APPENDIX 4

Submission to Leeds City Council Scrutiny Board by LGI Kidney Patients Association (KPA)

1. On 2 June 2009 following a number of questions raised by the KPA to the Trust regarding the lack of progress towards establishing the much promised and awaited LGI dialysis unit Lilian Black was informed by senior staff of the Leeds NHS Trust that the unit would not now go ahead.

2. To date, despite a variety of requests for information regarding the basis for such a decision we have received what we consider to be a totally inadequate response from the Trust – they have betrayed their promises to the chronically sick renal patients of Leeds and beyond. We have spent hours planning the unit with the Trust to the point of working with architects on detailed plans – the cost of the plans must be enormous. We have been engaged with the Trust over two years on this process.

3. After closing Wellcome Wing at the LGI, the cost of creating the temporary unit at Seacroft to be followed by closing this down and building another unit next door, to now be faced by having to replace the water treatment plant at St James Hospital and needing to find another place to dialyse patients whilst this work goes on beggars belief. The argument about having to make capital funding choices pales into significance against this mismanagement and waste of public money.

4. Everything we said when Wellcome Wing was to be closed has come true. Chronically sick patients living out of area and in parts of Leeds not near to Seacroft and within easy reach of a dialysis unit continue to be condemned to what is in effect an 7/8 hour day three times a week to receive their life saving treatment.

5. If the Trust approved the unit previously then what has changed now to say that there is no clinical need?

6. What is the meaning of the phrase 'clinical need' used by the senior management of the Trust? The only factor mentioned is the number of stations and even their location is secondary. Our contention is that location is fundamental both to patients within the boundary of the city of Leeds and beyond. Travel time to and from dialysis is fundamental to their quality of life.

7. Renal clinical guidelines for haemodialysis state that,

> *"Except in remote geographical areas the travel time to a haemodialysis facility should be less than 30 minutes or a haemodialysis facility should be located with 25 miles of the patients' home. In inner city areas travel times over short distances may exceed 30minutes at peak traffic flow periods during the day. Haemodialysis patients who require transport should be collected from home within 30 minutes of the allotted time and be collected to return home within 30 minutes of finishing dialysis."* (Renal Association Clinical Practice Guidelines for Haemodialysis 2007)

8. The paper produced by the Trust makes absolutely no reference to patients who are travelling to Seacroft from Halifax, Pontefract, Huddersfield and from the North/North West of the City. It makes no reference to patients waiting to go onto dialysis, it makes no reference to the projected growth projections for the increased need for dialysis, nor the fact that there will be a large population growth in Pakistani and Bangladeshi communities who have a five times higher propensity for renal failure than other members of the population. There is no reference to the separation from other major clinical centres such as the LGI which compounds the challenge these patients face with the ordeal sometimes of travel into Leeds centre for a morning clinic followed by the journey to Seacroft and then home.

9. So what is the Trust's definition of clinical need? Over what period is 'clinical need' assumed to be met? These capital spending decisions are clearly annual yet any responsible measure of 'clinical need' would have to be set within at least a medium time period of say three to five years. Where is their evidence that the current disposition and number of stations meets the needs of this part of the city region over such a period? We have evidence that there is a clinical short-fall already which can only get worse. We have not been presented with any evidence that this has been the subject of strategic planning or consultation.

10. What value can the Scrutiny Board or any of us place on the word of the Trust? The commitment made to open a ten station facility at the LGI was a critically important part of us all being reassured that the decision to close the Wellcome Wing was going to be mitigated by the restoration of a dialysis facility for out-patients in the LGI. Moreover we were encouraged to become actively involved in the decision process and help determine the precise location etc. It is difficult to see how we can trust the Trust again.

11. It is true that transport arrangements have been un-satisfactory but on this occasion that is a secondary issue. It is not acceptable for the Trust to deflect the argument in that direction. This is the sole responsibility of the management of the Trust and its Board.

12. The conclusion of the LGI KPA is that the need for the unit at the LGI has not changed and if anything, our experience since the closure of the Wellcome Wing proves even more than ever that we need a central location at the LGI. There are serious problems in Leeds for renal patients. Having 10 'spare' machines at Seacroft is not helpful in meeting the medium to long term needs of these patients.

Lilian Black
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