

An analysis of the impact of deemed consent in Wales

Sue Madden

NHSBT Statistics and Clinical Studies

Human Transplantation (Wales) Act

- Legislative change in organ donation in Wales (1 December 2015)
- Allows for consent to organ donation to be deemed, in certain circumstances, where a patient had not otherwise expressed a decision



Human Transplantation (Wales) Act

- Legislative change in organ donation in Wales (1 December 2015)
- Allows for consent to organ donation to be deemed, in certain circumstances, where a patient had not otherwise expressed a decision:
 - *Patient died in Wales and is aged 18 years or over at time of death, and*
 - *Patient has voluntarily lived in Wales for more than 12 months and is ordinarily resident there, and*
 - *Patient had the capacity to understand the notion of deemed consent for a significant period before their death*

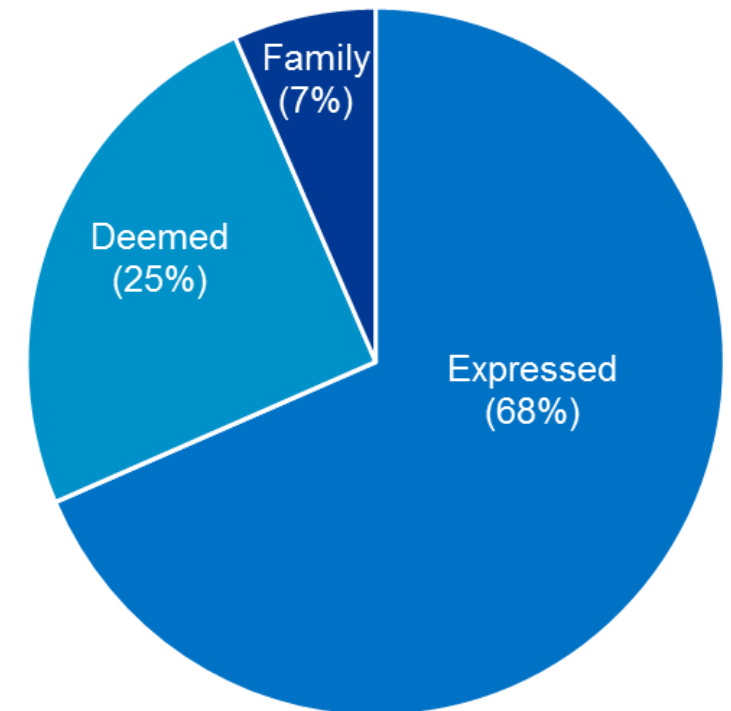


Methods of consent

- Different methods of ascertaining consent
 - Expressed consent (135)
 - Family/appointed representative consent (13)
 - Deemed consent (49)

42 eligible donors had expressed a decision to opt-out,
8 via the Organ Donor Register

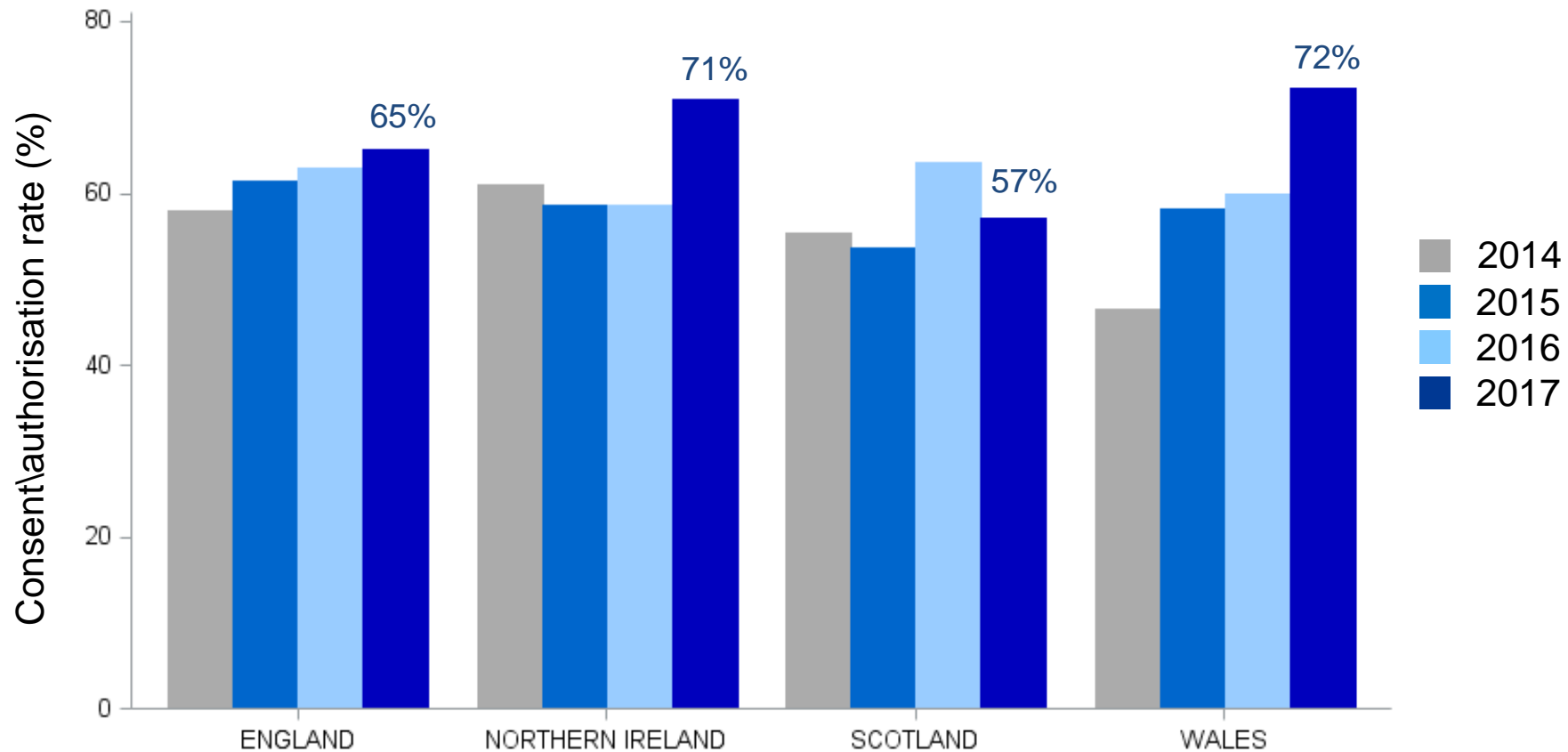
Consented patients
(1 Dec 2015 – 31 Dec 2017)



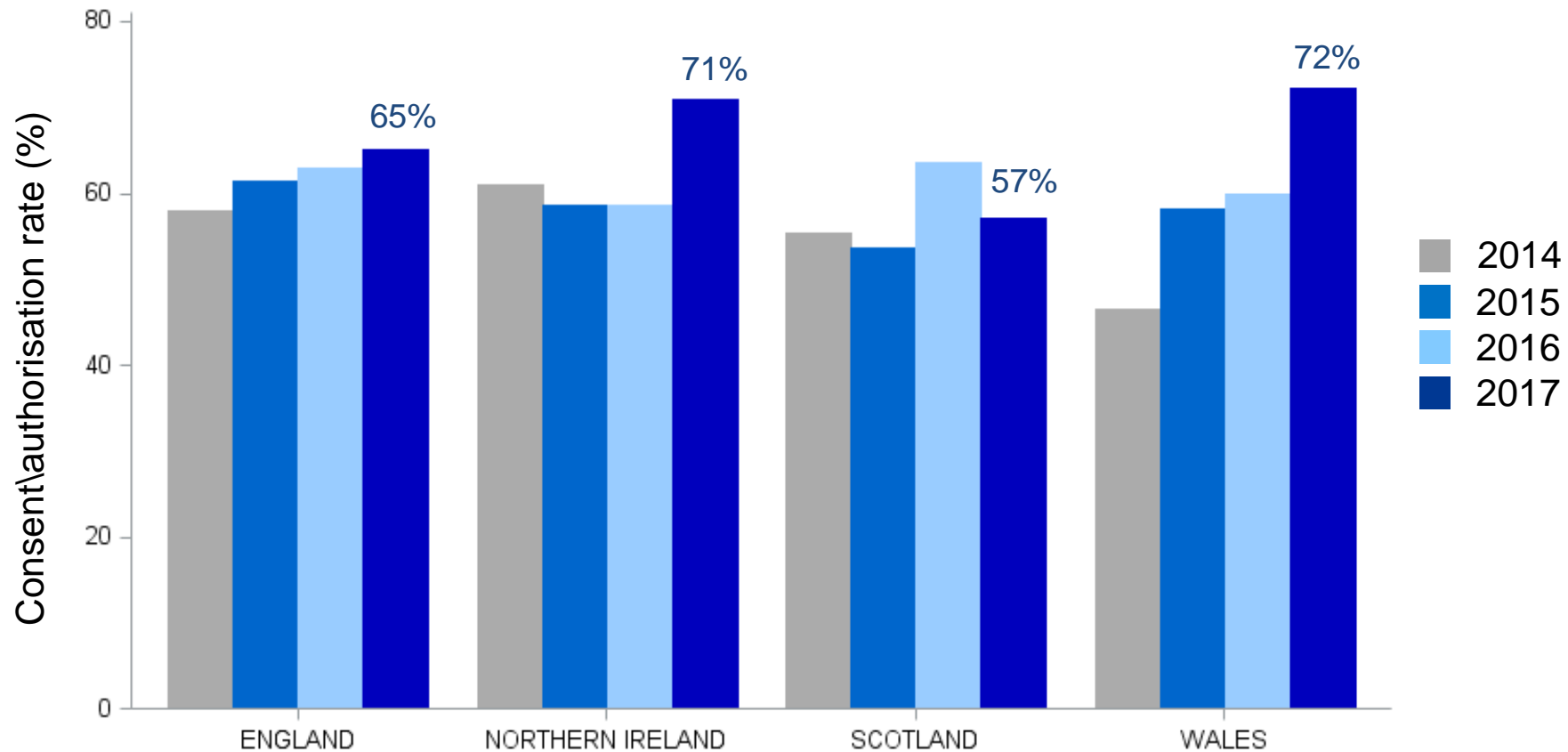
Monitoring the impact

- No conclusive international evidence of positive or negative impact
- NHSBT developed a formal evaluation of impact of deemed consent in Wales
- Sequential analysis aims to identify, at earliest possible opportunity, whether there has been a change in underlying consent rate
- Anticipated any observed change is associated with change in *consent* rate, rather than *donor* rate
- Eligible donors who opted out are included in the consent rate calculation

Consent / authorisation rates in UK nations 2014 – 2017



Consent / authorisation rates in UK nations 2014 – 2017



No. approaches 2017

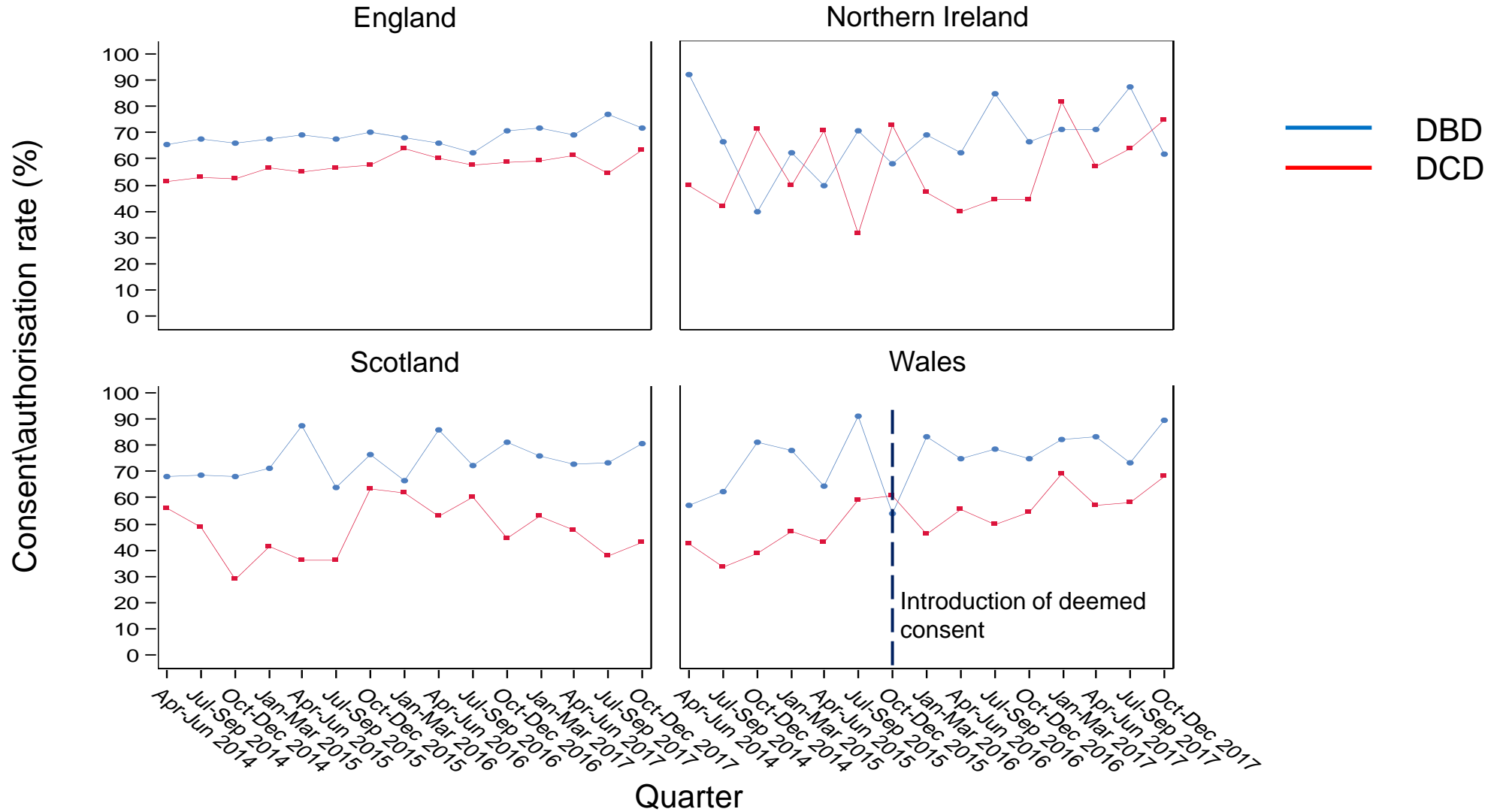
2754

79

261

147

DBD and DCD consent / authorisation rates



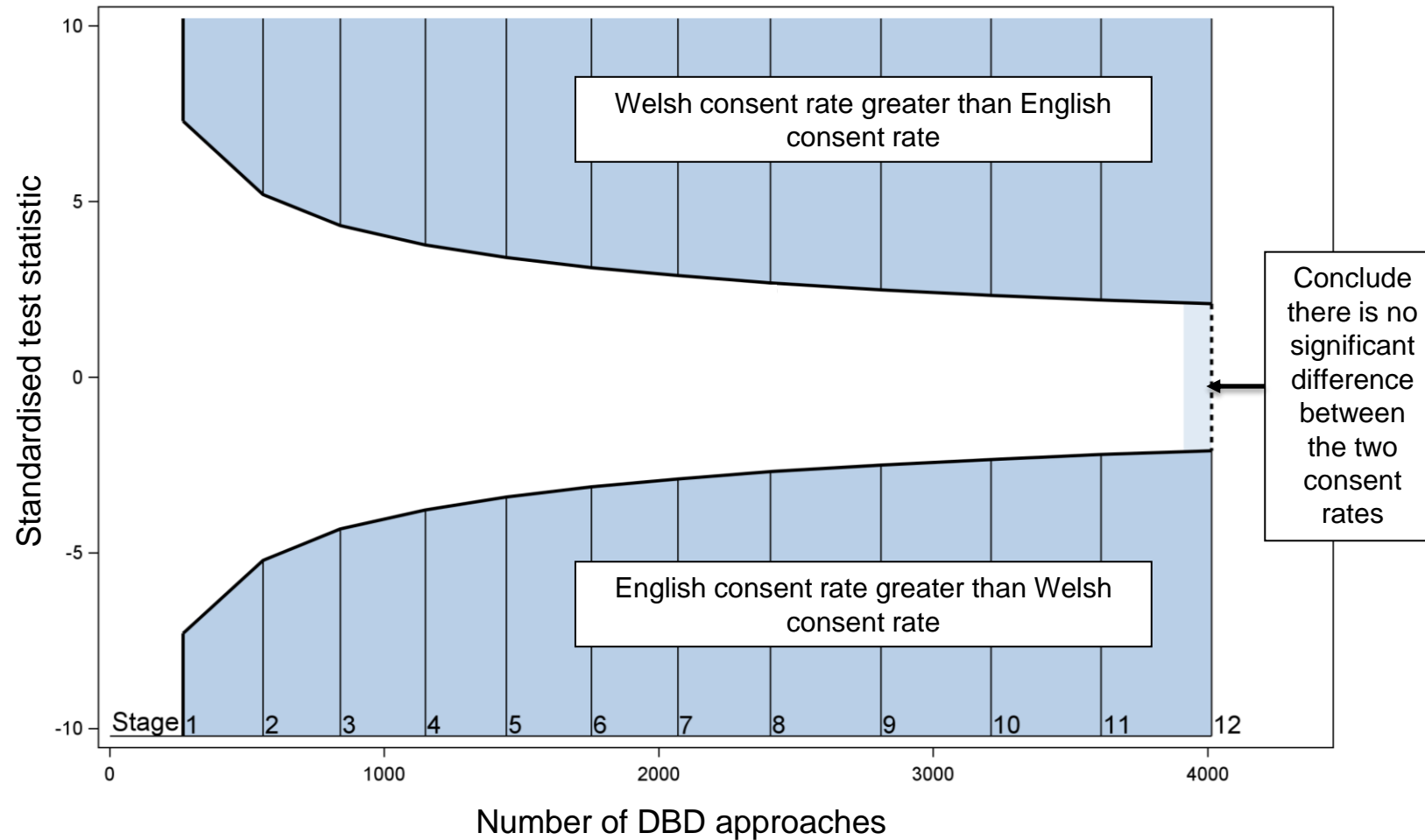
Sequential analysis

Comparing Welsh and English consent rates

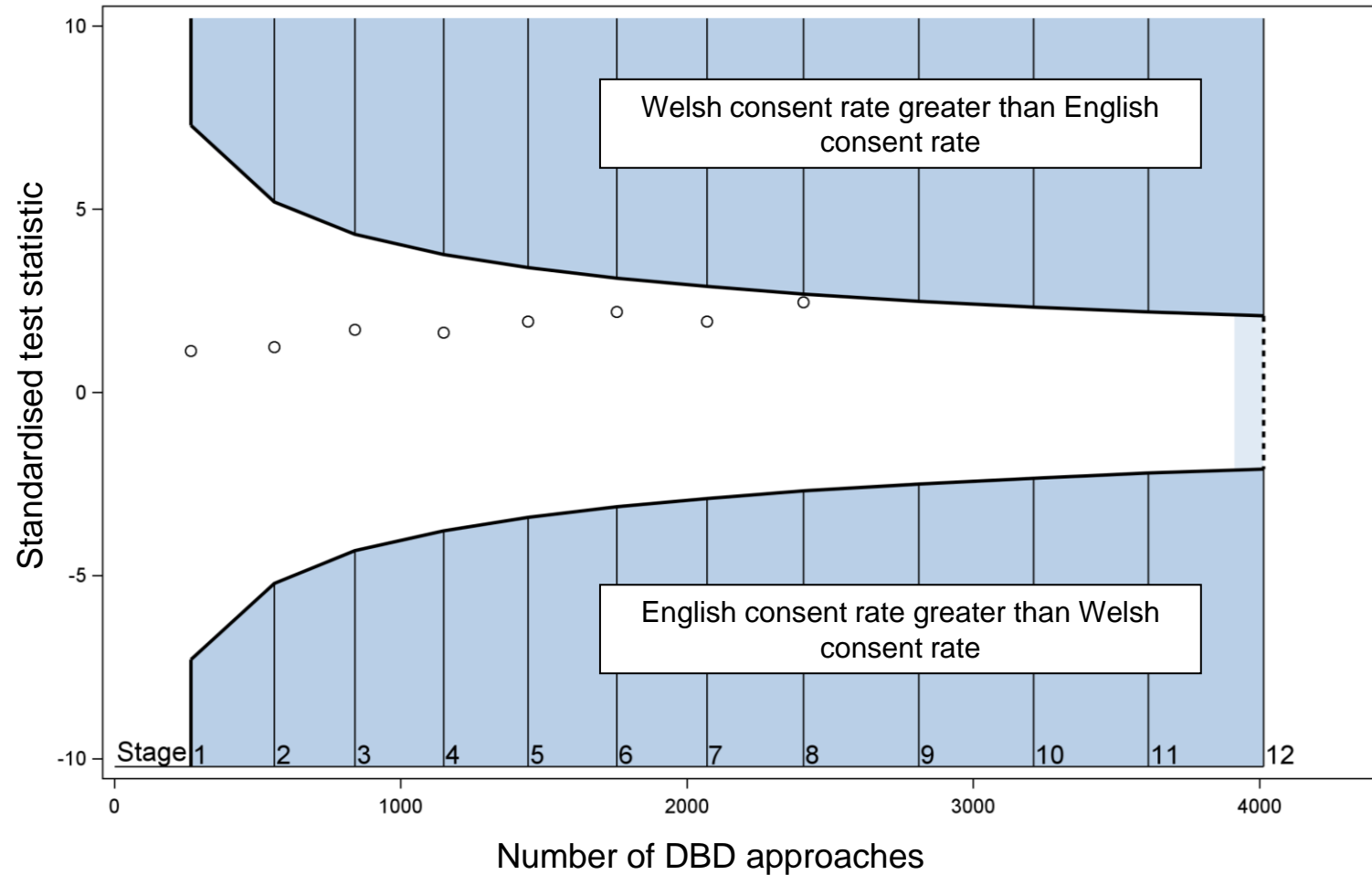
Sequential study design

- Compares Welsh and English DBD and DCD consent rates
- Assumes both countries have same underlying baseline rates
- Designed to detect absolute difference of 10%
- Test procedure accounts for multiple 'looks' at data, avoids conclusions being reached too early, when data are limited
- May take 3-4 years to reach conclusion
- Implementation of opt-out system in England unlikely to happen in timeframe which will influence outcome of our study

A sequential plot



DBD sequential plot – Q8 (Jan 2016 – Dec 2017)



Quarterly DBD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	255	68	12	83
2	283	66	8	75
3	267	62	14	79
4	298	71	12	75
5	279	72	17	82
6	298	69	12	83
7	299	77	15	73
8	319	72	19	90

Quarterly DBD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	255	68	12	83
2	283	66	8	75
3	267	62	14	79
4	298	71	12	75
5	279	72	17	82
6	298	69	12	83
7	299	77	15	73
8	319	72	19	90

Quarterly DBD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	255	68	12	83
2	283	66	8	75
3	267	62	14	79
4	298	71	12	75
5	279	72	17	82
6	298	69	12	83
7	299	77	15	73
8	319	72	19	90

Quarterly DBD data

Jan 2016 – Dec 2017

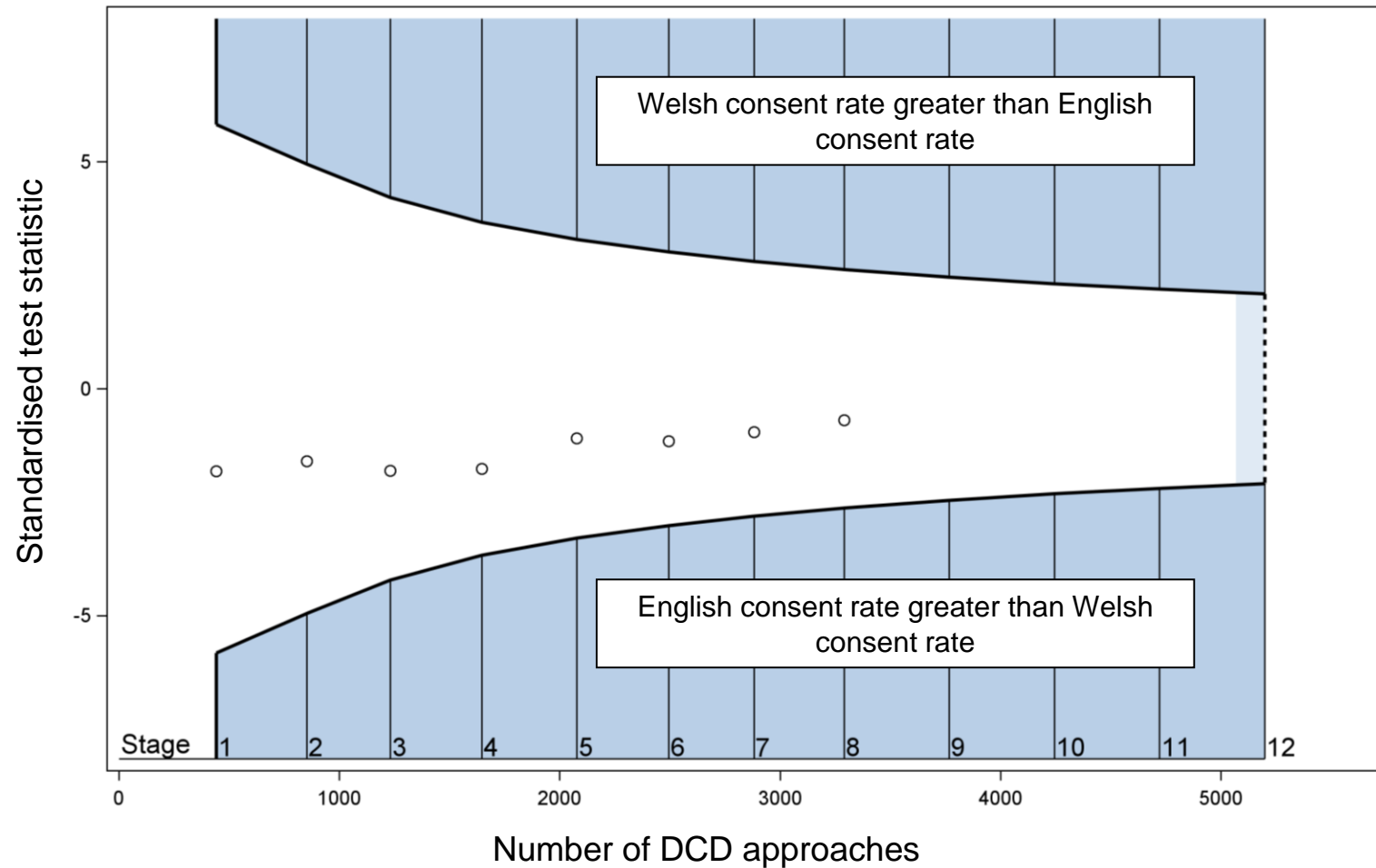
Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	255	68	12	83
2	283	66	8	75
3	267	62	14	79
4	298	71	12	75
5	279	72	17	82
6	298	69	12	83
7	299	77	15	73
8	319	72	19	90

Quarterly DBD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	255	68	12	83
2	283	66	8	75
3	267	62	14	79
4	298	71	12	75
5	279	72	17	82
6	298	69	12	83
7	299	77	15	73
8	319	72	19	90

DCD sequential plot – Q8 (Jan 2016 – Dec 2017)



Quarterly DCD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	416	64	26	46
2	392	60	18	56
3	351	58	28	50
4	394	59	22	55
5	404	59	26	69
6	404	61	14	57
7	367	54	19	58
8	384	63	25	68

Quarterly DCD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	416	64	26	46
2	392	60	18	56
3	351	58	28	50
4	394	59	22	55
5	404	59	26	69
6	404	61	14	57
7	367	54	19	58
8	384	63	25	68

Quarterly DCD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	416	64	26	46
2	392	60	18	56
3	351	58	28	50
4	394	59	22	55
5	404	59	26	69
6	404	61	14	57
7	367	54	19	58
8	384	63	25	68

Quarterly DCD data

Jan 2016 – Dec 2017

Quarter	England		Wales	
	Approached (N)	Consent rate (%)	Approached (N)	Consent rate (%)
1	416	64	26	46
2	392	60	18	56
3	351	58	28	50
4	394	59	22	55
5	404	59	26	69
6	404	61	14	57
7	367	54	19	58
8	384	63	25	68

Summary

Trends in consent/authorisation rates

- Combined deceased donor consent/authorisation rates - increasing all UK nations
- Combined deceased donor consent rate in Wales - 58% (2015) to 72% (2017)
- DBD consent rate in Wales in 2017 - 83%

Sequential analysis:-

- Too early to determine whether Welsh consent rates have improved relative to the English consent rates
- No evidence of a detrimental impact on Welsh consent rates
- To see if any observed change is a consequence of deemed consent, further analysis required to account for other influential factors eg Specialist Requester role

Acknowledgements

- Statistical guidance provided by Dave Collett
- All Specialist Nurses in Organ Donation for data collection and validation of the Potential Donor Audit which provides basis for our analyses



@NHSBT_Stats

www.odt.nhs.uk