Yorkshire & the Humber
Transplant Forum

Friday 4th April 2014
Hatfeild Hall, Wakefield, WF 2JP

Feedback Report

1. Background

April 1st 2013 saw the beginning of the new Y&H Strategic Clinical Networks (SCN) & Senate, bringing together the former Cardiac, Stroke and Renal Networks across Yorkshire and the Humber into one cardiovascular disease (CVD) area, also encompassing Diabetes. The pre-existing network area for the Renal Network has been carried forward into the new CVD Strategic Clinical Network structure.

The SCN Core team hosted a series of disease specific "Stakeholder" events. The purpose of these events was to support existing Networks, to engage with new stakeholders and to allow priority areas to be discussed and agreed. The CVD (Renal) Stakeholder event was held on 30th September 2013.

Priorities, previously identified through consultation, are aligned with the nationally agreed priorities

The agreed priority areas for Renal across Yorkshire and the Humber are:

i. Acute Kidney Injury (AKI)
ii. Transplantation
iii. Variation (primary and secondary care)
iv. Previous work areas that required continuation (local determination) and cross-cutting issues

2. Introduction

At the CVD (Renal) Stakeholder event, the transplantation workshops produced a range of feedback covering areas of work that could be looked into (generic and specific) as well as some recommendations to take forward by the Network. There were a number of areas that produced common themes, these included:

- Awareness of Living Donation
- Links to other CVD network areas e.g. Cardiology
- Learning from other Transplantation centres
- Work up for transplantation
- Decision Aids
- Patient experience and involvement

An area that all workshops agreed upon was that of the development of a Transplantation Forum to allow all the above areas to be discussed and agreed. This may then result in Task & Finish groups to take the work forward.

A collated list of the areas discussed in the workshops can be found in **Appendix A.**

3. Feedback from The Transplant Forum

The programme for the event is attached as **Appendix B.**

3.1 Welcome and Introduction

Dr John Stoves, Y&H Renal SCN Clinical Lead & Consultant Nephrologist, Bradford Teaching Hospitals FT, opened the meeting and gave an overview of the profile for Nephrology within a regional CVD Network:

- Promote current and future regional priorities
- Strengthen links with primary care, Clinical Commissioning Groups (CCGs) and sub-regional Collaborative Commissioning Groups – SYCOM, NEYCOM, 10CC
- Liaise with renal units, National Clinical Director, other SCN renal leads, specialty leads (cardiac, diabetes, stroke), Clinical Reference Group (CRG) leads
- Involve patients and patient representatives
- Summarise care quality indicators – Public Health England, Quality Outcome Framework, Renal Registry/HES, Service Specifications (best practice, current initiatives, barriers to change)
- Structure - Renal Strategy Group, Renal Clinical Expert Group, Local Implementation Groups, CVD Strategy Groups, MDT regional forums (AKI, transplant, home therapies and shared care, conservative care)
- Support from the Clinical Senate and Allied Health Sciences Network (AHSN) – implementing NICE guidance in primary care

Dr Stoves re-iterated that access to renal transplantation is a key renal priority for Yorkshire & the Humber and highlighted three specific first topics in relation to renal transplant:

- Making the link between the NBTA and local communities and Transplant 2020 http://www.nhsbt.nhs.uk/to2020/resources/nhsbt_organ_donor_strategy_summary.pdf
- Harmonisation of living donor and recipient work-up pathways
- Timely listing for renal transplantation

3.2 Promoting Organ Donation in Black, Asian and Minority Ethnic (BAME) Communities

3.2.1 The role of the National BAME Transplant Alliance

Mr Kirit Modi, Chairman of the National Kidney Federation and Co-Chair of the National Black, Asian & Ethnic Minority Transplant Alliance (NBTA), had a pre-emptive transplant in 2001 following kidney problems linked to high blood pressure. His wife, Meena was the transplant donor.

He shared information about the work of the NBTA and provided some statistics on BAME transplants, donors and consent rates. Consent rates remain low, around 30% for BAME (around 60% for White). Indian and mixed race registrations on the Organ Donor Register have increased but Black, Pakistani, Bangladeshi and African numbers have not.

Mr Modi spoke of the work that NBTA have done, the organisations, foundations and forums that make up the NBTA, supported initiatives, BAME media and celebrity sponsors.

He said that it is important to have someone to talk about the religious aspect, to look at communities and census data to get ethnic and, importantly, religious profiles of areas and to identify outreach workers from BAME backgrounds, to be supported by volunteers. Additionally, there is a need for more Clinical Leads for Organ Donation (CLOD) and Senior Nurses for Organ Donation (SNOD) from BAME backgrounds.

Mr Modi's presentation generated group discussion and prompted a number of questions:

Q. What is the Organ Donor Transplant consent rate for BAME?
A. 3%. We need to monitor any increase in consent rates and make sure that all registered consent (eg through Boots card or DVLA) is captured.

Q. What about the 'Opt Out' approach eg as in Wales?
A. It was found that Christian and Muslim communities were against Opt Out initially but now that the Act is passed the view is changing. People have to make a conscious decision to be 'in' or 'out'. Also, sometimes there is disparity between what community leaders say and what the community feels.

It was noted that opt-out starts in 2015 and that NKF supports opt-out.

Q. The refusal rate from BAME communities is high but what is the approach rate?
A. The approach rate by SNODs/CLODs for BAME communities is the same as for White communities – the conversations are taking place but the BAME refusal rate is higher. Sometimes religion is used as the excuse when there are other reasons for refusal. It is a complex issue.

Q. Have you achieved sustainability in Watford?
A. No, this is a challenge. Funding is an issue. If you ask NHS BT if there is funding, the answer is likely to be 'No'. However, if you approach with a project, there is more chance of a 'Yes'.

Mr Modi extended an invitation to attend NBTA meetings to anyone interested. Dr Stoves suggested that, to link with Mr Modi's presentation, some patients should be invited to speak at future forums to raise the profile.

3.2.2 Linkage to local initiatives and the patient perspective

Mohammed Islam, Chair of Bradford & Airedale Kidney Association spoke of his shock when receiving a diagnosis of kidney disease and also of his shock to learn of the long wait for transplant; he recognised this was because of a lack of donors. He was asked by Bradford Teaching Hospitals to become a patient leader whilst waiting for dialysis. He attended a patient leadership course and, ultimately, set up the Bradford & Airedale Kidney Association group. He wanted to empower himself and take control of his 'disability'. Whilst 'endless leaflets' are available he wanted to get patient to patient advice, to support people to take charge of their care and give patients a voice.

This group is now up and running and he is proud of his involvement.

He made a number of suggestions:

- Perseverance and persistence are essential
- Promotion of a patient representative to champion transplantation in areas where there is a low response to organ donation
- Some ethics to be considered but these need challenging. What are the ethics of doing nothing? What about the patient's right to life?
- Joint effort to consider a model - the right approach, patients and family together
- The 2020 strategy is the right approach and has the right aim.

Some questions were put to Mr Islam:

Q: What about sustainability?
A: All too often, things are spoken about once but then nothing further happens. There are lot of elements and some ethics to be considered but there is a need to continue the discussions. Take small steps and accept them but continue to keep at it. A change in attitude is required.

Q: You seem to take quite a blunt approach – how do people react to that? We, as doctors, are often frightened to do that.
A: Use outreach workers, let them come to clinics to tell their stories and answer questions - getting a patient's perspectives, their experiences and their mixed feelings.
Comment: Feel that it's true – what it's like as a patient from a patient is more powerful than what a clinician thinks it's like for a patient.
Comment: Liver clinics do invite transplant patients to the clinic to talk to potential patients.

3.2.3 Mr Mohammed Rafique Butt

Mr Butt spoke about his campaign in Bradford to raise the profile of the need for transplant donors. He is supported by a friend who helps with media releases. He shared his views and experiences as a renal transplant patient, following 4 years as a dialysis patient.

Mr Butt feels that everyone wants to get away from their problems. Some have more and some have less but all need to live this life and someone who has died can help people to live their lives. It is important to have good relations with people in life but also help in death.

He feels that religion is used as an excuse not to register as a transplant donor. Low donor rates plus limited availability of organs because of tissue types mean BAME patients wait longer. The Bradford campaign aims to stop suffering for Asian people.

3.3 Harmonisation of the living donor and recipient work-up pathways

Dr Richard Baker, Consultant Nephrologist, St James's University Hospital, Leeds, presented data on Living Donation in Yorkshire, which is in the lowest group for transplants. Other areas such as Newcastle and Guy's & St Thomas's do much better. His presentation gave information about the development of pathways in Leeds since 2011 and the successes achieved, acknowledging the work of Dr Chas Newstead.

He outlined the work of the team at Guy's & St Thomas's and what works:

- A positive attitude to living kidney donation
- Patient information material ('Gift of Live DVD www.transplant.org.uk)
- Patient and potential donor information meetings
- Peer support
- Alternative donation programmes

Dr Baker compared the historical approach with a new approach and highlighted some ideas to take this forward:

For information:
- DVD
- Transplant champions
- Web based presence
- Workshops
- Meeting patients at Support Evenings
- Family involvement (as per Norway) and consent clinics
- Target BAME community

For doctors:
- Positive approach
- Early referral
- Recognition of ABO Incompatible (ABOi) /HLA Incompatible (HLAi) Renal Transplantation, Paired Exchange programme

For the process:
- Streamline the pathway
- Separate primary care based altruistic pathway

A number of questions were asked:

Q. How are you going to get a national figure if you have different processes throughout the country?
A. There is a need to streamline resources. This is not about operating capacity. A new approach is needed - look at Guy's as an example. I like the idea of transplant champion.
Comment: Champion donors are needed as well as champion recipients

Q. I feel that we are more cautious than Guy's. They will transplant more patients than we do but I would defend our practice. There is long term uncertainty about the ultimate health of a kidney donor.
A. First protection is the health of the donor and some donors are patients on hypertensive medication, which we would not do. Three donors have ended up on dialysis.

Q. How long does work up process take? There is great variation around the country.
A. This needs to be quick. Currently it takes about 12 weeks but this could be done in 6 weeks. The Government says it is to be done in 18 weeks.
Comment: Consideration needs to be given to the healthy donors. The time of work can be problematic and it would be helpful if test could be completed in one day. Evening clinics would also be beneficial.

Q. There are currently around 1000 living donors per year. What about cadaveric donors? Where are we internationally?

A. About 2/3 of the way down the list. But DCD (Donation after Cardiac Death) is illegal in Germany and Croatia.
Comment: We may now be about half way up the list.

Discussion followed around live donor recipients and the transplant waiting list, when to take patients off the transplant list and what impact this has on live donation. 1 in 8 patients receive a cadaveric donation whilst a donor is being worked up. It was agreed that a step in the process should be agreed at which point the patient is removed from the transplant list. There needs to be conversations with the patient and a caveat that if there is a delay then the patient is re-activated on the list. For those using the BHLY system it is possible to print out a list of those suspended from the list, this can then be reviewed by the MDT on a regular basis.

3.4 Timely Listing for Transplantation

The presentation by Dr Mansoor Ali and Sister Claire Burton outlined the work of the Bradford Teaching Hospitals Transplant team with the renal transplantation project from October 2011 to March 2012, outlining the background to the project as a participating centre in NHS Kidney Care Timely Listing for Kidney Transplantation Project and subsequent work. This included timely initiation and streamlining of the transplant assessment pathway - 'getting started' and 'getting finished', standardisation of activities by health professionals and sustainability.

The global burden of end stage renal disease is increasing. The UK renal registry from 2009 estimated that over 47 000 people received renal replacement therapy in the UK and a recent UK estimate found that transplantation conferred a cost saving of £25 000 a year per patient with end stage renal failure.

Renal transplantation increases patient survival and quality of life and reduces costs of care for patients with end stage renal disease. Donations from living donors are increasing and pre-emptive transplantation from a living donor is the best treatment choice for patients with end stage renal disease and has been associated with improved allograft and patient survival.

In the UK rates of renal transplantation are increasing and since 2006 the number of patients waiting more than five years for a transplant has halved, but there is still a large number (about 7000) of patients on the transplant waiting list. Long term outcomes in kidney transplantation are improving.

Discussion followed about numerous issues and considerations. It was recognised that an agreed metric for pre-emptive transplant was needed and that this should be region-wide. Patient choice also needs to be considered as some patients with single figure GFR do not choose to go on dialysis or for transplant. Also, where no transplant coordinator, psychologist or social worker is in post this might impact on numbers on a transplant list.

A number of questions were put to the Bradford team and others:

Q. No one thing is going to make a difference. What is the one that has made the most impact?
A. Dental health and adherence to the national screening programme. Making small changes at the beginning of the process has gained time.

Q. Do all units use the Newcastle score for assessing patients' suitability for transplant?

A. There was a mixed response. This is a broad marker but not validated, for example, smoking status is not included. It can be useful as a lever to persuade patients.

Q. What about the issue of weight?
A. Evidence is that, as BMI goes up, there are poorer outcomes. But there is no threshold for BMI so it is not a perfect measure. Leeds has said 35, Manchester now uses 40. A threshold is required but it has to be transparent.
Comment: Patients need to know so that they know the targets. At present it may depend on the unit or even the consultant.
Comment: There is a need to review patients who have been on the transplant list for some time, as there have been cases where patients have gained weight since listing.
Comment: There seems no point in transplanting someone who, as an obese person, will not be healthy. I feel that transplant should be an incentive to lose weight.
Comment: Weight loss is a problem for patients who are on insulin. Leeds is now considering BMI 35-40.

Q. How successful has weight reduction clinic been?
A. This has not been working long enough to be able to measure the impact. We are liaising with psychologists and dietitians and badging it as a pathway rather than a weight reduction clinic. We have installed static bikes but these do not seem to have been that effective.

Q. York does a lot of exercise programmes – what is the purpose of these and what is the aim – weight loss or fitness?
A. Renal physiotherapy requires opt in from patients but covers all aspects of nephrology and the benefit to patients has been demonstrated. York has a strong patient voice. The renal physio would be happy to share.
Comment: I have found it good but not all patients do.
Comment: There is disparity across the region because there is no renal physio within some units.
Comment: Bradford had an initiative on the Diabetes Unit, with a community nurse working around the community, talking to groups of 25 people to inform/instruct on weight management, lifestyle and exercise. Peer support is great and also snowballs – members then take up as volunteers to lead walks etc. There are organised visits to markets (local, Asian) to look at foods and labelling to educate people. There are different needs and different models but some of the good ideas should be shared nationally on a national platform to save re-inventing the wheel.

Q. How is the York exercise programme funded?
A. Initially there was charitable funding and a BRS grant. The team was then able to show improvement in quality, particularly in relation to shortness of breath and quality of life.

3.5 Group Discussion:

The presentations generated much discussion (as outlined above) and further discussion ensued about future meetings. A number of suggestions were made including:

- Harmonisation of pathways (suggested speaker)
- MDTs to discuss complexities - red list, primary care, currencies and tariff

- Sustaining the role of young adult worker
- Transplant service specification
- Case reviews
- Telephone clinics
- Feedback from national meetings (eg 3rd National Transplant & Carers' meeting).
- Invitation to delegates (including patients) to lead on a topic at the future meetings

It was, however, suggested that Transplant Forum meetings were not an appropriate venue to discuss medical issues.

It was noted that the West Yorkshire Police & Crime Commissioner has launched a fund for potential community projects. Further information is available on the website: http://www.westyorkshire-pcc.gov.uk/safer-communities-fund.aspx

3.6 Closing Remarks & Evaluation

Dr Stoves summarised the meeting:

- Need to sustain all the suggestions made this morning and support them strongly.
- Involve patients in decision making and in the pathway – patient educators.
- Harmonisation of the live donor pathway – Newcastle and Guy's models. More direct approaches to the family to make a difference.
- Exercise programmes – sharing ideas.
- Pathway effectiveness – can we use a metric or is it enough to talk and share and take things away and let them develop in our own teams? Do we want measurable and tangible? Maybe just start with one – suggestion is the metric for timely listing. Is that a useful measure?
- Start with something soft – look at the number of people coming through the living donor pathway.
- The Bradford, Hull, Leeds & York shared data system (BHLY) would produce a complete list of patient status when a date is entered.

3.7 Next Steps

- Maintaining momentum as a regional group
    - Transplant Forum in October
    - Clinical and patient champions from each centre
    - Exploring the full range of relevant topics
- Longitudinal metrics

3.8 Evaluation

The Evaluation forms have been analysed and a brief summary produced. This can be found in **Appendix C**.

Transplantation Areas to explore – From Group Discussions on 30.09.13

- Development of a Forum, to oversee/direct pieces of work covering for example best practice, referral pathways, work up, aftercare
- Awareness of Living Donation – earlier identification e.g. GFr 20% - commencement of earlier thinking/planning ahead
- Will National service specifications affect delivery of the service in Y&H – Need commissioner views
- Lack of evidence for transplant work up – cardiac work up, variation in centres re required work up / suitability. Cardiology tests done in parallel to other tests like urology. Statements and principals
- Potential exists between the transplant and non transplant units for development
- Co-morbidities affect who is eligible for pathways (links to work up)
- Really important to keep the patient in the loop when they have been listed
- Links to CVD network essential where crossover happens (cardiac)
- Live donor pathway could be speeded up if it didn't just happen in centres
- Get transplant co-ordinators to visit other units to help with education
- Could delays in the system be removed if it decentralized? Better for live donors to have work up closer to home, may improve numbers wishing to donate
- Transplant donors are flagged so results are a priority within the trust
- Where donor kidneys are declined (border line) in one trust then accepted in another MDT meetings between the 2 to discuss outcomes
- Specialised commissioning for work up but cardiology assessment would be CCG commissioned???
- Work up a quick win – easier than AKI, could demonstrate improvement within a couple of years
- How did Guy's become successful? What can be learnt from them?
- Awareness – help identify what factors assist across region, where skills are? List of contacts, directory
- Highlight best/good practice
- Education
- Better access to kidney related information for primary care
- Access to better psychology support – link to other conditions
- Access to survivorship programmes
- Monitor quality of services/outcomes across region through dashboard info. QOL/Patient related outcomes
- Decision Aids tool needed
- Survey of attitudes towards donation, what influences decision
- Non face to face consultation – tariff is the discentive
- Are some places transplanting where there is higher level of function GFR 20% - lower work up threshold

- Pooled donors – operations to remove kidney synchronised operations, kidneys transferred at same time, needs to be well organised
- All patients who have had a transplant are followed up for life on NHS
- Discuss live donor early in pathway, survival rates better for living donation
- Encourage cultural shift where patient is encourages to transplant early – timing issue here to be considered.
- Y&H 2 years ago bottom of list for living donor rates, need to learn from other areas
- Need to collect local data – set improvement trajectory, might want to look at CCG level rather than unit level
- Discrepancy in pathway AND in funding currencies difference between non transplanting centre and transplanting centre – no incentive for non transplanting centres to do work ups – rates lower in referral in non transplant centres?
- Patients getting stuck between centres
- Medicines management and follow up
- At what point is patient voice heard?
- Link into advocacy team (Linda) re new draft guidelines for dialysis away from home
- Look into Hulls work on transition to young adults
- Shared care programme – Harrogate self care unit

APPENDIX B

Yorkshire and the Humber Strategic Clinical Networks

Yorkshire & the Humber Kidney Transplant Forum

Friday 4th April 2014
0930-1300

Hatfield Hall - Aberford Road - Stanley - Wakefield - WF3 4JP

A G E N D A
(Lunch & Networking Opportunities from 1300 onwards)

0900	**Coffee & Registration**
0930	**Introduction & Welcome** Dr John Stoves Renal Clinical Lead, Yorkshire and the Humber Strategic Clinical Network
0940	**Promoting Organ Donation in Black, Asian and Minority Ethnic (BAME) Communities** **The role of the National BAME Transplant Alliance** Mr Kirit Modi Chairman of the National Kidney Federation **Linkage to local initiatives and the patient perspective** Mohammed Islam Chairman, Bradford and Airedale Kidney Patients Association
1030	**Harmonisation of the living donor and recipient work-up pathways** Dr Richard Baker Consultant Nephrologist, St James's University Hospital, Leeds
1120	**Tea & Coffee**
1135	**Timely Listing for Transplantation** Dr Mansoor Ali and Sister Claire Burton Bradford Teaching Hospitals NHS Foundation Trust
1215	**Group Discussion:** - Further actions - Proposals for future meetings
1245	**Closing Remarks & Evaluation** Dr John Stoves Renal Clinical Lead, Yorkshire and the Humber Strategic Clinical Network
1300	**Meeting Close – Lunch Available**
PLEASE RETURN COMPLETED EVALUATION FORMS!	

NHS England

Yorkshire and the Humber Strategic Clinical Networks

Yorkshire & the Humber Kidney Transplant Forum: 04.04.14
Hatfeild Hall, Normanton – EVALUATION

RESPONSES (30 OUT OF 37 ATTENDEES)

1. How would you rate the content of the sessions?

Session Title	Excellent	Good	Average	Fair	Poor	No Response
Welcome & Introduction – Dr John Stoves	13	15				2
Promoting Organ Donation in Black, Asian and Ethnic Minority (BAME) Communities: **The Role of the National BAME Transplant Alliance** – Mr Kirit Modi, Chairman of the National Kidney Federation	23	6				1
Linkage to local initiatives and the patient perspective – Mohammed Islam, Chairman, Bradford & Airedale Kidney Patients' Association	22	7	1			
Harmonisation of the living donor and recipient work-up pathways – Dr Richard Baker, Consultant Nephrologist, St James's University Hospital, Leeds	21	9				
Timely Listing for Transplantation – Dr Mansoor Ali & Sister Claire Burton, Bradford Teaching Hospitals NHS FT	16	12	2			

Group Discussion – Further actions and proposals for future meetings	12	13				5
Closing Remarks & Evaluation	15	11				4

Please comment:

- Patient input is essential; liked how people were welcome to comment throughout – and did.
- Good opportunity to benchmark and to maintain contacts to share what works well.
- Enjoyed discussing our local issues and relating to other centres.
- Good update on work done elsewhere. Sharing experiences was good; suggestions from patient representatives were good.
- Excellent agenda.
- Useful, informative and constructive.
- Interested in what SMART outcomes derive from this forum. Perhaps consider an e-learning module as a way to promote live donor details to support CD. E-learning can be updated.
- Found it all very informative and interesting.

2. Overall how would you rate the methods used?

Tick as applicable	Excellent	Good	Average	Fair	Poor	No Response
Presentations	15	15				
Opportunity for Questions & Answers	13	14				3
Networking Opportunities	16	14				

Please comment:

- Very helpful.
- Good presentation and interaction from all.

- Work closer as a region. It looks like Dr Stoves is going to make a very good clinical lead!
- Very helpful for progressing the issues.
- List of participants be made available.
- Enjoyed the networking, particularly with local centres to us, with similar issues.
- The patients' presentations were quite motivating.
- Well balanced; mixture of professionals and patients.
- Some slides difficult to read (small fonts); couldn't always hear everybody.

	Excellent	Good	Average	Fair	Poor	No Response
3. How would you rate the overall organisation of the Forum?	22	8				

4. How would you rate the venue and facilities?

Tick as applicable	Excellent	Good	Average	Fair	Poor	No Response
Venue	22	7	1			
Catering	10	5	2		1	12
Access	21	8				1
Car parking	24	5				1

	Definitely	Probably	Unsure	Probably Not	Definitely Not	No Response
5. Would you attend another Forum?	21	9				

Please comment:

- Very informative.
- Get more knowledge and awareness about kidney transplant.
- Very interesting and informative.
- Networking.(x 2)
- We wish to use the contents to organise our campaign in Bradford.
- As a patient. I am interested to help in whatever way I can to improve the patient quality of life.
- Patient – willing to help.
- Good to share ideas and get ideas for service development.
- Informative, good for networking and feedback to CCGs.
- Opportunity to learn and share experiences, and for networking.
- Good opportunity to network and learn about what is happening around the region.

6. Do you have any suggestions for the content and format of the next Forum?

- Format – continue to involve expert patients.
- Impact of implementation of strategies discussed today on donor/transplant numbers; management of altruistic, pool, ABOi and HLAi
- Work e-mail; issues on which patient group can contribute; compliance.
- Recipient pathways; pre-transplant surgical reviews; review outcomes and aim for each centre to benefit from good practice, ideas from centres with improved performance.
- BHLY*(Bradford, Hull, Leeds & York data system)*, SystmOne *(primary care data system)* and MDTs *(Multi-Disciplinary Teams)*
- Audit presentation opportunities.
- Marginal and altruistic donors; waiting list review; compliance.
- Annual consent/ recipient workup; transplant work up in general. Audit of Newcastle scores and outcomes.
- Role of primary care in transplantation issues.
- BHLY & MDT Forum; repatriation of medicines.
- Good to share ideas / get ideas for service development.

- Very relaxed.
- More patient views; review of NHS England service specification.
- Telephone clinics – not currently used at our centre so it would be interesting to find out more.
- Laboratory updates – explanation re: the red list and explanation of challenge scores; any interesting case studies.
- Follow up this meeting's discussions; anything that has started as a result to improve current systems.
- Open for all communities.
- Service specification; primary care involvement.
- Case reviews; post-transplant care; patient participation.
- Discuss what we talked about in the previous meeting and have we done anything towards the goals or aims that we wanted to achieve.

7. Would you be interested in supporting organisation of a future forum meeting?	**No Response**	**No**	**Yes**	**Email Address:**
	9	5	16	*Contact details provided*

8. About you

Role:	**Admin**	**Carer**	**Dietitian**	**Doctor**	**Nurse**	**Patient**	**Social Worker**	**Other**	**No Response**
	1	2	1	8	8	5	1	8	1

Organisation:	**CSU**	**Hospital**	**NKF**	**University**	**Other**	**No Response**
	1	10	2	1	3	13

Area:	Bradford : Doncaster : Hull & E Yorks : Leeds : Sheffield : York

9. Any other comments:

- Thank you for a very good event.
- Made me think about ways to improve my practice and ways to improve communication methods for difficult to reach groups.
- I am doing my campaign to make a documentary about kidney transplant. I hope that I will succeed.
- Welcome tea and coffee very good; lunch very poor.
- Really found the day insightful and have lots of good ideas to take away and implement in our centre; feel more positive about the programme.
- Thanks for your effort.
- Could be a little shorter as a meeting.
- Really enjoyed attending this helpful forum and I really support my dad with the awareness of donating a kidney. He is doing an amazing job.
- Hopefully see results in stats after the ideas mentioned.
- Really glad to attend this meeting. This is the best way to share our ideas with each other. This meeting should be in Bradford.
- Meeting room extremely cold.
- I could help with community participation, media presentation and co-ordinating patient campaigns.
- Thank you. Please keep up the good work. Use a region metric – something measurable; agree status listing.
- Enjoyable – interesting to see if ideas are put into practice.
- Very pleased with your effort.
- I would like to attend more meetings like this, in the Bradford area.