SUBMISSION BY THE KPA (LGI)
TO SCRUTINY BOARD HEALTH , LEEDS

1. Introduction

1.1 At issue is the way the Leeds Teaching Hospital NHS Trust (LTHT) has planned and provided care for patients with Chronic Kidney Disease (CKD). It has:

- **Reneged on its promises and decisions made by its Board to provide the dialysis unit at the LGI site;**
- **Misled kidney patients, carers and elected members by providing information confirming it was proceeding with the unit – even commissioning the full plans at a cost of £83,000 and engaging the KPAs in visits to look at wards and holding discussions at meetings right up until 2 June 2009 when we were called in and told the unit would not be going ahead;**
- **Continued to <u>not</u> listen to the needs of our patients who are suffering long journeys three times a week for their life saving treatment, making the quality of their lives intolerable;**
- **Presented information about patients wishing to dialyse at the LGI which is fundamentally flawed through its research methodology;**
- **Failed to involve and consult us properly when plans were to be changed;**
- **Failed to meet Department of Health policy 'to bring care closer to patients homes', providing 'Patient Choice' and meeting national standards for renal patients to dialyse within 30 minutes of where they live;**

Our assertion is that the Trust does not approach the care of these patients holistically and within the wider regional context has configured dialysis services in an entirely inappropriate way. The most recent evidence we have in support of this assertion is the letter dated 26th October from the Chief Executive of the Trust to Councillor Mark Dobson. However before examining that letter it will help to consider the advice and guidance from the National Kidney Federation.

2. National Kidney Federation.

2.1 In a paper dated the 29th April 2009 there is a helpful definition of what constitutes a 'patient centred service'. A key section of this report reads as follows: *"Renal services of the future should be centred on the needs of people with established renal failure and designed to facilitate their 'journey of care'. Wherever possible, haemodialysis treatment should be delivered at a time and place convenient for patients, in an environment that is clean, comfortable and conducive to treating them with respect and dignity. It is essential that all stakeholders and particularly patients are consulted at all stages in the development, expansion or any other changes affecting renal services provision."*

2.2 It should be self-evident that a key decision any Trust must make is where to locate a renal unit or satellite. Before a decision is taken there should be a full study of the current and projected population, disease demographics, transport links, ethnic mix etc. Again to quote from the NKF paper, *"A site should not be chosen because it is conveniently available or cheap because of location".*

2.2 The paper continues: *"A main unit should be attached to an acute hospital as this allows the unit easy access to the hospital services and departments that the patients (particularly those with multiple co-morbidities) and renal medicine require. Services should particularly include radiology, cardiology, Diabetology, vascular surgery, critical care and urology".*

2.3 In summary this paper describes what we in Leeds and West Yorkshire do not have. In the catchment area covered by the Leeds Trust only 83 patients are provided for in a main acute hospital, which is 22% of all such patients, by far the lowest in the region. Even in Hull and East Yorkshire, covering a wide urban and rural area their Trust has planned and delivered provision allowing half of their haemodialysis patients to attend the main hospital. The Trust Board itself describes Seacroft as a 'Main Dialysis Unit' – to be used for patients who are not as poorly as those dialysing at SJU but not suitable for dialysis in the satellites and yet Seacroft does not have the service standards required for a main unit which should be located on a main hospital site with a wide range of services available. Clearly Seacroft Hospital does not fit this bill.

2.4 The NKP paper describes what constitutes holistic care, defined as treating the patient not the disease, and lists what patients themselves have identified as essential for their long term care. These include emotional/psychosocial support, drugs management, advice, guidance and information; holiday planning, faith observance facilities, ready access to doctors, and not least transport. Of fundamental importance to these patients is that there should be *"no silos".*

3. LTHT Chief Executive's letter.

3.1 <u>Re Question 1</u>: What was and indeed is, "the longer term plan for the provision of renal services"? It cannot possibly have been to locate the main facility at a location which, whatever its other strengths, is described on the Trust's web site as a hospital which "currently provides an integrated acute and elderly medicine services, predominantly serving the eastern half of Leeds". For those not intimately aware of the hospital it is instructive to read more on the official web page. The hospital was "originally opened in 1904 as an infectious diseases hospital for the city. This early history explains the vast size of the site and its rather curious layout, with wards located well away from each other".

3.1.1 In the Business Case for creating a facility at the LGI, presented to the Trust Board on 29 November 2007 the risks of <u>not</u> going forward with the plan are stated thus: ' *By not providing this unit, there is no <u>local</u> dialysis for the population of west/northwest Leeds who require dialysis. Inpatients at the LGI who require dialysis will continue to be treated by a locally based renal support team, which is less cost effective, in staffing, than treating the patients from a static dialysis unit.'* These risks remain.

3.1.2 The letter states that neither KPA responded to the draft proposals. This does not accord with historical fact as will be articulated at the meeting.

3.1.3 The insistence that there is "no clinical need" for a facility at the LGI is precisely the thinking in a silo savaged by the NKF paper (above); in this

instance the approach to "clinical need" is disease defined not patient responsive. We have never argued about the 'quantity' of renal stations but the 'quality' of their location and the impact this has on patients' lives.

3.2 Re Question 2: The answer to this question contains the material from which we can see the pattern of CKD care across the region (pages 3 and 4). For the Leeds Trust area the provision at St. James's University Hospital, at 83 patients, is the only example in the region where care at a satellite, Seacroft, is greater than in the main acute centre. What does this say about the quality of the long term planning by the Trust?

3.3 Re Question 3: The financial year for the Trust runs from the 1st April and in common with all public sector corporations the budget for that year will have been determined months before. It is surprising that as late in the cycle as the 28th January 2009 a Capital Planning Group was meeting to hold the "first discussion on the overall capital programme". Discussions with KPA representatives before that date had clearly given the impression that the work on the unit at the LGI would proceed, so why was this meeting in late January the first to consider the plan? Moreover compounding this why was it that "Design work was not stopped until 1st June 2009"? By that time spending decisions within the 2009-10 financial budgets would be operative.

Towards the end of page 6 there is a curious phrase dealing with the point about a parallel process. The letter states that discussions with the KPAs were continuing in early 2009 "because the decision was still to deliver the unit at this time, pending any future Trust Board decision". Yet the Trust had promised and committed itself to delivering this unit, and had spent money on preliminary work, so why was this suddenly contingent on *"any future Trust Board decision"*? This is not how public corporations are or should be managed.

3.4 Re Question 4: It is not my intention to ascribe 'bad faith' to the approach taken by the Trust, but the clear impression that there never was a sincere commitment to deliver a unit at the LGI is conveyed in these paragraphs. While the Trust was continuing to develop Seacroft, what were those managers doing about the commitment to the LGI. The fact is that by expanding the facility at Seacroft they have been able to argue the 'quantity' case (see para 3.1.2 above).

3.5 Re Question 7: We accept that forecasting likely demand over the next five years is difficult. It is not however impossible to arrive at a robust estimate. We have examined the draft report of the regional renal network strategy for 2009 – 2014, dated 9th November 2009. The draft states that between those five years there will be an increase of 1806 patients requiring haemodialysis. The paper also helpfully describes the characteristics of disease prevalence, notably the importance of age, male sex and South Asian and African Caribbean ethnicity. The renal National Standards Framework predicted overall growth is 4.5% to 5.0% but 6%-8% for hospital based HD and older patients. 'There is a move now to increase all home based 'therapies', (i.e, Home HD, CAPD. APD and AAPD), and the organ donor transplant report aimed for a 50% increase in transplant rates by 2013. However, even if both the above are achieved, these will still only be suitable for a minority of patients requiring RRT, so the demand for

hospital based HD will continue to grow for a considerable time'[1] . It should be noted that West Yorkshire has high numbers of ethnic minorities who are five times likely to require renal replacement therapy than their white counterparts.

We look forward to further work being completed on future demand and are happy to help the Trust in any way we can, especially in creating a better understanding of local community needs.

3.6 Re Question 10: The draft regional report referred to above deals with the issue of home haemodialysis and points to a very low figure for this area. Sheffield records the highest figure in the region at 5.5% with that in Leeds significantly below that level. It is interesting that Manchester demonstrates one of the highest figures at 8.6%. It remains un-clear to us quite how the Leeds Trust is going to be able to offset its delivery problems by increasing home based treatment which is only suitable for a minority of patients.

3.7 Re Question 11: We now expect the Trust to acknowledge that this patient survey was so flawed as to be of no help whatsoever in this issue about the location of haemodialysis. This was confirmed at a recent meeting with the Chair and Chief Executive of the Trust.

3.8 Re Questions 12 and 13: It will be helpful we believe to take these together. It is indeed true that there is a notable disparity between demand and supply for the non-Leeds postcodes and have already pointed out in this paper that the Leeds Trust area is over-dependent on satellite facilities, made all the worse of course by closing the unit at the LGI. Location of these facilities is absolutely crucial to the quality of the patient experience and for people travelling into Leeds, either to the minority unit at St. James or the largest at Seacroft, the demand on their body and mind is intolerable.

It is also unacceptably intolerable that patients from North West Leeds have to travel to Seacroft. About 26% of patients receiving haemodialysis there come from the six post-codes identified by the Trust as those between LS16 and LS21. In short from only six of the 29 post-codes which range across the second largest city in England more than a quarter of our patients have to travel to the other end of the metropolitan district.

Appendix 3 of the letter purports to describe the patient journey times to and from both Seacroft dialysis units. We submit that this table should be withdrawn and an apology issued for us having wasted our time in considering it. A brief glance at it will tell the reader that it rests on a mis-truth. We are supposed to believe that on 58 occasions patients spent up to only 10 minutes in the vehicle travelling home from Seacroft and that on 39 occasions the journey there only took up to that ten minute threshold. The figures for 11 to 20 minutes are respectively 50 and 52. Not even in a race between Jensen Button and Lewis Hamilton would this be possible outside of a grand prix circuit.

[1] National Kidney Federation

It is not clear how these data came to be produced let alone printed and submitted to this Board. In any event no reliance can be placed upon them.

3.9 <u>Re Question 14</u>: From what we have said throughout this paper and particularly in regard to 3.8 above our views are very clear as to how the Trust has dealt with the statutory duty of local authorities to exercise scrutiny.

3.10 <u>Re additional responses to Mrs Lilian Black</u>: Much of what is written in this section has been covered above. However it is unfortunate that the paper has to adopt such a tendentious approach as exemplified in the reference to the unit at Beeston and its opening in 2005. With the benefit of all we now know about how these decisions were taken it is erroneous and irrelevant to point out that "none chose LGI". We are left to speculate what advice, guidance and counselling was given to these vulnerable people and why the Trust should adopt an almost gloating tone to the fact that nobody wanted to go to the LGI.

I am also advised by patients attending Seacroft that there is not "dedicated medical cover between the hours of 0900 to 1700 Monday to Friday''. In fact at best there is a doctor between 11am – 3pm and on 20 November 2009 for example there was no doctor at all. In addition we are advised that there is a 'crash' trolley but staff are only intermediately trained to use the defibrillator and not to use the drugs. We are still awaiting answers to our numerous questions regarding the patient who died this year and why it took 20 minutes for paramedics to arrive in response to emergency calls made by the renal unit staff, causing enormous stress to patients on the ward and no doubt to staff.

4. Summary and Conclusion

We are left with an impression that the Trust made a promise in 2007 in bad faith, with hardly an intention to re-establish a facility at the LGI; that the provision on a sub-regional basis is over-reliant on satellites with the consequential burden of travel time and the 'silo' approach to patient care; and that at least two elements of the case as presented in the letter from the Chief Executive should be struck out.

Renal patients in this part of the Leeds City Region deserve a better deal from the Trust and the Commissioners of services and promises made should be honoured. Patients want to be treated with dignity and humanity and should be treated in line with national renal guidelines. Despite the poor treatment we have received both KPAs remain willing to work with the Trust to remedy the serious breakdown of trust.

Francis J Griffiths
LGI Kidney Patients' Association
November 2009