



Queensland Clinical Senate

Clinician leadership. Consumer collaboration. Better care.

Adolescent to young adult care: doing better meeting report

4 December 2020

Meeting report: 'Adolescent to young adult care: doing better'

Published by the State of Queensland (Queensland Health), March 2021.



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Chair's report

As clinicians, the work that we do can have a profound impact on our patients' lives. The reality of this can weigh heavily but it must drive us to do better, particularly for our adolescents and young people navigating the space between the paediatric and adult health care system. Too often, our young patients fall through the gaps, having a detrimental impact on their health.



We must do better for young people like Ellie who found the experience of transitioning into the adult health care system distressing.

And we must do better for Kellara, who is scared of moving to a new doctor for fear they won't understand her condition.

And we must do better for Ella, 12, and her mum Keren who fears her daughter's transition in the years ahead will be harmful if it isn't planned and coordinated well.

The powerful and very personal stories shared by consumers at our December 2020 meeting brought home the importance of 'adolescent to young adult care' and why getting it right is so critical.

But how do we get it right and do better for these amazing young people?

Our young consumers and clinicians who work in this space, tell us that we must listen to our young people and their families and learn from their experiences. We must reach out to our consumers and offer help (not wait for them to come to us) and involve consumers in every step of the process. It has to be a coordinated and planned team approach – no one should have to do this alone.

A number of great initiatives in Queensland are paving the way for better care for our young people. A program in Townsville is supporting young people with diabetes to prepare for the journey into the adult health care system. And our colleagues at the Gold Coast Hospital and Health Service are taking a multi-disciplinary, multi-pronged approach to help our young people move from the familiar surrounds of the paediatric ward to the unfamiliar adult system. The Mater Health Service in Brisbane and GCHHS are the only sites in Queensland accredited by the Royal Australasian College of Physicians for adolescent and young adult medicine specialty training. Queensland is fortunate to have local experts and champions who are passionately progressing these issues.

President of the International Association for Adolescent Health, Professor Susan Sawyer, stressed the importance of investing in the health and wellbeing of our young people for their future and for future generations.

'This generation of adolescents can transform all our futures; there is no greater priority in global health than ensuring they have the resources to do so.' Patton GC, Santelli JS, Sawyer SM et al, 2016.

Adolescent and young adult care is such an important thing for us to get right for the lives of young people and their families. We can't let them down.

Dr Alex Markwell
Chair, Queensland Clinical Senate



Recommendations

The healthcare needs of adolescents and young adults are different to those of adults. The delivery of the right care and support is critical to improving the health outcomes and experience of young people and their families and carers.

The Queensland Clinical Senate makes the following recommendations to improve the provision of healthcare to adolescents and young adults. Adolescents and young adults (AYA) should be included in the planning, design, implementation and evaluation of all the recommendations.

System:

1. Co-design (with consumers and carers) a **statewide system level strategy** addressing AYA Care that:
 - i. clearly **defines** the group and commits to recognising their specific needs;
 - ii. clearly defines the **specific responsibilities** within paediatric, adult and general practice services;
 - iii. is used to support the delivery of a consistent and overt **statewide approach**
 - iv. guides and directs service **standards**;
 - v. embeds **equity** for all patients as a consideration in all policy decisions, including those:
 1. from rural and remote areas,
 2. who are First Nations people,
 3. who identify as LGBTIQ+,
 4. from culturally and linguistically diverse backgrounds,
 5. who are people with disability, and
 6. who are in other vulnerable groups
 - vi. acknowledges the need to leverage **across sectors**:
 1. between primary and acute care
 2. between public and private providers
 3. between health and education, employment, justice and social services
 - vii. acknowledges that **holistic care** requires attention to social, psychological and physical health, and integrates wellbeing promotion, disease treatment and mental health services

2. Develop an AYA **Clinical Services Capability Framework** module to support the development of standardised practice, capability, and service provision reflected in service agreements and KPIs.
3. Advocate for the establishment of specific AYA medicine units with dedicated **training positions** in adolescent medicine to accelerate the development of clinical expertise across the state.
4. Explore options and advocate at a national level for specific **Medicare codes** for AYA healthcare service provision which also extends to nursing and allied health services.

Hospital and Health Service (HHS) / Organisation:

5. Formalise processes to **support transition** of care including early collaborative planning and effective communication with all stakeholders. Each clinical service should design and implement its own transition planning, in consultation with other relevant services (including the National Disability Insurance Scheme) and consumers and carers.
6. Formalise **education and training** support for staff working in AYA care, in consultation with consumers and carers. New positions should be filled by staff who are suitably trained in AYA healthcare.
7. Identify and support clinical and consumer **champions** (who receive appropriate training to perform the role) in AYA care to enable a strong AYA focus within their organisation as well as within each clinical service.
8. Optimise use of **digital health technology** to support AYA participation and incorporate flexible service provision across the state.
9. Develop specific dedicated adolescent units that provide adolescent-appropriate healthcare environments with staff trained in AYA. If this is not possible, encourage **cohorting** relevant patient groups and co-locating clinical services to realise health outcome and financial benefits.

Consumers:

10. Each HHS should form a broadly representative **youth advisory panel** that involves young people in the planning, design, implementation and evaluation of AYA services.

Introduction

The Queensland Clinical Senate in collaboration with the Queensland Child and Youth Clinical Network, hosted more than 115 clinicians, consumers and health executives from across the state on Friday, 4 December 2020 in a virtual meeting to discuss 'Adolescent to young adult care: doing better'.

The meeting explored the unique needs of these young people and looked at the opportunities to improve healthcare services, planning and integration for adolescents and young adults.

We know that if this experience for young people is poorly managed, the risk trajectory increases. Their health and wellbeing outcomes can be affected, potentially impacting all areas of their life now and into the future.

'Adolescence is a profound period of human growth and development in which the assets and capabilities that underpin future adult health and wellbeing, social relationships, parenting and employment are established.'

Lancet Commission on adolescent health and wellbeing.

Facts about the Queensland context

- Adolescents and young adults accounts for 13 percent of the Queensland population
- Seven per cent of 15 to 24-year olds identify as Indigenous
- The adolescent and young adult population is not so visible in our health system for a number of reasons:
 - this cohort is more likely to present to emergency or outpatients than be admitted
 - data doesn't necessarily identify them as adolescents. A 15-year-old is potentially counted as an adult occasion of service
 - top hospital separations reflect once in a lifetime conditions like injuries and fractures (except for mental health)— the adolescents and young people with high needs are not really reflected.

See Appendix 1 for the meeting agenda.

Speakers and panellists

Meeting facilitator

Ms Jordana Rigby, Project Officer, Queensland Child and Youth Clinical Network and Social Worker, Child Development Services, Children's Health Queensland.

Keynote speaker

Prof Susan Sawyer AM, President, International Association for Adolescent Health; Professor of Adolescent Health, The University of Melbourne; Director, Centre for Adolescent Health, Royal Children's Hospital, Melbourne

Clinicians

- Dr Lisa Beecham, General Practitioner, Robina, and Director Gold Coast Primary Health Network
- Dr Cameron Bennett, Physician, Medical Director Metro North Hospital and Health Service (MNHHS) Virtual Ward, Assistant Director Internal Medicine and Aged Care Department, Royal Brisbane and Women's Hospital (RBWH), Acute Admitting Ward Consultant, RBWH, Complex Needs Clinic Consultant, Community and Oral Services, MNHHS.
- Dr Simon Denny, Director of Mater Young Adult Health Centre, Mater Health
- Ms Samantha Horgan, Nurse Navigator Transition —General Paediatrics, Queensland Children's Hospital, Children's Health Queensland
- Dr Penny Larcombe, Paediatrician, Gold Coast University Hospital
- Ms Sheree Menon, Senior Paediatric Psychologist, Townsville University Hospital: Project Lead Statewide Diabetes Clinical Network, T1DM Transition Pilot Project
- Ms Susan Moloney, Director of Paediatrics, Gold Coast University Hospital
- Dr Judy Williams, Clinical Director Paediatrics, Medical Services, Bundaberg Hospital
- Dr Jason Yates, Medical Director, Health and Wellbeing, Townsville University Hospital and Chair of the Type 1 Working Group, Statewide Diabetes Clinical Network

Health Consumers

We sincerely thank our young health consumers and carers for being part of our meeting and sharing their experiences and perspectives.

- Ellie (Caboolture)
- Kellara (Central West)
- Lachlan (sibling carer, Brisbane)
- Ms Keren Pointon (carer of daughter, Brisbane)

Presentations and key messages

Session 1— Adolescence: What is it? Why is it important? What's the problem?

Adolescence: The ideas we have of our possibilities

Prof Susan Sawyer AM, President, International Association for Adolescent Health; Professor of Adolescent Health, The University of Melbourne; Director, Centre for Adolescent Health, Royal Children's Hospital, Melbourne

'We need to recognise that our consumers are really the experts here. In terms of their own lived experience, families are too often having to work through a very complex patch work of services themselves to make something work for them and their children, when they rightly have the expectation that we in health services should be working with them to develop a care pathway that works. It's just not good enough.'



- During adolescence, the ideas about ourselves and our future capabilities get bedded down.
- The people around us, particularly our families but also health professionals, are critical in helping shape the ideas we might have of our possibilities, especially for young people with complex health conditions including disabilities.
- Adolescent development reflects biological changes that are shaped by nutrition, physical, social and cultural environments. Getting these investments right will help promote the health of adolescents and young adults.
- Investments in adolescent health brings a triple dividend of health benefits: for adolescents now, for their future lives, and for the next generation (intergenerational benefits).
- At its core, working with young people is about engaging with them as active participants in driving their best possible futures.
- Strategies in adolescent health:
 - Engaging and focusing on the young person themselves - normalise confidentiality, involve them in decision-making, build health literacy, support appropriate parent involvement, build parent understanding of adolescent and young adult development and what quality healthcare is about. Routinely assess emergent health issues and have a strong understanding of referral networks and pathways.
- Young people with chronic health issues are not immune from the issues affecting young people in the community—indeed they may be at higher risk.
- Key elements of a successful transition are good coordination, good communication, early planning, engagement of family, identifying adult services, and preparedness to tailor care paths to individual circumstances.
- Focused investments include statewide leadership in adolescent and young adult medicine, collaborations across sectors, health service transition coordinators, and consumer engagement.

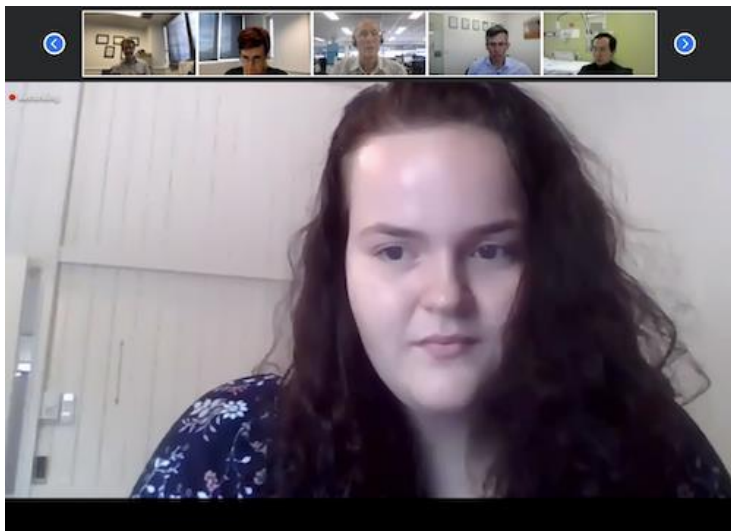
Ms Keren Pointon, carer for her daughter Ella, 12

'Transition is a time of high risk; it is a time of change and people don't know Ella or our family and there is great potential for harm. Like all good health care, transition planning needs to be with Ella and our family, not to us. It won't be one size fits all – what works for us might not work for other families and vice versa.'



Kellara, Health Consumer, Central West Queensland

'I can't tell you how many young people specifically around the 16 – 17 years age range I know that should really be accessing more health care services. But they either don't know what's available or don't know how they would be able to access it because of barriers. I'm lucky to have a mother who has always been my biggest supporter and can find answers when I can't. But when you're that young and you need to learn to be self-reliant without the health literacy, it's impossible.'



Ellie, Health Consumer



'Australia has one of the best public healthcare systems in the world. Resources and services that are available to support patients and their families are often exemplary, however the promotion of their existence falls short of the mark. Our healthcare system needs to start treating patients as people to be met not simply just a problem or an issue to be diagnosed and treated. Patients need to be aware of all the support services that are available to them. It should be the right of every healthcare consumer to make informed decisions regarding their care. Consumers and their families need to feel empowered. Patient care should always be seen as an equal partnership where the patient and their family are firmly in control.'

Session 2— Transition: What is it? Why is it important? What's the problem?

Panel discussion: perspectives on transition – what is transition and what is best practice?

Chair: Dr Simon Denny, Director of Mater Young Adult Health Centre, Mater Health

Consumer perspective: Lachlan (consumer/sibling carer, Brisbane)

Adult Physician: Dr Cameron Bennett, Physician, Medical Director Metro North HHS Virtual Ward, Assistant Director Internal Medicine and Aged Care Department, Royal Brisbane and Women's Hospital (RBWH), Acute Admitting Ward Consultant, RBWH, Complex Needs Clinic Consultant, Community and Oral Services, MNHHS

Paediatrician: Dr Judy Williams, Clinical Director Paediatrics, Medical Services, Bundaberg Hospital

Nurse Navigator – Ms Samantha Horgan, Nurse Navigator Transition – General Paediatrics, Queensland Children's Hospital, Children's Health Queensland

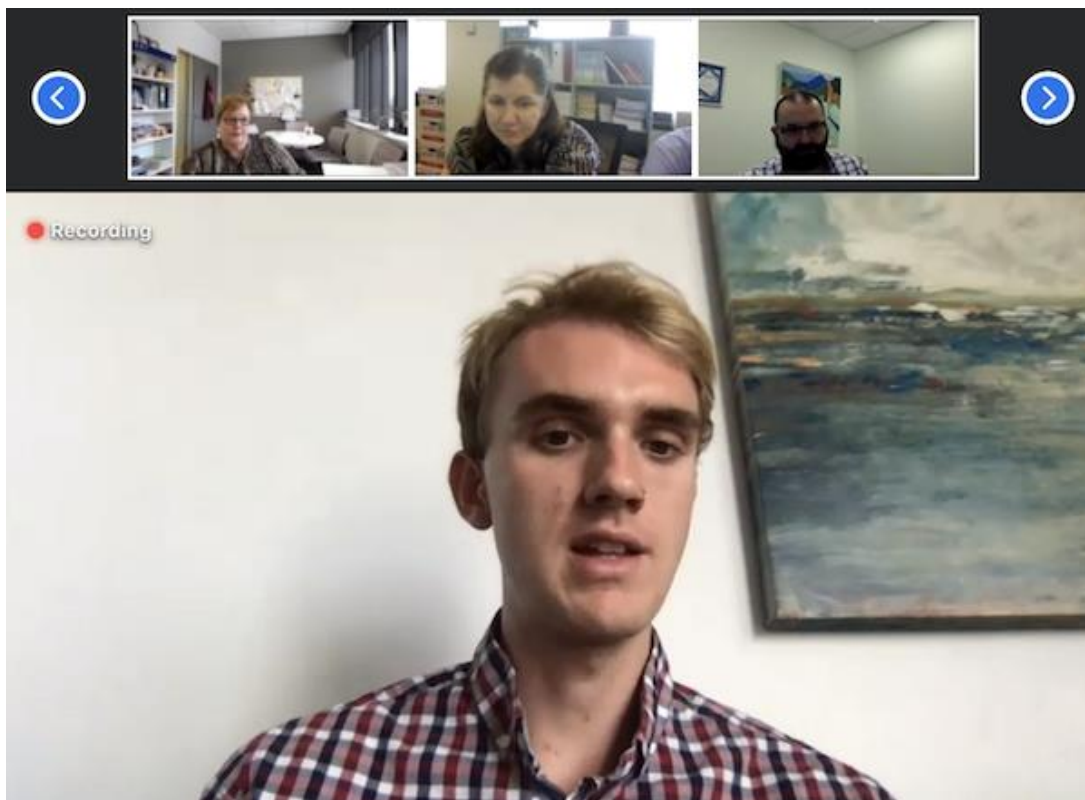
General Practitioner – Dr Lisa Beecham, General Practitioner, Robina and Director, Gold Coast Primary Health Network

Key messages

- There are different contexts for transitions. Four of the main contexts include:
 - young people with chronic conditions such as diabetes for which pathways are quite well established
 - young people with complex care
 - young people with intellectual disability and complex medical conditions
 - young people navigating mental health services.
- As a generalist paediatrician in a regional setting, it is very challenging to transition young people in a coordinated manner that meets their individual plans and also their medical needs, regardless of the complexity.
- A 16-year-old treated as an adult patient can be sharing a four-bed bay and facilities with elderly patients -we have to consider whether a young person having that experience would come back to that health system.
- Young people do get lost in the adult system – they really are invisible.
- Hospitals, in particular larger health services, can cohort young patients at relatively low cost.
- Nurse Navigators play an important role in supporting adolescents to transition to adult care and beyond.
- Children's Health Queensland, through its Nurse Navigators, has developed a [suite of resources to support adolescents to transition](https://qheps.health.qld.gov.au/childrenshealth/html/transition-of-paediatric-to-adult-services/_nocache). The resources help to inform clinicians about the patient's history and situation and create relevant networks and collaborations. Resources available only to QH staff:
https://qheps.health.qld.gov.au/childrenshealth/html/transition-of-paediatric-to-adult-services/_nocache

- The Nurse Navigator role in conjunction with the patient's General Practitioner (GP) is a great partnership for transitioning adolescents.
- Advocate for adolescents to find a GP who can support them holistically throughout all stages of their life and be involved in the transition.
- Advocate for Medicare item number for adolescent health assessment – a prompt for GPs to consider all aspects of a young person's life and link them to important statewide health services.
- If we are going to make a difference to a young person's life, the patient / practitioner relationship is critical. Speak to young people about confidentiality from a young age so they know they can trust the GP/doctor.

Lachlan, sibling carer



'When somebody is facing a lifelong condition and they are transitioning, it's quite difficult for parents to pass on that burden of health care and it's important in pre-transition and transition phase to empower a young patient, as an emerging young adult, to take on that medical responsibility. And I think a nurse navigator is a brilliant initiative and one that can start to foster a chain of trust and consistency throughout that process and that's a powerful tool that has certainly helped my family, having a transition team with a specific focus on transition.'

Session 3— Action planning

Statewide Diabetes Transition Model of Care

Dr Jason Yates, Medical Director, Health and Wellbeing, Townsville University Hospital and Chair of the Type 1 Working Group, Statewide Diabetes Clinical Network

Ms Sheree Menon, Senior paediatric Psychologist, Townsville University Hospital; Project Lead Statewide Diabetes Clinical Network, T1DM transition pilot project

- Four-phase, multidisciplinary [model for transition care](#)
 - Planning (age 12-14 years or when developmentally appropriate), which includes an introduction to the concept of transition.
 - Preparation (age 14-16 or when developmentally appropriate), focused on the young person developing skills and knowledge to manage diabetes independently – building confidence and empowering.
 - Transfer (age 16+) a specific phase where the young person moves into the adult service. The bulk of the work has been done before this phase to ensure the young person is ready to transfer.
 - Evaluation phase is where the paediatric services relinquish care and it is taken over by the adult service.
- A feedback process ensures the young person's ongoing psycho-social and treatment needs are being met in the adult system.
- The evidence-based service is a family-centred, highly individualised plan that comes from a systematic and formal transition process that is about empowerment and self-management.
- During each of the phases of transition, specific screening tools are utilised to cover topics such as diabetes distress and disordered eating to allow for early intervention
- As part of the model, a virtual outpatient integration for chronic disease (VOICeD) program will be trialled to enable young people to be in touch with clinicians for virtual appointments and meetings.



We're not kids, we're not adults, we're lost in the system: a proposed Gold Coast Adolescent model

Dr Penny Larcombe, Paediatrician, Gold Coast University Hospital

Assoc Prof Susan Moloney, Director of Paediatrics, Gold Coast University Hospital

- A proposed Gold Coast adolescent inpatient /outpatient and community-based model:
 - Targeting ages 14 to 20 (with the aim of going to 24 years) with a multidisciplinary approach, straddling children and adult services
 - Staffed by adolescent and young adult physicians from adult and paediatric backgrounds, and junior medical staff
 - Nursing and allied health staff would be trained in the supports these young people need and want.
- The dedicated adolescent/young adult services could improve care, reduce length of stay and increase bed capacity throughout the organisation.
- Progress to date:
 - COVID-19 response has stalled implementation of dedicated beds
 - Increase in eating disorder presentations during the last 12 months
 - Introduced inpatient meal support for eating disorders and more structured multidisciplinary team
 - Started an outpatient multidisciplinary team clinic for young people with functional disorders
 - Introduced nurse practitioners in cystic fibrosis and diabetes working across the age spectrum from young people into adulthood, and a transition nurse navigator is supporting young people with complex and rare disorders
 - An adolescent nurse navigator is helping to integrate young people with community resources
 - Adult physicians visit young patients in the paediatric ward pre-transition to establish relationship
 - As a result of these initiatives, the length of stay for older children has been reduced.



Next steps

The recommendations in this report will be presented to the Department of Health for endorsement.

The Senate will seek updates on the implementation of endorsed recommendations to keep members and other interested parties informed of progress and provide further input into bodies of work as appropriate.

Special thanks to

The Hon. Yvette D'Ath MP, Minister for Health and Ambulance Services

Dr John Wakefield PSM, Director-General, Queensland Health

Dr Jillann Farmer, Deputy Director-General, Clinical Excellence Queensland

Organising committee

Adj. A/Prof. Chris Raftery, Deputy Chair, Queensland Clinical Senate (meeting Co-Chair)

Dr Kerri-Lyn Webb, Chair, Queensland Child and Youth Clinical Network (meeting Co-Chair)

Dr Alex Markwell, Chair, Queensland Clinical Senate

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Ms Rachel Olorenshaw, Principal Project Officer, QCS Secretariat

Appendix

Appendix 1 – Meeting agenda

Queensland Clinical Senate

Clinician leadership. Consumer collaboration. Better care.

Adolescent to young adult care: doing better

10am – 2pm, Friday 04 December 2020

Please click on the following Zoom link to join (from 9.45am):		
Web browser (desk top / laptop):	Link removed	
Via Zoom App:	Meeting ID:	Passcode:

9.45am

JOIN (See link above)

10.00am

Welcome, acknowledgement and context

Adj. A/Prof Chris Raftery, Deputy Chair, Queensland Clinical Senate

Meeting facilitator introduction

Ms Jordana Rigby, Project Officer, Queensland Child and Youth Clinical Network and Social Worker, Child Development Services, Children's Health Queensland

10.10am

Session 1: **Adolescence**: What is it? Why is it important? What's the problem?

Objective: raise awareness and improve integration of support for adolescents within the health context

Adolescence: the ideas we have of our possibilities (30 mins)

Introduced by Dr Kerri-Lyn Webb, Chair, Queensland Child and Youth Clinical Network

Prof Susan Sawyer AM, Geoff and Helen Handbury Chair of Adolescent Health, Department of Paediatrics, The University of Melbourne; Director, Centre for Adolescent Health, Royal Children's Hospital; Murdoch Children's Research Institute; and President, International Association for Adolescent Health (IAAH.org)

Consumer experience, outcomes, expectations (15 mins)

Pre-transition: Ms Keren Pointon, Carer Representative

In transition: Ms Kellara Harney, Consumer Representative

Post-transition: Ms Ellie Buchan, Consumer Representative

10.55am

Short break

11.05am

Session 2: **Transition**: What is it? Why is it important? What's the problem?

Objective: Understand the current context and the principles of transition that support evidence-based care with a focus on adolescents and young adults

Panel: Perspectives on transition – what is transition and what is best practice? (35 mins)

Chair: Dr Simon Denny, Director of Mater Young Adult Health Centre, Mater Health

- **Consumer perspective:** Mr Lachlan Kelly, Consumer and Carer Representative
- **Adult Physician:** Dr Cameron Bennett, Physician, Medical Director MNHHS Virtual Ward, Assistant Director Internal Medicine and Aged Care Department, RBWH, Acute Admitting Ward Consultant, RBWH, Complex Needs Clinic Consultant, Community and Oral Services, MNHHS
- **Paediatrician:** Dr Judy Williams, Clinical Director Paediatrics, Medical Services, Bundaberg Hospital
- **Nurse Navigator** – Ms Samantha Horgan, Nurse Navigator Transition – General Paediatrics, Queensland Children's Hospital, Children's Health Queensland
- **General Practitioner** – Dr Lisa Beecham, General Practitioner, Robina and Director, Gold Coast Primary Health Network

Group Work (break-out rooms – GroupMap)

- How does our HHS/Organisation (in my clinical service area) manage transition from *paediatrics* to *adolescent* to *adult* health care?
- What opportunities are there to affect change?

12.15pm

Lunch

12.35 pm

Session 3: Action planning

Objective: identify opportunities for improvement at a system and service level to drive change

Statewide Diabetes Transition model of care (10 mins)

Dr Jason Yates, Medical Director, Health and Wellbeing, Townsville University Hospital and Chair of the Type 1 Working Group, Statewide Diabetes Clinical Network.

Ms Sheree Menon, Senior Paediatric Psychologist, Townsville University Hospital; Project Lead Statewide Diabetes Clinical Network, T1DM transition pilot project

We're not kids, we're not adults, we're lost in the system: a proposed Gold Coast Adolescent model (10 mins)

Assoc Prof Susan Moloney, Director of Paediatrics, Gold Coast University Hospital

Dr Penny Larcombe, Paediatrician, Gold Coast University Hospital

Group Work (stakeholder engagement activity: GroupMap)

- What should we do at the:
 - Policy Level / Systems level / HHS level
 - In the short / medium / long term?
 - And how?

1.35pm

Address by the Minister for Health and Ambulance Services (10 mins)

Hon. Yvette D'Ath, Minister for Health and Ambulance Services

1.40pm

Summary & Close

(incl. opportunity to complete meeting evaluation via SurveyMonkey)

Wrap-up and reflection

Dr Alex Markwell, Chair, Queensland Clinical Senate

2.00pm

Meeting Close

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