



ANZDATA Registry New Data Collection

ANZSN ASM 2020 - ANZDATA Session

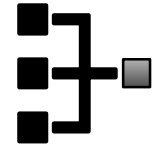
Kylie Hurst
General Manager



Clinical quality registries (ANZDATA) collect and analyse **clinical data** to identify benchmarks for **clinical** performance and related variation in **clinical** outcomes



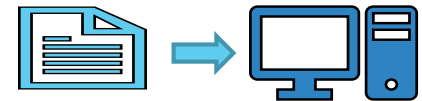
Systematic collection of identical '**minimum data sets**' using **identical definitions**, collected in the **same way** and at the **same time** in relation to a treatment and outcome



Data collected by **clinicians, nurses**, allied health professionals, patients and their carers, or from linkage with other data sources (secondary data)



Electronic data input should replace **paper based collection**, over time





Introducing new data elements 2020

Dialysis Level

- Self-care

Treatment Codes

- Community House Haemodialysis
- Withdrawal From Dialysis

Cause of Graft Failure

- Chronic Allograft Nephropathy categorisations

Graft Rejection Types

- Rejection subtypes including additional diagnostic parameters

Community House Haemodialysis

is defined as a “sub-modality” of haemodialysis that enables patients/carer to undertake haemodialysis, independent of nursing or medical supervision, in a shared house or community facility.

Treatment History

Sequence	Description *	Treatment Date
1	BC - HD Hospital - Conventional	17/02/20
2	DC - HD Satellite - Conventional	06/03/20
	<input type="text"/>	

Save

- BC - HD Hospital - Conventional
- BQ - HD Hospital - Quotidian
- DC - HD Satellite - Conventional
- DQ - HD Satellite - Quotidian
- YC - HD Community House - Conventional**
- YQ - HD Community House - Quotidian**
- FC - HD Home - Conventional
- FQ - HD Home - Quotidian

COURSE OF TREATMENT COMPLETE ACCORDING TO CODE

E APD / IPD
M CAPD
BC HD Hospital-Conventional
BQ HD Hospital-Quotidian
DC HD Satellite-Conventional
DQ HD Satellite-Quotidian
YC HD Community-Conventional
YQ HD Community-Quotidian
FC HD Home-Conventional
FQ HD Home-Quotidian
G Transplant in AUST/NZ
H Date of last post graft dialysis
X Transplant Overseas
T Graft function ceased-Temporary
P Graft function ceased-Permanent
J Own kidney function recovered.
Dialysis ceased
K Date of last visit if lost to follow up
W Withdrawal from Dialysis
Z Date of Death

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Withdrawal from Dialysis

defined as the intentional and long-term cessation of dialysis

treatment by a patient in the context of a change to a conservative (palliative) treatment pathway. This is captured as the 'Date of Last Dialysis'.

Treatment History

Sequence	Description *	Treatment
1	BC - HD Hospital - Conventional	17/02/201
2	DC - HD Satellite - Conventional	06/03/201

W

J - Own Kidney Function Recovered

K - Date of Last Visit if Lost to Follow Up

W - Withdrawal from Dialysis

Save

COURSE OF TREATMENT COMPLETE ACCORDING TO CODE

- E APD / IPD
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- BC HD Hospital-Conventional
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Self-care

defined as dialysis performed by the patient with minimal assistance from a health care professional. Selfcare enables patients to perform dialysis procedures independent of nursing or medical assistance in any type of facility or community setting.

Survey Period	Dialysis Type*	Self Care*	Dry Weight (kg)*
31/12/2020	12 - Haemodialysis	<input type="checkbox"/>	
31/12/2019	12 - Haemodialysis	<input type="checkbox"/>	

THIS SECTION IS FOR ALL PATIENTS DIALYSED AT ANY TIME

TYPE OF DIALYSIS	SELF CARE	DRY WEIGHT AT LAST DX kg	UNCORRECTED CALCIUM mmol/L	PH
<input type="text"/> (see list)	<input type="checkbox"/> Y=Yes N=No	<input type="text"/> HD and PD Patients	<input type="text"/>	<input type="text"/>

Chronic Allograft Nephropathy (CAN)

- Chronic Antibody Mediated Rejection - **Code 41**
- Interstitial Fibrosis/Tubular Atrophy (Biopsy Proven) - **Code 42**
- Gradual Graft Failure (Not Biopsy Proven) - **Code 43**

Country	Cause of graft failure	First year	> First year	Total
Australia	Acute rejection	24 (17%)	49 (4%)	73 (5%)
	Chronic Allograft Nephropathy	9 (6%)	780 (63%)	789 (57%)
	Hyperacute rejection	3 (2%)	-	3 (<1%)
	Vascular	37 (26%)	16 (1%)	53 (4%)
	Technical	17 (12%)	4 (<1%)	21 (2%)
	Glomerulonephritis	5 (3%)	79 (6%)	84 (6%)
	Non-compliance	3 (2%)	49 (4%)	52 (4%)
	Other	41 (29%)	165 (13%)	206 (15%)
	Not reported	4 (3%)	106 (8%)	110 (8%)
	Total	143 (100%)	1248 (100%)	1391 (100%)
New Zealand	Acute rejection	1 (5%)	12 (7%)	13 (7%)
	Chronic Allograft Nephropathy	1 (5%)	113 (63%)	114 (58%)
	Vascular	5 (25%)	1 (1%)	6 (3%)
	Technical	3 (15%)	1 (1%)	4 (2%)
	Glomerulonephritis	3 (15%)	10 (6%)	13 (7%)
	Non-compliance	-	8 (4%)	8 (4%)
	Other	6 (30%)	19 (11%)	25 (13%)
	Not reported	1 (5%)	14 (8%)	15 (8%)
Total	20 (100%)	178 (100%)	198 (100%)	

Rejection subtypes and Banff parameters

More precise classification has been introduced with addition of further Banff classification variables and categorisation of the type of rejection.

IF BIOPSY PERFORMED

What type of rejection did the biopsy show? **Please complete all boxes**

Antibody Mediated	<input type="text"/>	1 = Nil	BANFF CLASSIFICATIONS (Enter either Grade 0,1,2,3 for each box)									
T-cell Mediated	<input type="text"/>	2 = Mild	g	i	t	v	ptc	c4d	cg	ci	ct	cv
		3 = Moderate	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
		4 = Severe	mm	ah	ti	i-IFTA						
Presence of Donor Specific Antibody (DSA)	<input type="text"/>	1 = Pre-transplant	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>						
		2 = De Novo										
		3 = Pre-transplant & De Novo										
		4 = No DSA detected										

Add Rejection Episode

Rejection Date *

Was a Biopsy Performed? *

C - Yes (Clinical Suspicion)

C - Yes (Clinical Suspicion)

D - Yes (Delayed Graft Function)

N - No

P - Yes (Protocol)

What type of rejection did the biopsy show?

Antibody Mediated

T-Cell Mediated

Banff Classifications (if known)

g	<input type="text"/>	i	<input type="text"/>	t	<input type="text"/>	v	<input type="text"/>	ptc	<input type="text"/>
c4d	<input type="text"/>	cg	<input type="text"/>	ci	<input type="text"/>	ct	<input type="text"/>	cv	<input type="text"/>
mm	<input type="text"/>	ah	<input type="text"/>	ti	<input type="text"/>	i-IFTA	<input type="text"/>		



Data Elements Added 2019

- ▶ Ethnicity (1&2)
- ▶ Calciphylaxis Episodes
- ▶ HDF Substitution Volume (HD)
- ▶ 24 Hour Residual Urine Volume (PD)
- ▶ Transplant Anastomoses
- ▶ Pregnancy data

Calciphylaxis Episodes

- **73 patients** with a diagnosed episode during **2019**
- **median** time on RRT to first diagnosis date **3.3 years**

Modality	2019 (n)
HD	50
PD	19
Tx	3
Prior to RRT start	1

CO-MORBID CONDITIONS AT ENTRY

DISEASE AT ENTRY AND DURING CURRENT SURVEY

Y=Yes N=No S= Suspected	CHRONIC LUNG	CORONARY ARTERY	PERIPHERAL VASCULAR	CEREBRO VASCULAR	DIABETES (see codes)	CALCIPHYLAXIS EPISODE	POSTCODE
AT ENTRY							
LAST							
CURRENT							

dd/mm/yy

Postcode and Co-Morbidity

Patient	Parent Renal Unit	Facility	Registry Number
Date of Birth	Current Treatment	MRN	Physician

Survey Period: 31/12/2019

Postcode:

Chronic Lung Disease: N - No

Coronary Artery Disease: N - No

Peripheral Vascular Disease: N - No

Cancer Survey Checked: Yes

Cancer Ever: Y - Yes

Hepatitis C Antibody: Z - Negative

Calciphylaxis Episode:

First Diagnosis Date:

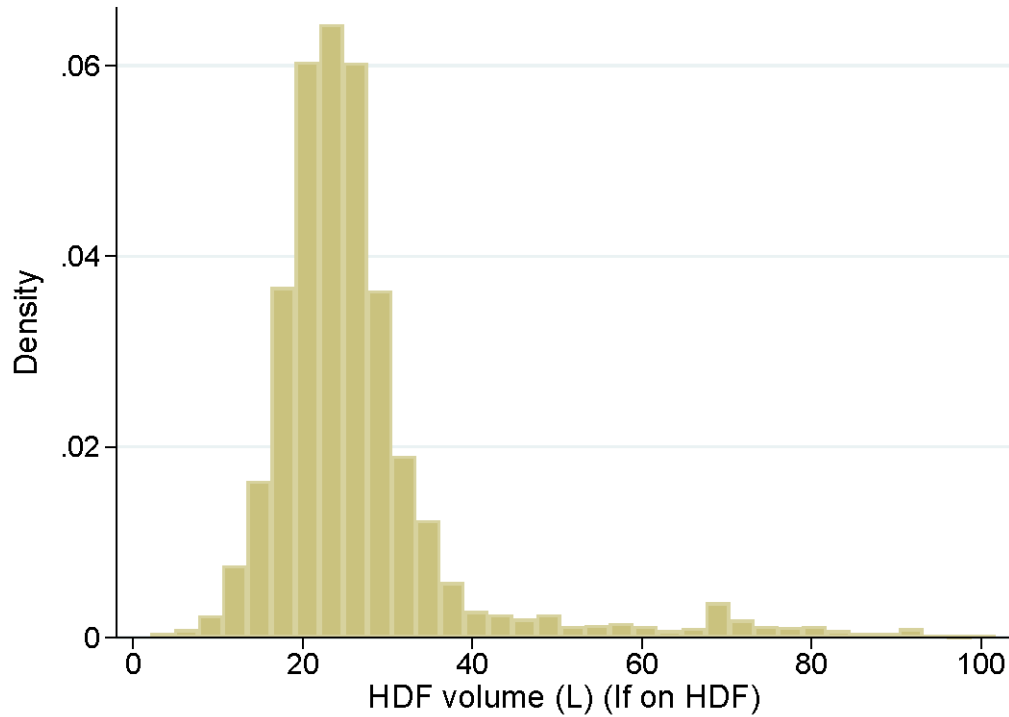
HD – HDF Substitution Volume

- Of **4,357 pts** reported to be **on HDF** at the end of 2019, **88%** reported a volume
- with a **median** volume of 24L

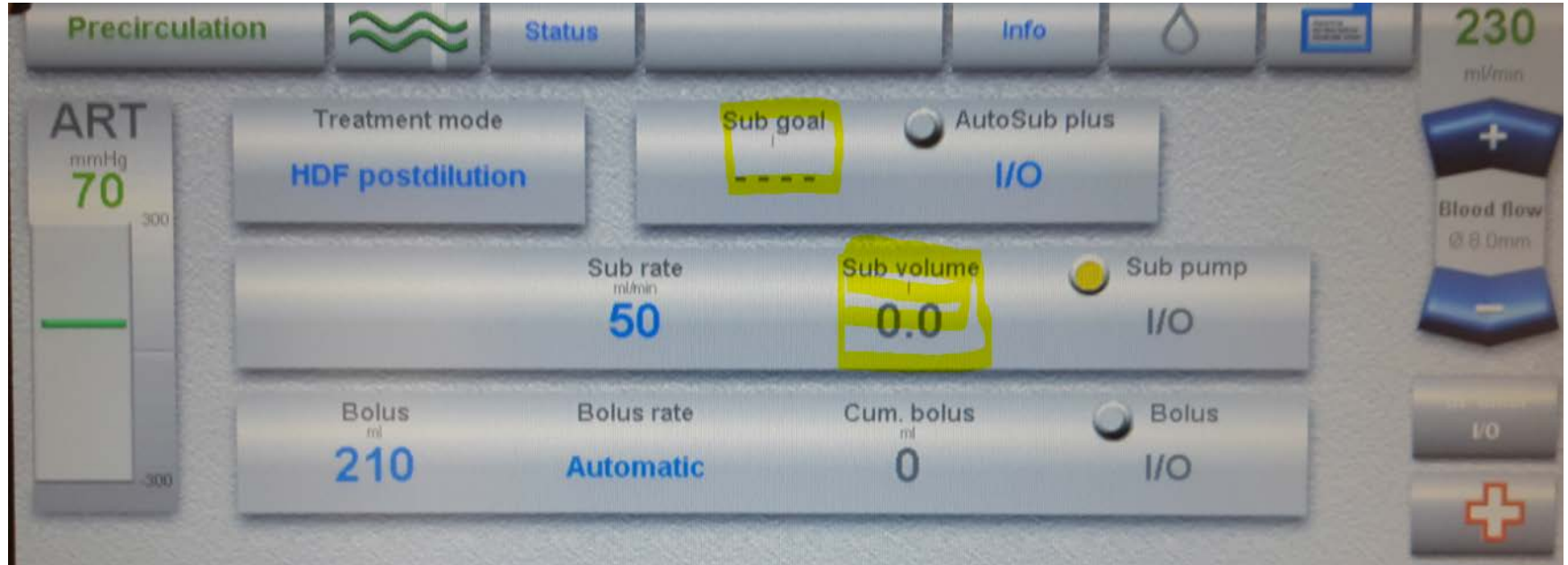
Blood Flow Rate (mls/min)*	HDF Volume (L)*	Sessions Per Week*	Hours Per Session*
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Country	On HDF	Reported	Median
Australia	3,965	3,516 (89%)	23.9
New Zealand	392	316 (81%)	27.0

HD - HDF Substitution Volume



HD - HDF Substitution Volume



PD - 24 hour Residual Urine Volume

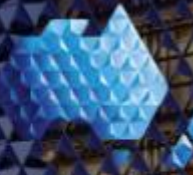
- **1,597 (49%)** reported a residual urine volume
- with a median volume of **786mL /24 hrs**

Creatinine Clearance Dialysate Only (Litres/week/1.73m ²)	Weekly Kt/V Dialysate Only	Residual Renal Function Creatinine Clearance (Litres/week/1.73m ²)	PD Adequacy Residual Urine 24hr Volume (ml)	Data Not Available
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	

Country	On PD	Reported	Median Volume
Australia	2,387	1,400 (59%)	650mL /24h
New Zealand	868	197 (23%)	800mL /24h



www.anzdata.org.au



ANZDATA

AUSTRALIA &
NEW ZEALAND
DIALYSIS & TRANSPLANT
REGISTRY



ANZOD

AUSTRALIA &
NEW ZEALAND
ORGAN DONATION
REGISTRY



ANZLKD

AUSTRALIA &
NEW ZEALAND
LIVING KIDNEY DONATION
REGISTRY



ANZETD

AUSTRALIA &
NEW ZEALAND
EYE & TISSUE DONATION
REGISTRY