

HEALTH CARE FOR ADOLESCENTS
AND YOUNG ADULTS
(AYA LIVER SERVICE)

OBJECTIVES

- Issues facing adolescent and young adult (AYA) liver patients
- NZ demographics
- Models of care
- Roles and responsibilities
- Ongoing and future developments

Health for the world's adolescents - a second chance in the second decade

- Adolescence is one of the most rapid phases of human development.
- The characteristics of both the individual and the environment influence the changes taking place during adolescence.
- Younger adolescents may be particularly vulnerable when their capacities are still developing and they are beginning to move outside the confines of their families.
- The changes in adolescence have health consequence not only in adolescence but also over the life-course

(World Health Organisation
2014)

Youth health and wellbeing

How NZ fared out of 19 countries*

Mortality Rate	10-19 year olds	19th
Birth Rate	15-19 year olds	18th
Not in education or training	15-19 year olds	8th
Asthma mortality rate	10-24 year olds	18th
Obesity rate	15-19 year olds	18th
Diabetes rate	10-24 year olds	11th
Cancer mortality rate	10-24 year olds	7th
Suicide rate	10-24 year olds	17th
	15-19 year olds	19th
	10-14 year olds	19th
Road crash deaths	10-24 year olds	17th

*UK, Australia, Austria, Belgium, Canada, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Japan, Netherlands, NZ, Portugal, Spain, Sweden, US
(International comparisons of health and wellbeing in adolescence and early childhood)

Nuffield Trust 2016

POOR OUTCOME FOR YOUTH AFTER TRANSPLANT

- SRTR (1988 – 2013) 2540 liver graft failures in recipients <40
 - Graft loss highest 25-29 years
 - 21-24 years greater loss than <17 or > 34 years
 - Foster et al 2016
- SRTR (1989 – 2010) all solid organs
 - 12-17y X2 RR graft failure compared with <12 years old
 - Dharnidharka et al 2017
- Non adherence associated with re-tx and death
- Often striving for normalcy

GRAFT LOSS IN AYA AT NZLTU:

- **6 graft loss in AYA years** in New Zealanders since paediatric liver transplant service set up (2000), 5 times after transition to adult services
- **4 re-transplanted (3 in adults)**
- **2 died (in adults).** complex livers, non adherence, graft failure
 - Both mid 20's, Maori
 - 1 after 3 transplants, 1 died before 3rd transplant
 - Another facing death from graft failure (18yrs old)

- an adult services issue

AYA: PROBLEMS IN ADULT SERVICES

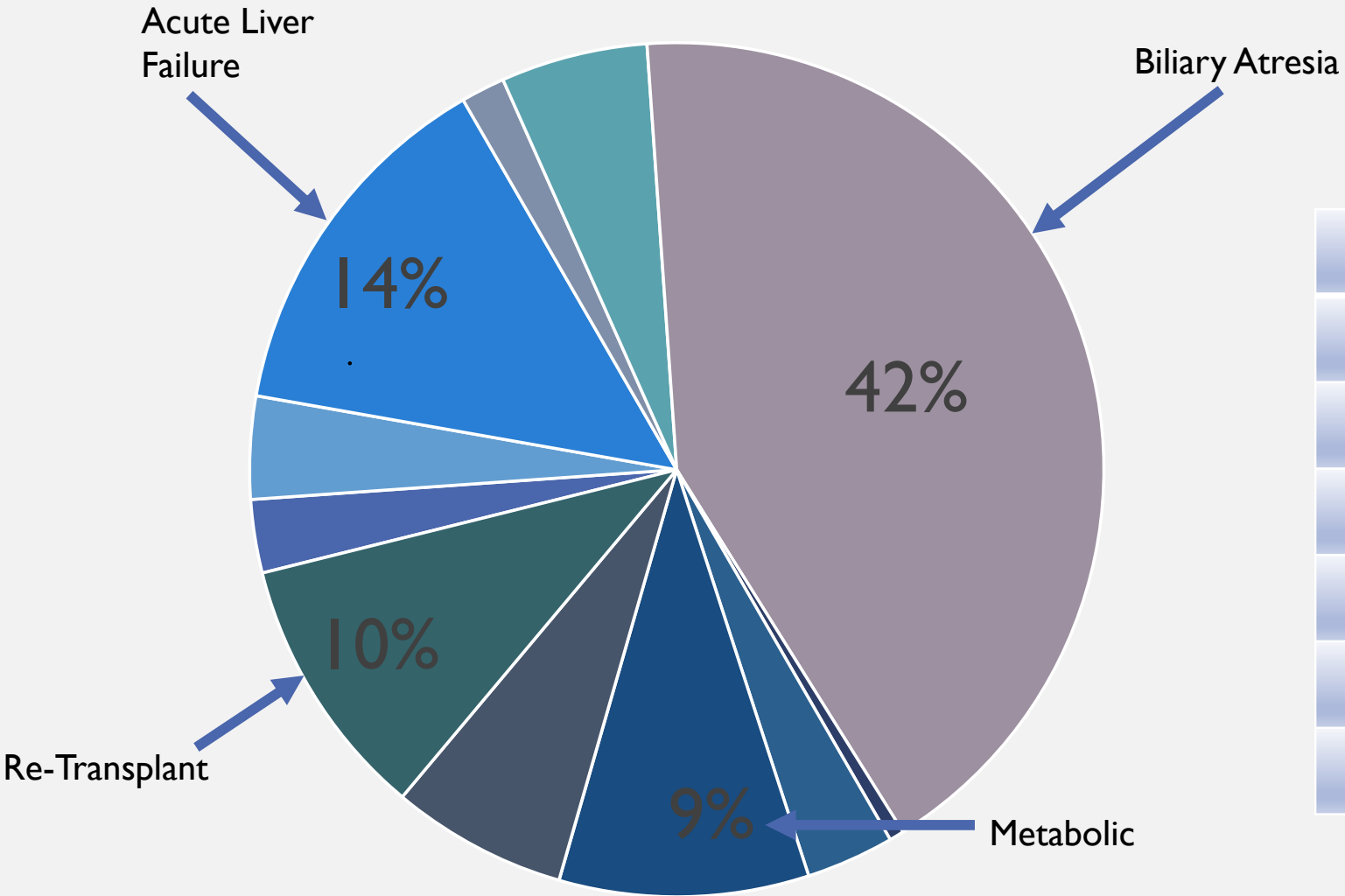
- 5 year data of Young Person Liver Clinic (YPLC)
 - 30% graft related problems
 - 50% other medical problems (including mental health)
- Current clinic population
 - N=40
 - Psychosocial issues in approx 50% (cognitive, learning, mental health)
- 1/3 Maori
 - Worse outcomes in social domains
 - All deaths in Maori/ PI

CURRENT COHORT

149 Patients transplanted aged 24 or younger

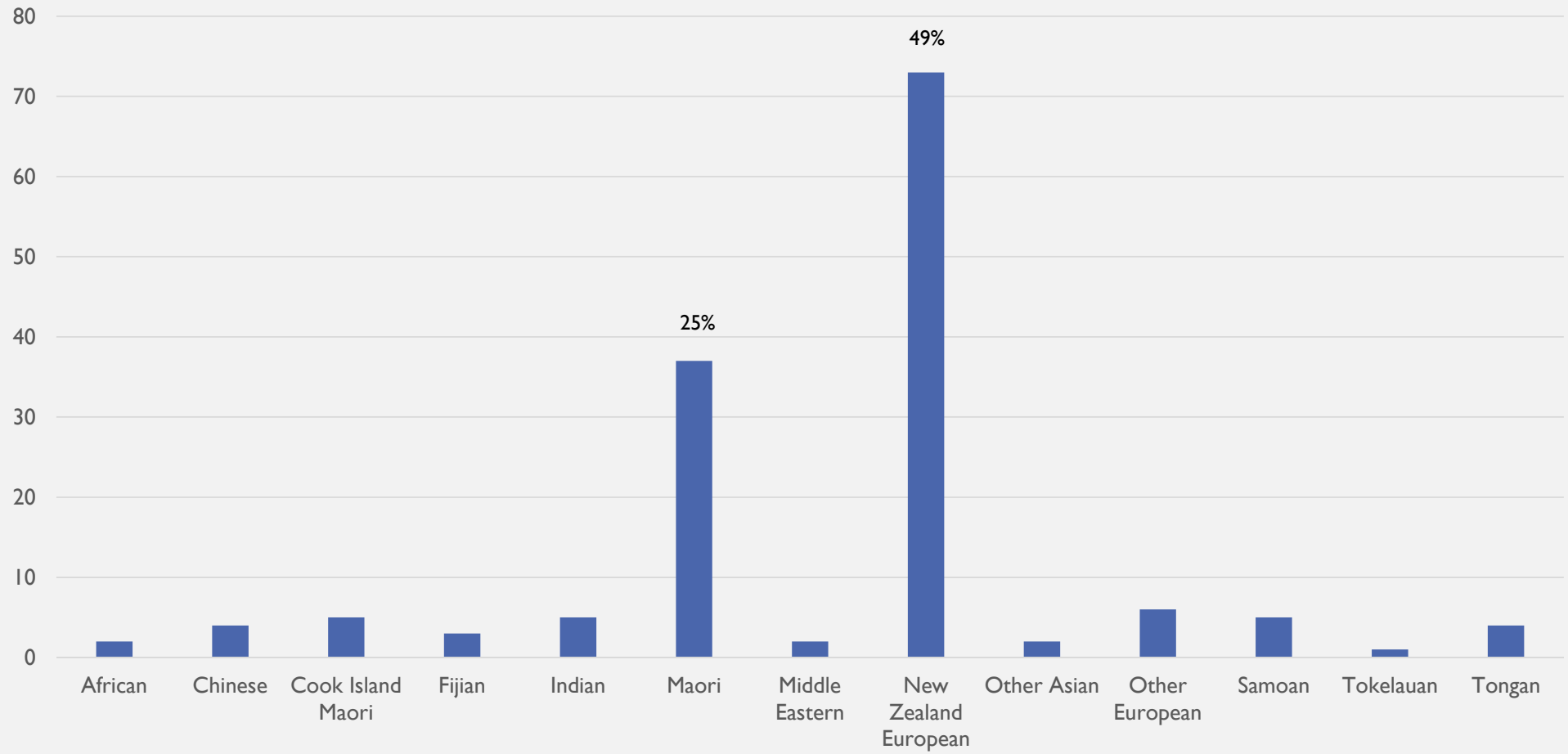
- 89 – before 5yrs of age
- 33 – between 5 and 15yrs
- 18 – between 15 and 20 yrs
- 9 – between 20 and 24yrs

Diagnosis of all transplants under age 24

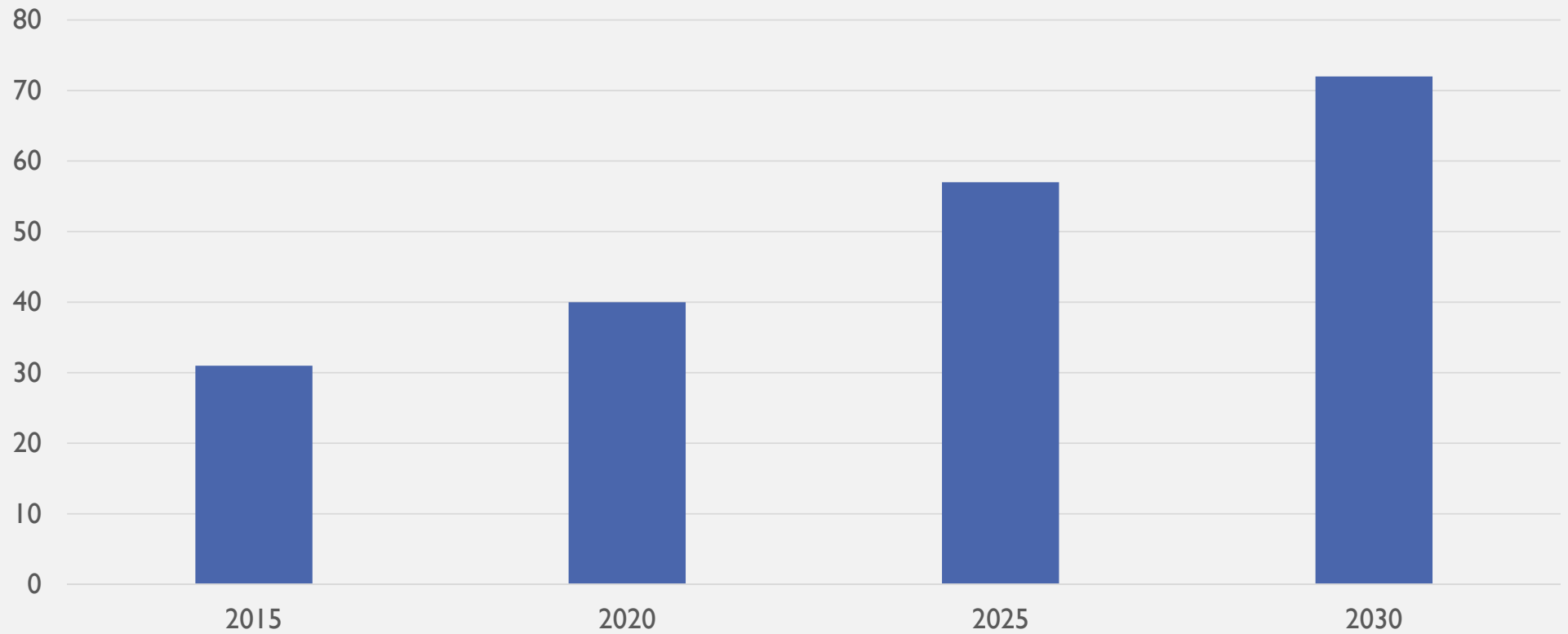


AIAT	3%
Alagille	4%
Autoimmune	2%
Cholestatic	5%
HBV	1%
Hepatoblastoma	3%
Other	7%

ETHNICITY OF RECIPIENTS TX'D UNDER AGE OF 24

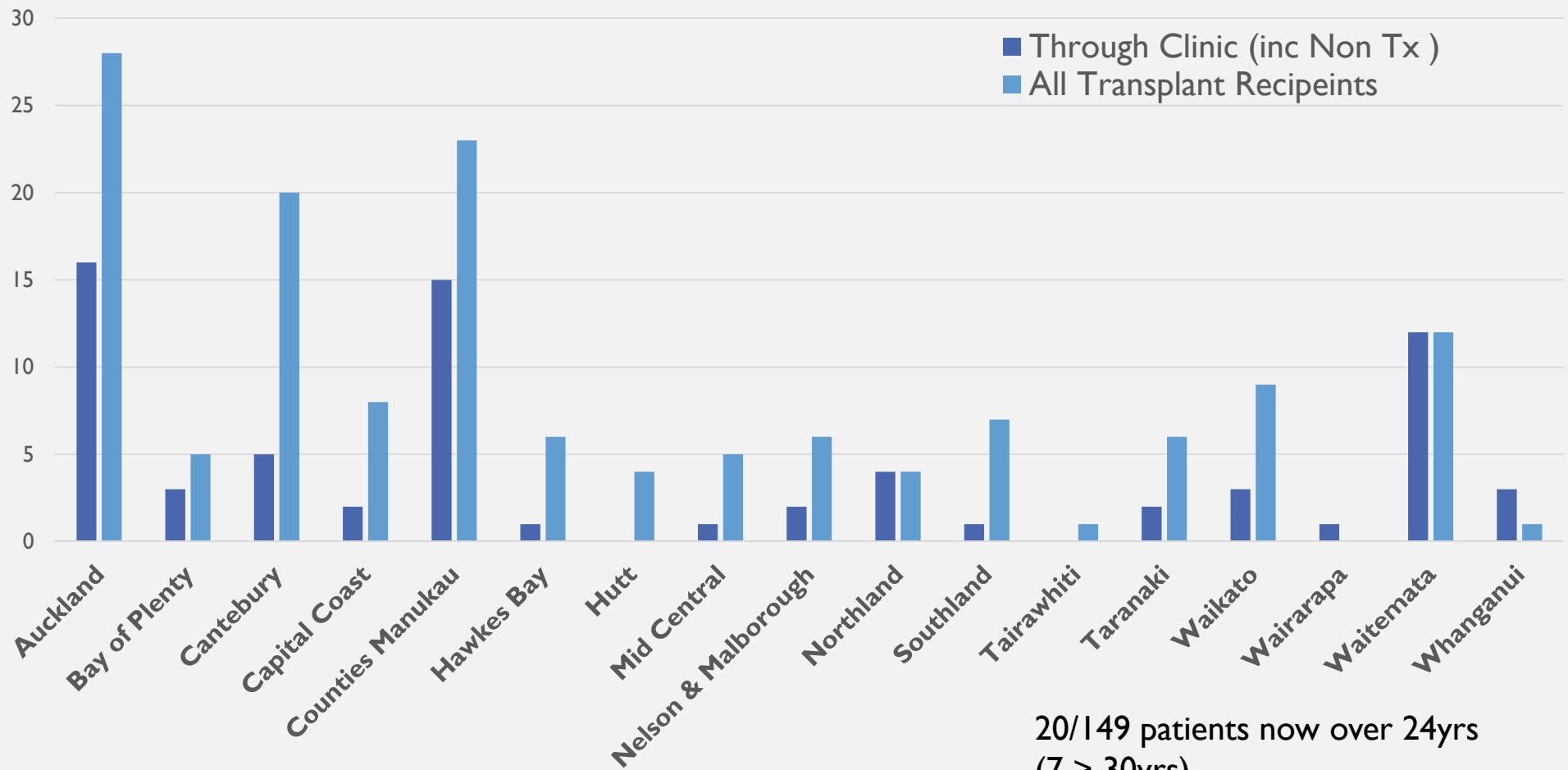


NO OF LIVER TX RECIPIENTS BETWEEN THE AGE OF 15 AND 24 YEARS*



*Based only on patients currently transplanted

RECIPIENTS BY REGION



20/149 patients now over 24yrs
(7 > 30yrs)

DIAGNOSIS IN ADOLESCENTS ASSOCIATED WITH WORSE OUTCOME

- A diagnosis of AILD between the ages of 14-20 is an independent predictor of liver related death or the need for liver transplant (Hames et al 2016)
- Adolescence is also the peak time for the onset of mental health problems, including anxiety, depression. Behavioural difficulties are further elevated in children and adolescents with physical health problems and this has been borne out but studies into the psychosocial wellbeing of young liver transplant recipients
- Psychological distress was significantly associated with non adherence one year after transition into the adult service (Annuziato 2015)
- Within the transplant realm non adherence is *understandably* associated with graft loss and the need for re-transplant however within our cohort other factors have also contributed to the need for re-transplant.

THEY'RE DOING OK... MOSTLY

- 80% of young people, in the general population do ok despite risk taking behaviours
- Young people with long term health conditions have an increased rate of distress and risk taking, and worse consequences
- Often in the pursuit of normality (rather than wilful disobedience)
- Adverse consequences seemed to be exacerbated in the absence of family and community support

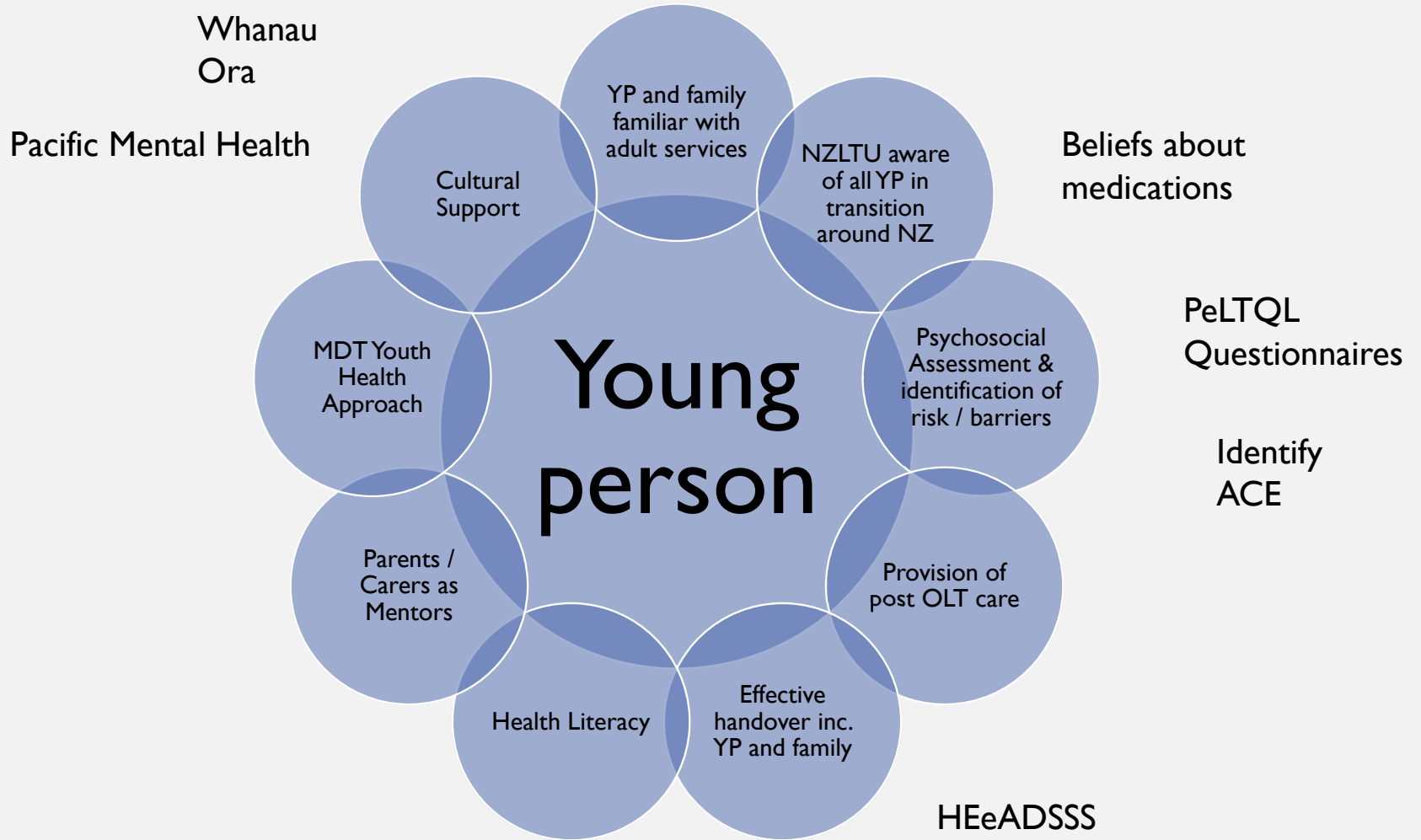
PROPOSED NZLTU AYA MODEL



Age	12	14	18	25
Providing Service	Paed	Transition		Adult
Doctors	Paed	Paed / Adult		Adult
Psych	Paediatric Psychologist			
SW	Paed SW		Adult SW	
NP / CNS	Paed CNS / Adult NP		Adult NP	
	Pharmacist			

In addition:

- MDT Patient reviews (complex pts)
- Build on Regional/Outreach Services that Paed service already offer
- Youth Representation



PROVIDING SUPPORT LOCALLY

- Explore help from external agencies
- **Cultural support**
- Provide single point of contact (*this may have to be you*)
- Liaise with AYA service e.g. neuropsychological assessments

TAKE HOME MESSAGES

- 80% of young people are doing ok



- Validated tools available



- Population that is growing



- Be that point of contact

