#### **UK LKD Network Meeting**

24 Jan 2019

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## HEALTH INEQUALITY AND LIVING DONATION: LESSONS FROM CLINICAL PRACTICE

### 3 things to start with... 1: a disclaimer

- The following is not the outcome of a randomised controlled trial
- I have no statistical evidence that proves our system overcomes the barriers of deprivation

This is the narrative of who we are, where we are, how we got here and what we learnt along the way

#### 2: I represent a team















#### 3-Teesside is so much more than deprivation statistics





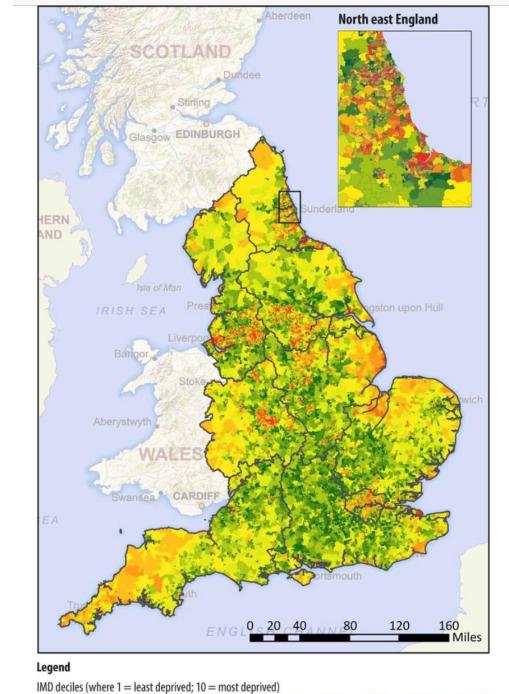






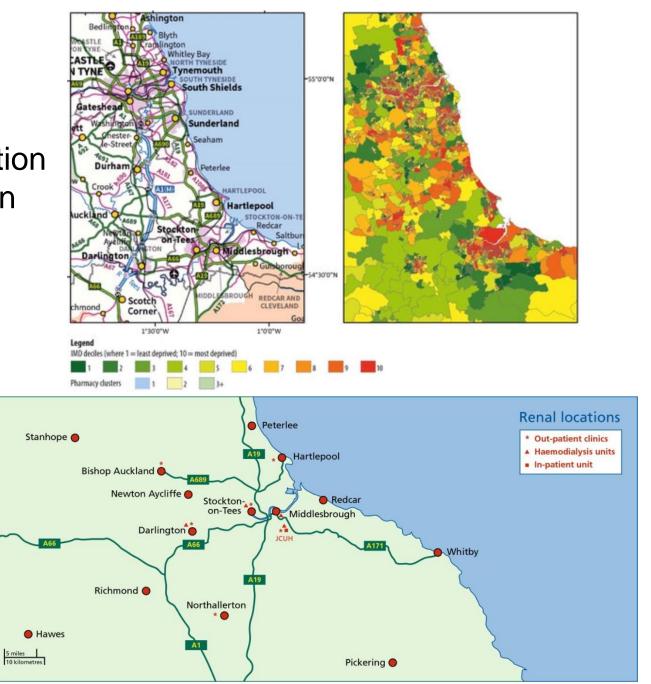


# Teesside –facts and figures

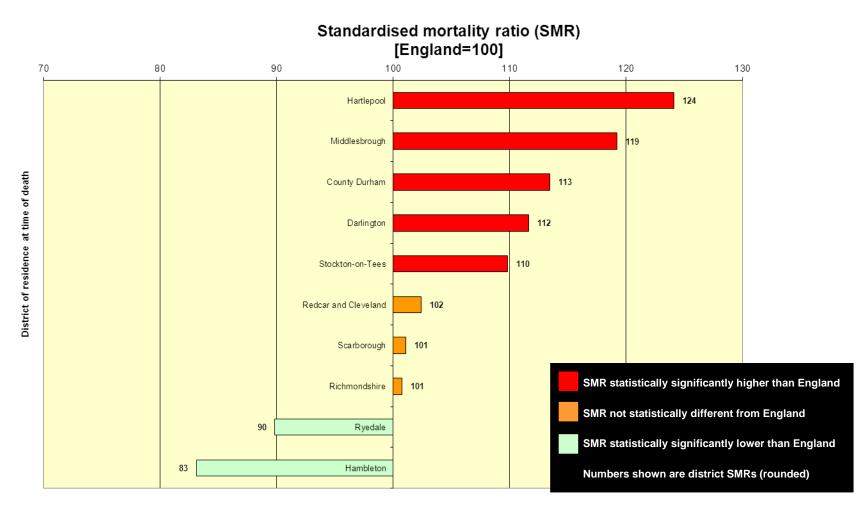


Indices of Multiple deprivation 2018 PHE

### RRT population 1 Million



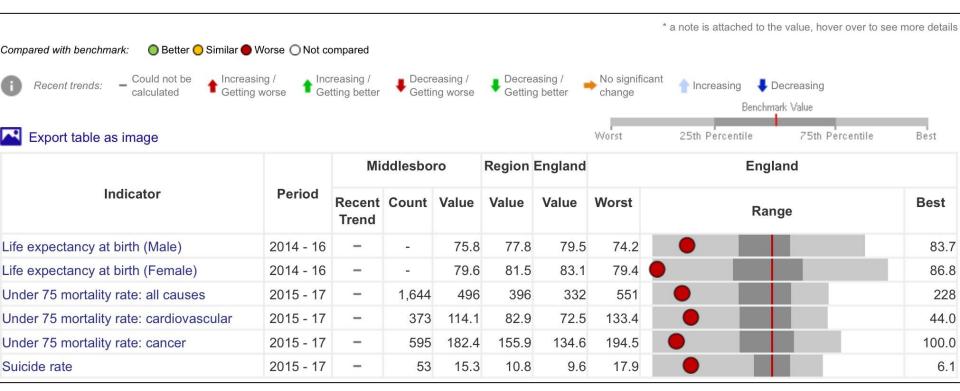
#### Mortality from all causes, males, all ages, 2008-2010



#### Mortality from all causes, females, all ages, 2008-2010



#### PHE data for Middlesbrough ward 2015-17



#### **Dramatic local variation**





Stockton-on-Tees is the town the biggest gap in life expectancy, those living in the wealthier areas can expect to live 18 years longer that those in the more deprived parts of town

#### **Ethnicity**

The UK Renal Registry

The Sixteenth Annual Report

of 15

Table 6.1. Percentage of incident RRT patients (2003-2012) in different ethnic groups by centre

	Percentage in each ethnic group					- N with	%
Centre	White	Asian	Black	Chinese	Other	data	completeness
Leeds	82.4	12.7	3.8	0.1	1.0	1,388	89.3
Leic	80.0	15.7	3.0	0.3	1.0	2,213	98.3
Liv Ain	95.7	1.4	0.7	1.4	0.7	277	78.3
Liv RI	93.3	1.2	1.6	1.7	2.3	1,018	87.6
M RI	77.0	11.9	8.0	0.9	2.3	890	98.0
Middlbr	95.9	3.7	0.2	0.2	0.0	979	97.1
Newc	93.8	4.2	0.6	0.4	1.1	1,009	99.2
Norwch	95.8	0.8	0.3	2.5	0.6	649	77.6
Nottm	89.2	4.9	4.7	0.0	1.3	1,202	99.9
Oxford	85.6	7.5	4.0	0.6	2.2	1,570	96.6

#### Literacy

- 1 in 100 UK are illiterate
- 15% UK adults (of working age 16-65) functionally illiterate
- 17% Middlesbrough adults functionally illiterate
- 45% UK adults don't have the literacy skills they need to understand and make use of everyday health information ??Middlesbrough
- Low health literacy is associated with a 75% increase risk of early death

#### **Teesside Summary**

- High levels of deprivation
- Poor health outcomes
- Low ethnic diversity
- But wide variation across the catchment population for both of the above
- Lower than average levels of literacy
- Highest level of preschool obesity in England

So we would expect lower levels of LKD transplantation ...?

#### Teesside –the Living Kidney Donor Service

#### Teesside LKD service

- 2011 £3K Kidney care timely listing grant
- Need for LKD pathway identified:
  - Standardise donor work up
  - Improve length of work up time
  - Improve the number of donors completing the pathway
  - reduce time taken to work up donors
  - Give all recipients the same opportunities for living donation

### LKD pathway 2012

#### Initial Contact

- Telephone interview
- send out health questionnaire and information pack
- Arrange appointment for initial visit

nitial Visit

- Initial blood tests and health check
- Opportunity to ask questions and meet with Specialist nurse
- Book second visit

Second Visit

- Check the donor kidney is suitable for the intended recipient by 'Cross match'
- Book appointment for Specialist Nurse assessment

Specialist Nurse ssessmen

- 2 hour appointment with discussion about the risks and benefits of kidney donation
- Bloods, virology, CXR, ECG

One Stop clinic

- All day appointment with Physician Medical assessment and imaging of kidney structure and function (Nuclear Physics and CT appointments).
- Further opportunity to discuss the risks and benefits of donation specific to the individual donor

Freeman Hospital

- Refer to local transplant centre
- Out patient clinic with anaesthetic assessment

Presurgery

- Independent Assessment from a Human Tissue authority representative
- Final blood tests

Freeman Hospital • Transplant Surgery

Follow up

- Outpatient visit at 6-8 weeks
- Life long monitoring discussed, care handed back to GP for annual follow up on CKD register

Offer of 1:1 conversation with previous donor 2012

Invitation to bi-annual open day 2013/14

#### 1st year outcomes from new LKD

1/3 reduction in waiting time to complete work up

50% reduction in the number of donor hospital visits

Survey at end of first year:

- Good donor feedback (76% rated their experience of donor work up as excellent)
- 96% felt they had enough time and understanding of the process and information given during the appointments

"Easier for me to get one day off rather than several half days"

"Less time off work and a smoother process"



### **Teesside LKD service-impact on number of LKD transplants**

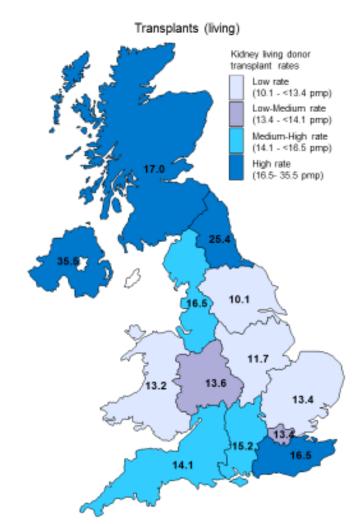
Year	LKDT rate pmp	% pre-emptive LKD's	% LKDT of total activity
2012	16	50%	34%
2013	16	13%	35%
2014	25	56%	53%
2015	19	47%	41%
2016	19	63%	38%
2017	24	24%	53%
2018	20	45%	53%



Figure 2.7 Living donor kidney transplant rates (pmp) by recipient country/Strategic Health Authority of residence

SHA data shows contribution of all renal units

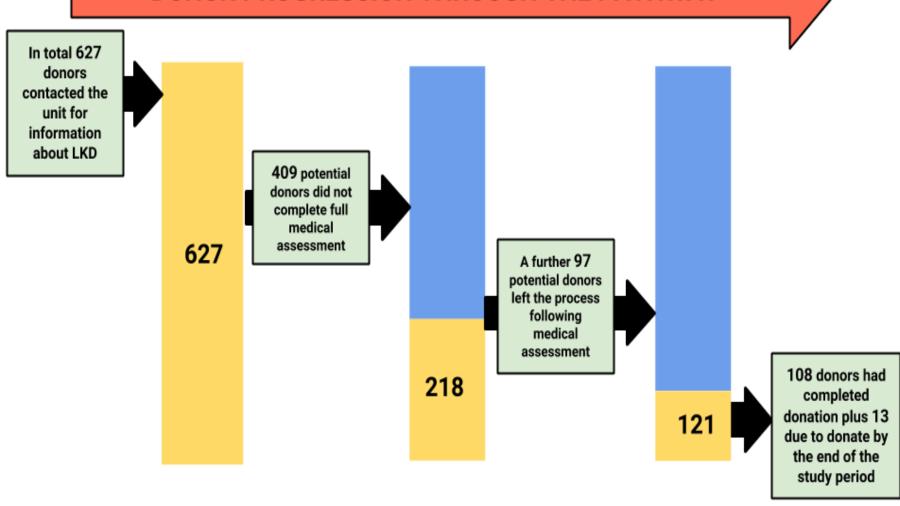
FRH, 30pmp JCUH 24pmp SRH 25pmp



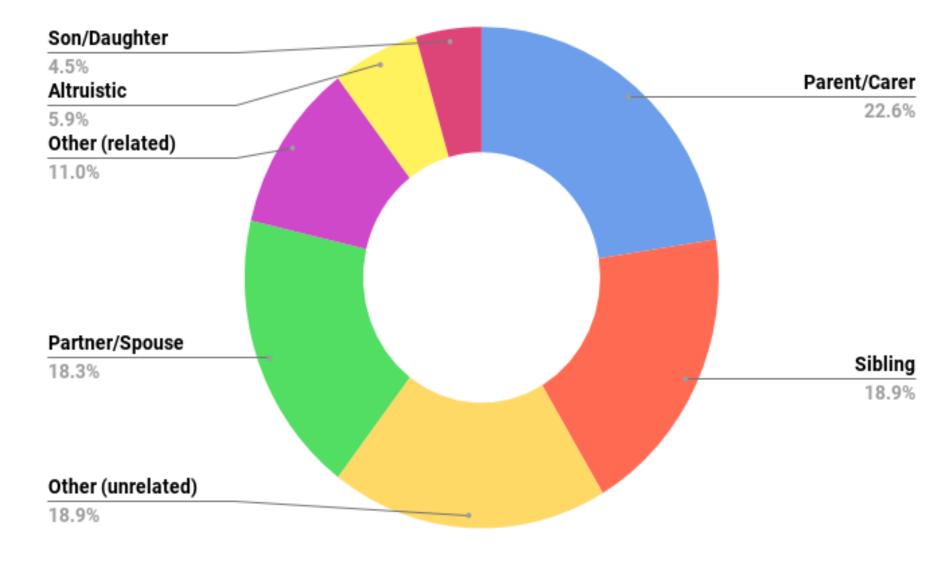
#### Teesside LKD prospective study

- Data collected prospectively between
   01/01/12 31/12/17 on all potential donors:
  - Relationship of donor to recipient
  - Progression through the pathway for each donor from initial enquiry to tissue typing, specialist nurse assessment, medical review, surgical review and donation
  - Reasons for not progressing through each step of the pathway

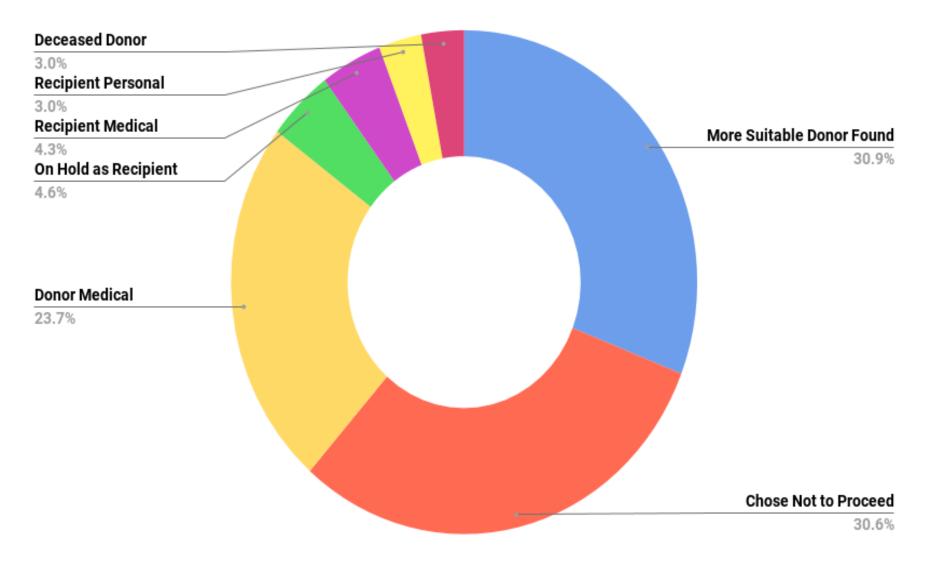
#### DONOR PROGRESSION THROUGH THE PATHWAY



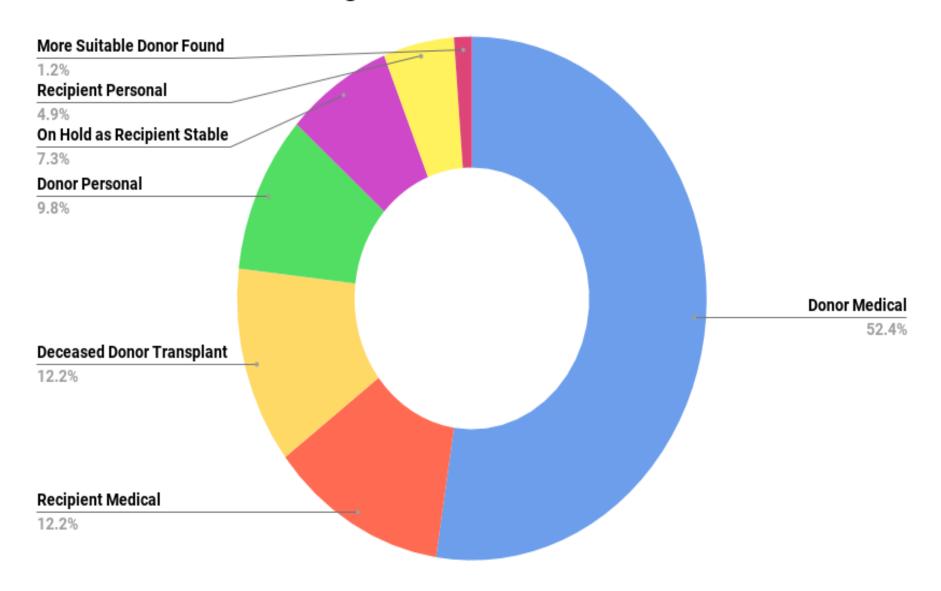
#### Relationship of Potential Donor to Recipient



#### Reasons For Withdrawal Prior to Medical Assessment

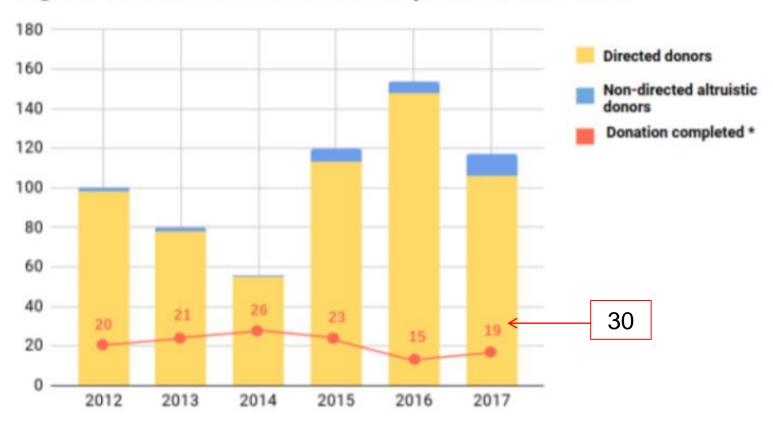


#### Reasons For Withdrawing After Medical Assessment



#### Outcomes of Teesside LKD service

Figure 1: Number of Donor Enquiries Each Year

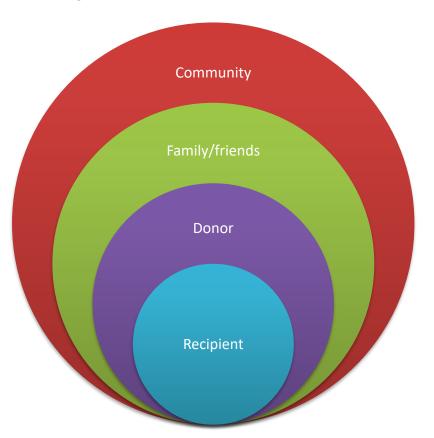


<sup>\*</sup> does not include sharing scheme patients or those waiting to donate

# Teesside –overcoming barriers to Living Kidney Donation

#### Addressing health literacy

- Cultivate your community
- Educate the recipients family and friends
- Empower your donor
- Entitle your recipient
- Learn from the council



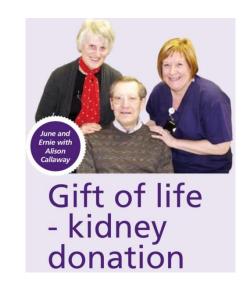






One-stop clinic for living kidney donation launched in Middlesbrough

Posted on 16th July 2012 in Hospitals, Services



Tell stories-they are powerful 'My friends Dad donated-he's OK'

#### Include meaningful others in conversations Living donation is a team sport

**Family Friends** 



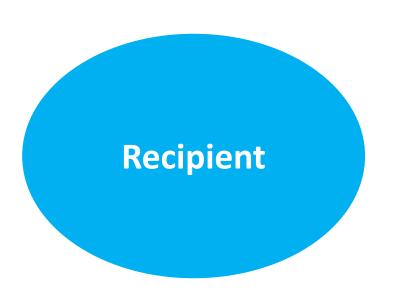


- Clear and simple process
- Do not rely on written information
- Listen and modify your language
- Build in peer review



Had I the heavens' embroidered cloths,
Enwrought with golden and silver light, The blue
and the dim and the dark cloths Of night and
light and the half-light, I would spread the
cloths under your feet: But I, being poor, have
only my dreams; I have spread my dreams under
your feet; Tread softly because you tread on my
dreams.

(William Butler Yeats)



- Early conversations-relationship led
- Be open about potential negative responses
- Create space to tease out self worth and guilt
- Peer support
- Don't write off LKD at the first failure



Peer review

all invited if GFR<15 café style lunch included

#### Special considerations

- Single parent family
- Low income families
- Lifestyle choices not compatible with long term health
- Previous or current drug use
- Mental health
- Protein intake and testosterone supplements

#### **Conclusions**

We can all take steps to tackle the barriers of poverty and health literacy for living donors

We are all experts in your own localitieswhat works for your population and what can you learn from your local council?



#### Next steps-work in localities

- Fingertips.phe.org.uk
  - Choose your area, understand local demographics

#### Group discussion:

