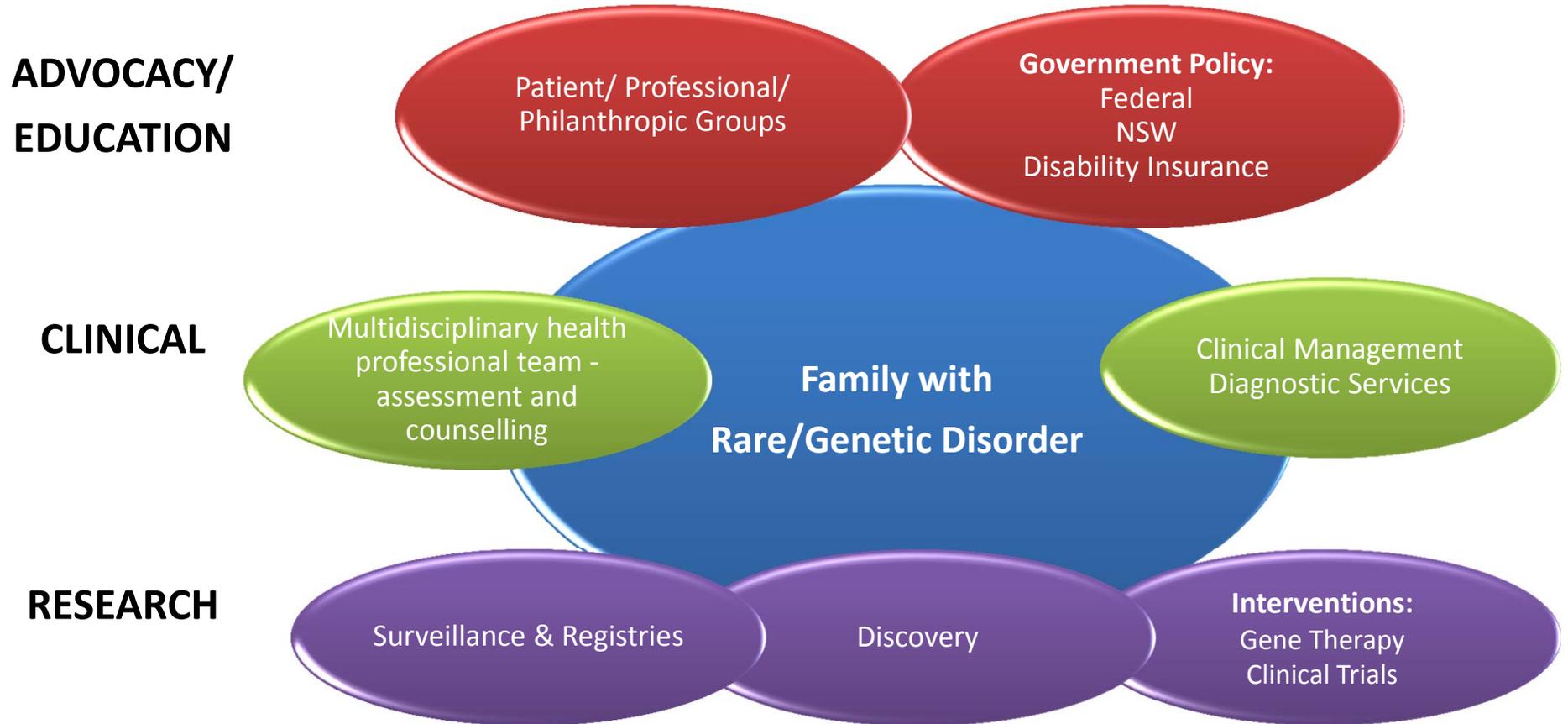
\* *Statistics of Statisticians: critical mass for research group Ralph Kenna, Bertrand Bercke. Significance: 2012 December: 22:25*

# SCHN Research Strategy Initiatives

## *“Better health for children and young people by research”*



# SCHN Research Strategy –Rare Diseases



# SCHN Rare Diseases Research

SCHN research activity

- **Australian Paediatric Surveillance Unit**
  - ARC Linkage Grant
  - DOHA chronic care funding
- **Orphan Lung Diseases**
- **Neuromuscular**
  - Southern Hemisphere Lead
- **Many other disease based registries**
- **Tissue Banks**

- **Clinical Genetics**
- **Diagnostic Laboratories**
- **Neuromuscular**
- **Metabolic**
- **Eye Disorders**
- **Genomics Network**
- **Orthopaedics and Bioengineering**
- **Infectious Disease**
- **Cardiac**
- **Renal**
- **Immunology**
- **Neurology**

- **Gene Therapy**
  - Cell-based therapies
  - Cancer
  - Single Gene Disorders
  - Blinding disorders
- **Clinical Trials – novel therapies**
  - DMD
  - Metachromatic Leukodystrophy
  - NF1
  - Tuberous Sclerosis
- **Personalised Medicine**

Surveillance, Registries and Biobanks

Discovery and Diagnostics

Interventions

Partners

OrphanNet - international rare disease registry

CMRI  
CCIA  
SESLHD  
Garvan Institute  
National and International academic centres

GOSH  
Pharma  
National and International centres

# Metrics to measure impact of strategic plan

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- Funding *Grants, Donations*
- Talent *number of students, postdocs, fellowships*
- Creation *Clinical Trials, Intellectual Property*
- Validation *Publications, Intellectual Property*
- Dissemination *Publications, Education, Guidelines*
- Uptake *Commercialisation, change in practice*
- Collaboration *SCHN/State/National/International partnerships*

# Next steps

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- Broad dissemination and feedback from the research community and the SCHN Executive received. The Chief Executive and SCHN Board endorsed the strategy in June 2013.
- Development of operational and business plans with researchers and key stakeholders in May and June 2013;
- Implementation commencing July 2013.
- Annual review of progress vs. deliverables

# Matrix structure – new programs

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## Strategic Priorities:

- Multidisciplinary
- Evolving strengths; capacity, grant funding
- Opportunity based on SCHN, state and national priorities

## *Examples might include:*

- Centre for Children's Bone Health
- Health Services Research
- Allergy and autoimmunity
- Psychological Medical and Adolescent Health

## Appendix A

### SCHN Rare Diseases Research - draft

*Objective; Develop centre for excellence in research in diagnoses, therapies and healthcare for children and families with Rare Diseases.*

Goals	Action Plan	Measurable Outcome	Impact
<b>Develop excellence in research in diagnoses and therapies for rare disorders through specialised resources and facilities</b>	<ul style="list-style-type: none"> <li>• Develop a gene discovery and diagnosis pipeline across multiple research groups.</li> <li>• Establish a National Centre for Research Excellence in Cell and Gene Therapy (based on the established Westmead Research Hub, Sydney Cell and Gene Therapy collaboration)</li> <li>• Fortify, consolidate and integrate research activity in the areas of enzyme replacement therapy and genetic pharmacotherapies</li> </ul>	<ul style="list-style-type: none"> <li>• A State / National funded Centre Expertise in transcriptomics for Rare Disorders within SCHN and its partners</li> <li>• Progressive growth in competitive grant income</li> <li>• Increasing clinical trial activity investigating novel genetic therapies</li> <li>• Senior positions in bioinformatics.</li> <li>• Collaboration with various animal facilities</li> <li>• Establishment of a stable recurrent funding strategy for core staff               <ul style="list-style-type: none"> <li>○ Quality System staff</li> <li>○ Core administration staff</li> <li>○ Production staff</li> <li>○ Access to Research Pharmacist</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Sustainable profile of Rare Diseases for SCHN Research</li> <li>• More attractive site for industry trials.</li> <li>• Improved diagnosis and management of children and facilities with rare disorders.</li> <li>• Global recognition as a leading entity in the development of genetic therapies</li> <li>• Attractive to high calibre staff</li> </ul>
<b>Improving connectivity to facilitate research outcomes for families with rare disorders</b>	<ul style="list-style-type: none"> <li>• Promote rare disorders registries via national/international collaborations</li> <li>• Improve coordination of existing genomics research units within SCHN (and with key local institutions)</li> </ul>	<ul style="list-style-type: none"> <li>• National variant database accessible at a National level</li> <li>• Appointment of Rare Disease Fellow</li> </ul>	<ul style="list-style-type: none"> <li>• Reduce work that interprets and filters data – in turn reduces time, saves money and fastens research project output.</li> </ul>
<b>Develop capacity and expertise in personalised medicine</b>	<ul style="list-style-type: none"> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>•</li> </ul>

## Appendix B

### Centre for Children's Bone Health - draft

Over-arching Objective	Action Plan	Measurable Outcome	Impact
<b>Improve the bone health and quality of life for children through basic, translational and clinical bone research.</b>	<ul style="list-style-type: none"> <li>Unify the ORB and PMR to strengthen collaboration and unify objectives</li> <li>Develop national research centre for paediatric bone research</li> <li>Develop basic, translational and clinical research to address clinically relevant questions</li> <li>Work with KRI to raise funds for Chair of Paediatric Bone Health</li> <li>Appoint Senior Clinical Researcher</li> </ul>	<ul style="list-style-type: none"> <li>Number of research projects</li> <li>Number of competitive grants</li> <li>Number of publications</li> <li>Number of internal/ external collaborations</li> <li>Appointment of Chair of Paediatric Bone Health</li> <li>Appointment of Senior Clinical Researcher</li> <li>Funds raised</li> </ul>	<ul style="list-style-type: none"> <li>Research that influences clinical practice</li> <li>Holistic approach to management of bone health that encompasses orthopaedic, medical and allied health</li> <li>Raise profile of paediatric bone health</li> </ul>
<b>Education and Training</b>	<ul style="list-style-type: none"> <li>PhD</li> <li>Senior Medical Staff</li> <li>Junior Medical Staff</li> </ul>	<ul style="list-style-type: none"> <li>PhD completions</li> <li>Other</li> </ul>	<ul style="list-style-type: none"> <li>Increase trained researchers in bone field in clinical and basic research</li> </ul>

## Appendix C

### SCHN Bio-banking - draft

Over-arching Objective	Action Plan	Measurable Outcome	Impact
<p><b>Facilitate translational research through a common bio-banking strategy, embedded within patient management streams, centred within pathology and routine across the SCHN.</b></p>	<ul style="list-style-type: none"> <li>Tissue collection strategy with pathology departments as the central collection point</li> <li>Simple, common and general consent, addressed during admission. Consent for 'storage of residual tissue for future unspecified research'.</li> <li>Storage facilities, sample quality assessment protocol along with value added tissue handling expertise to be performed in a single specialised facility linked to the pathology department which meets worlds best practice standards.</li> <li>Details of tissue specimen collection, storage and use to be considered as part of the patient record, facilitating data linkage at the source.</li> <li>Appointment of a SCHN Bio-banker to oversee, manage and develop bio-banking across the SCHN.</li> <li>Develop an SCHN access policy and procedure for scientists requesting tissue for research investigations.</li> <li>Establish an independent "Tissue Access Committee" as part of the SCHN Governance structure to review and approve research access requests. Reports and makes recommendations to the SCHN Ethics Committee.</li> <li>Public awareness and education campaign.</li> <li>Staff training and education program.</li> </ul>	<ul style="list-style-type: none"> <li>Numbers of collaborative research projects being undertaken between SCHN, its researchers and external scientists and clinicians.</li> <li>Improved and standardized tissue handling processes for research leading to efficiencies within pathology and related departments.</li> <li>Incorporation of tissue collection methods and standards within departmental SOPs.</li> <li>Numbers of patients consenting for sample storage.</li> <li>Numbers and types of samples being made available for translational research.</li> <li>Research institutions connected with SCHN and their geographical distribution.</li> <li>Research outcomes as determined by publications, patents and grant successes.</li> <li>Reduced time and staff hours taken between application initiation and receipt of data-linked samples by researchers, indicating a minimization of paperwork.</li> <li>Financial savings based on cost per samples provided to research studies.</li> <li>Increased consumer awareness of translational research activity across the SCHN.</li> <li>Less reliance on specialist bio-bank staff to enable 'on the ground' bio-banking across the SCHN network.</li> </ul>	<ul style="list-style-type: none"> <li>A translational research environment that creates the foundation for the introduction and development of improved health care strategies.</li> <li>Opportunities for health care practice to be advanced through evidenced based research and clinical trials.</li> <li>Biobanking activity that is straight forward operationally being performed across the network.</li> <li>Worlds best practice bio-banking that is embedded into hospital standard operating procedures.</li> <li>Research to be integrated as an extension of healthcare, ensuring government investment in research benefits all Australians through better health outcomes and economic gain.</li> <li>More scientists doing research within and with SCHN clinicians and investigators leading to an increase national and international recognition of the SCHN as a leading childhood health centre.</li> <li>Sustainability of bio-banking and translational research activity across the SCHN underpinned by viable economic models and appropriate investments.</li> <li>Public awareness and acceptance of research involving human tissue.</li> </ul>

# Research Strategic Framework



The Sydney Children's Hospitals Network Research Strategic Plan for 2013 – 2017 provides the strategic direction for Research over a four year period from 1 July 2013 to 30 June 2017.

The Strategic Plan drives the activities and priorities of the organisation at all levels. The goals and objectives translate directly into strategic priorities as agreed by the Chief Executive and the SCHN Board.

The SCHN Research Strategy demonstrates how research will contribute to SCHN achieving its vision, purpose and strategic goals over the four year period.

Against each of the strategic goals, action plans are developed which have measurable targets and timelines.

The Director of Research is accountable to the Chief Executive for demonstrating progress and achieving our research strategic objectives and goals.

The Strategy will be reviewed on a continuous basis and progress will be reported to the Chief Executive regularly.

Each year the Director of Research will develop an annual plan to evaluate our progress against an agreed set of progress measures. This evaluation will help us review our existing strategy and inform the development of an annual plan. It will also support us to revise our objectives and actions on an ongoing basis and to develop new approaches.

# SCHN Strategic Plan 2012-2016

Our Vision		Our Mission	
Children first		To improve the health and wellbeing of children through clinical care, research, education and advocacy	
Our Outcomes			
Clinical Care	Research	Education	Advocacy
	<ul style="list-style-type: none"> <li>✓ Network research governance model in place</li> <li>✓ Formal relationships with hub research partners and other affiliated research entities</li> <li>✓ Identified recurrent funding mechanism to support research activities</li> <li>✓ Established Clinical and Rare Disorders Research Translation Centres and Population Health Research Collaborative</li> <li>✓ Established Research Program attracting, supporting and training young clinicians and researchers</li> </ul>		

Key Strategic Areas & Actions				
Quality & Excellence	People & Leadership	Financial & Business Sustainability	Infrastructure & Technology	Partnerships & Networks
<ul style="list-style-type: none"> <li>• Ensuring patient safety</li> <li>• Delivering quality services</li> <li>• Improving access</li> <li>• Encouraging research excellence</li> <li>• Fostering education and learning</li> </ul>	<ul style="list-style-type: none"> <li>• Creating a safe environment</li> <li>• Promoting clinical leadership capabilities</li> <li>• Building high performing teams</li> <li>• Developing a sustainable workforce</li> <li>• Building an engaged and resilient workforce</li> </ul>	<ul style="list-style-type: none"> <li>• Achieving operational efficiency</li> <li>• Optimising revenue</li> <li>• Seeking commercialisation opportunities</li> <li>• Fundraising strategically</li> <li>• Investing prudently</li> <li>• Managing corporate governance and risk</li> </ul>	<ul style="list-style-type: none"> <li>• Optimising existing physical infrastructure</li> <li>• Developing new infrastructure</li> <li>• Investing strategically in technology</li> <li>• Positioning the Network as a leader in e-Health</li> </ul>	<ul style="list-style-type: none"> <li>• Strengthening patient, family and community engagement</li> <li>• Strengthening health professional networks</li> <li>• Building strategic partnerships and collaborations</li> <li>• Seeking global alliances</li> </ul>

# SCHN Research Strategy

