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-Teeside is so much more than deprivation statistics
Teesside – facts and figures
RRT population 1 Million
Mortality from all causes, males, all ages, 2008-2010

Standardised mortality ratio (SMR) [England=100]

- Hartlepool: 124
- Middlesbrough: 119
- County Durham: 113
- Darlington: 112
- Stockton-on-Tees: 110
- Redcar and Cleveland: 102
- Scarborough: 101
- Richmondshire: 101
- Ryedale: 90
- Hambleton: 83

Numbers shown are district SMRs (rounded)

SMR statistically significantly higher than England
SMR not statistically different from England
SMR statistically significantly lower than England
SMR statistically significantly higher than England
SMR statistically significantly lower than England
SMR not statistically different from England
Numbers shown are district SMRs (rounded)
PHE data for Middlesbrough ward 2015-17

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Middlesbrough</th>
<th>Region England</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy at birth (Male)</td>
<td>2014-16</td>
<td>-</td>
<td>75.8</td>
<td>74.2</td>
</tr>
<tr>
<td>Life expectancy at birth (Female)</td>
<td>2014-16</td>
<td>-</td>
<td>79.6</td>
<td>79.4</td>
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<tr>
<td>Under 75 mortality rate: all causes</td>
<td>2015-17</td>
<td>1,644</td>
<td>496</td>
<td>551</td>
</tr>
<tr>
<td>Under 75 mortality rate: cardiovascular</td>
<td>2015-17</td>
<td>373</td>
<td>114.1</td>
<td>133.4</td>
</tr>
<tr>
<td>Under 75 mortality rate: cancer</td>
<td>2015-17</td>
<td>595</td>
<td>182.4</td>
<td>194.5</td>
</tr>
<tr>
<td>Suicide rate</td>
<td>2015-17</td>
<td>53</td>
<td>15.3</td>
<td>17.9</td>
</tr>
</tbody>
</table>
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

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

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

LiteracyTrust.org.uk-Literacy and life expectancy report Feb 2018
Middlesbrough Reads, Health Literacy Trust, 2017
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

Initial 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 assessment
- 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
- Outpatient clinic with anaesthetic assessment

Pre-surgery
- 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

<table>
<thead>
<tr>
<th>Year</th>
<th>LKDT rate pmp</th>
<th>% pre-emptive LKD’s</th>
<th>% LKDT of total activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>16</td>
<td>50%</td>
<td>34%</td>
</tr>
<tr>
<td>2013</td>
<td>16</td>
<td>13%</td>
<td>35%</td>
</tr>
<tr>
<td>2014</td>
<td>25</td>
<td>56%</td>
<td>53%</td>
</tr>
<tr>
<td>2015</td>
<td>19</td>
<td>47%</td>
<td>41%</td>
</tr>
<tr>
<td>2016</td>
<td>19</td>
<td>63%</td>
<td>38%</td>
</tr>
<tr>
<td>2017</td>
<td>24</td>
<td>24%</td>
<td>53%</td>
</tr>
<tr>
<td>2018</td>
<td>20</td>
<td>45%</td>
<td>53%</td>
</tr>
</tbody>
</table>
SHA data shows contribution of all renal units:

- FRH: 30pmp
- JCUH: 24pmp
- SRH: 25pmp

Source: Annual Report on Kidney Transplantation 2017/18, NHS Blood and Transplant
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
In total 627 donors contacted the unit for information about LKD

627

409 potential donors did not complete full medical assessment

218

A further 97 potential donors left the process following medical assessment

121

108 donors had completed donation plus 13 due to donate by the end of the study period
Relationship of Potential Donor to Recipient

- Parent/Carer: 22.6%
- Sibling: 18.9%
- Partner/Spouse: 18.3%
- Other (unrelated): 18.9%
- Other (related): 11.0%
- Altruistic: 5.9%
- Son/Daughter: 4.5%
Reasons For Withdrawal Prior to Medical Assessment

- More Suitable Donor Found: 30.9%
- Chose Not to Proceed: 30.6%
- Donor Medical: 23.7%
- On Hold as Recipient: 4.6%
- Recipient Medical: 4.3%
- Recipient Personal: 3.0%
- Deceased Donor: 3.0%
Reasons For Withdrawing After Medical Assessment

- More Suitable Donor Found: 1.2%
- Recipient Personal: 4.9%
- On Hold as Recipient Stable: 7.3%
- Donor Personal: 9.8%
- Deceased Donor Transplant: 12.2%
- Recipient Medical: 12.2%
- Donor Medical: 52.4%
Outcomes of Teesside LKD service

Figure 1: Number of Donor Enquiries Each Year

* 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
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

Donor

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 localities—what 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: