Response from NKF (National Kidney Federation) to consultation on the *'2015/16 National Tariff Payments System: Engagement on national prices'.*

Introduction

This submission is made by the NKF in response to the consultation by Monitor and NHS England of proposed changes to the National Tariff Payments System with specific reference to **Renal Dialysis** and the pathway of care for patients with End Stage Renal Failure.

The NKF is the largest kidney patient charity in the UK, forms part of Kidney Charities Together (an alliance containing Kidney Research UK, British Kidney Patient Association, Polycystic Kidney Disease (PKD) Charity and the Kids Kidney Charity), has support of the All Party Parliamentary Kidney Group (Co-Chair, Madeleine Moon MP) and works in close partnership with various NHS organisations (including NHS England and the Clinical Reference Group for Renal Dialysis) and Associated Renal Industry to improve the quality, provision and equity of access of services for kidney patients.

The NKF supports the interests of all kidney patients (and their carers/family) with Chronic Kidney Disease (CKD) and those being treated with either renal replacement therapy (RRT) which included Haemodialysis (HD) or Peritoneal Dialysis (PD) or conservatively managed.

The proposed reductions to the tariffs for Renal Dialysis (and modalities therein) are of major significance and we believe will have a potentially devastating impact for the care of our patient community, their quality of life and length of life.

Consultation notice

It was with great surprise and dismay that as a major patient stakeholder and working partner with the NHS, our organisation was not directly consulted and only found out, by chance, on 8th August 2014, well after the start of the consultation on 22nd July, leaving only nine days before the end of the consultation period.

The National Clinical Director for Renal, Chair of the Clinical Reference Group for Renal Dialysis and Clinical Directors across the country were also unaware of the consultation until a similar date.

Furthermore, the consultation documents are complicated, lengthy and finding parts which have relevance to the treatment for our patient community is a time consuming and difficult process. Considering the changes are serious and will have major implications to the entire kidney community we have found this particular consultation lacking in transparency and openness; furthermore given the timing in the summer months one can only assume this is no coincidence.

We find it very difficult to believe that "Stakeholder engagement on this proposal has been extensive – it was one of the main topics of discussion at our recent workshops, and we have received upwards of 70 written responses to the methodology paper." We would dearly love to know which "stakeholders" from the kidney community have been engaged?

We therefore demand that the consultation period is extended.

Lack of evidence

Whilst of course it is pleasing to read that "NHS England and Monitor are committed to setting the national tariff in a manner consistent with our principles of transparency, evidence-based policy-making, consultation with the sector, and impact assessment; as well as in accordance with our statutory duties" there is no evidence of this either within the consultation or by the very process itself – this surely represents a flaw in the consultation process having not met the statutory needs of your stakeholders. The service users, NHS service providers and private providers appear to have been circumvented by a lack of professional communication.

We note that “reference costs” have been used; however we believe these costs to be inherently inaccurate and reflect a range of costs from various trusts. There is no new evidence to base costs on or at least none that we can find in the document.

Our understanding from those who work in commissioning is that Trusts receive money from commissioners for their renal service based on forecasts provided by that service; the Trust then gives money to their own renal department. We are led to believe that the money actually received by renal sometimes falls well short of what has been given provided in the first instance by commissioners - this represents the reality; the function of tariff and the process of payment assumed in theory, does not happen in practice.

Therefore we firmly believe that the reduction in the tariff will prevent the service doing so much more and its impact will be so severe for Home Haemodialysis that aspirations will become completely limited. We fear for lack of any real quality improvements over the next few years; patient safety and patient quality of life will be in jeopardy; we anticipate the effects will continue to demoralise an already overstretched workforce, while Independent Sector Providers and partners in care will become financially constrained, unable to develop service and invest in infrastructure development – all issues which have the potential to deliver damaging costs of their own to the NHS.

We therefore demand that further evidence and information is provided to both the clinical and patient stakeholder community as a matter of urgency.

Tariff proposals

The tariff figures affecting the renal community can briefly be broken down as follows:

- 13% reduction for the Haemodialysis (HD)
- 39% reduction for follow up appointments
- 18% reduction for the Continuous Ambulatory Peritoneal Dialysis (CAPD)
- 13% reduction for the Home Haemodialysis (HHD)
- 4% increase for the Automated Peritoneal Dialysis (APD)
- 24% increase for first nephrology-led outpatient appointment (multi-professional)
- Introduction of a new tariff for Acute Kidney Injury (AKI)

Over all tariffs have fallen by 3-5% however there is a worryingly disproportionate reduction in the renal tariffs particularly for Haemodialysis (HD) and Peritoneal Dialysis (PD), and Out Patient follow-up, of over 15%.

The CAPD and HHD prices are shown to have been reduced by 13-18% in this consultation; such reduction is contrary to the clinical imperative of increasing Home Therapies and to the improved quality of life that Home Therapy brings to patients, and their carers/family. The NKF held a summit on Home Therapies in the House of Lords in early 2013, facilitated by the All Party parliamentary Kidney Group (APPKG), and attended by all sections of the kidney community including NHS England, the Department of Health, kidney patients, carers, kidney doctors, Industry and the Renal Registry. The APPKG published a manifesto on Home Therapies on the outcome following the summit, a copy can be obtained from NKF Head Quarters (01909 544 999)**.** Evidence heard was compelling and focussed on the benefits of Home Therapy (PD & HHD) which can be summarised below:

- Patients in control and concordant
- Improved quality of life outcomes for patient and importantly family or carer
- Better clinical outcomes with improved blood results, especially with more frequent home dialysis
- Nocturnal Haemodialysis offers patients treatment almost equal to a deceased kidney transplant
- Reduced need for medication; blood pressure, hyperphosphatemia and anaemia better managed
- Reduced infections
- Fewer costly hospital admissions
- No need for costly patient transport service
- Increased life expectancy
- The potential for patients to recommence work, training or education
- Increasing the capacity at satellite or hospital dialysis centres, therefore minimising new infrastructure costs
- Improved patient experience and control with the ability to dialyse at a convenient time

These points illustrate the potentially significant savings and improvements in quality of life that can be achieved through sustained 'championing' of Home Therapy by NHS England. The take-up of Home Therapy, as evidenced by the Atlas of Variation and reports at Conferences such as the Annual Home Dialysis Conference in Manchester, is patchy and only through confidence, shared practice and better understanding by service providers and patients can the true benefits of Home Therapy be fully realised. The very real fear with this ill-advised reduction is that the UK will be set back and fall well behind European and World leaders in dialysis, in doing so reducing the quality of provision and care for patients, damaging the reputation of the NHS, ultimately being more expensive and working contrary to putting patients at the centre of health care. The risk of destabilising the quality, provision and choice of dialysis services is very real especially when choice is very vulnerable in some locations.

We therefore demand that these figures are reviewed as a matter of urgency both in terms of future care but in terms of financial due diligence to assess the benefits from Home Therapy that would be lost.

Outpatient tariff

There is an increase in the new patient tariff which of course is thoroughly welcomed, however CKD is a long-term health condition and within the acute setting in secondary care the need to be seen regularly is inevitable, due to complications, medication reviews, education and shared decision making, therefore the large reduction in follow up tariff is detrimental to the long-term care of our patient population for whom support and education is critical in both their empowerment and decision making for life saving treatment for a long-term condition.

Outpatients	2014/15	2015/16 (£)	% Change
1st Visit	182	264	+45
1st Visit MDT	148	308	+24
Follow Up	190	126	-34
Follow up MDT	243	147	-40

We therefore demand that these figures are reviewed as a matter of urgency as they compound the effect of the reduction in treatment tariff for patient care and the resultant impact on quality of life.

Dialysis for Acute Kidney Injury

The Introduction of a new Acute Kidney Injury tariff is welcome, but cannot be funded from a reduction of existing dialysis & follow-up outpatient tariffs.

The quality of the service

"Patients and taxpayers expect that providers will become more efficient over time. This means that they should deliver services at a lower cost while improving value and quality. The efficiency factor quantifies our expectation." Unfortunately this statement has all the hallmarks of a complete disconnect between 'economic theory' and 'clinical reality'. Increasing efficiencies in reality means less staff, doing more work, with less time for patient contact with increasing likelihood of costly mistakes – this is not what the renal patient community expects. A large percentage of our patient community are physically disabled, reliant on patient transport to receive treatment and reliant on safe assistance within the treatment setting. Being disabled is a 'protected characteristic' and we strongly believe that the effect on the quality (grade) of staff employed and the ratio of staff to patient will be significantly affected with one prejudicial result being the inability to care properly for those in most need.

We expect a quality service, where patient safety does not come second best, where compassion can exist, and carers feel reassured. The likely NHS service that will result from the tariff reduction for our kidney patient community is not what we want – nor is it what NHS England should want.

The overall reduced tariffs for renal activity will be detrimental to the multi-disciplinary team and the value which that provides to our long-term condition patients.

Impact on Independent Sector Providers (ISP's)

The new tariff will result in only very large satellite units being feasible in the future (i.e. those with enough patients to allow fixed costs to be covered).

The tariff will have an immediately negative impact on many contracts between NHS Trusts and ISP's. Many contract prices are higher or bordering the proposed tariff (please note that the Trusts also have their own costs to add to the ISP's contract prices such as medical supervision). The new tariff would therefore in result many NHS Trusts facing an immediate deficit with the likelihood that Trusts will respond by re-negotiating their contracts with ISP's, leaving them with no option but to cut costs risking quality and patient safety (UK contract prices are among the lowest in Europe and there is very little scope to simply reduce prices – profit margins are low already).

On a macro level, if the ISP's are squeezed, there is a potential result of reducing their investments in the UK, and this could have a major negative impact on care, given that much of the capital investment to upgrade and develop new services now comes from the ISP's.

Impact on Small ISP's & Dialysis Away From Base (DAFB)

Small ISP's based in popular holiday locations in the UK provide what can only be described as a life-line for some patients and carers in terms of the respite that comes with a 'dialysis holiday' or commonly referred to as DAFB. Contracts are negotiated locally, and have been agreed above the tariff rate due to the smaller nature of these operations, the economies of scale that cannot be achieved and due to the seasonal fluctuation in forecasted activity. The potential impact of the reduced tariff has the very real likelihood of driving these small ISP's out of business, limiting opportunity for patients & carers to have a life enhancing holiday and escape the monotony of a thrice weekly routine, every week, and every year until death or a transplant.

The provision for DAFB is an imperative lifeline for dialysis patients and carers. We demand that a full assessment of the impact of DAFB be undertaken before the proposed cuts in tariff are agreed.

Impact on patient transport

As has been said earlier Home Therapies by their very nature mean that the individual patient does not need transport; transport costs are ultimately paid by Clinical Commissioning Groups and with the reduced incentive for Home Therapy are unlikely to go down. For a haemodialysis unit with 66 patients transport costs can exceed £250,000; where patients need individualised transport, the cost can be £300 per week resulting in over £15,000 for one patient. This is based on standard three sessions of haemodialysis per week requiring six journeys.

Conclusion

We demand that Monitor & NHS England reconsider these proposals that will have a dramatic and destabilising effect on renal services which have been identified through this submission; engage in meaningful consultation with the range of stakeholders who form the kidney community; and finally provide up-to date evidence on which your reasoning can be justified.

We therefore request an urgent meeting with Monitor and NHS England to discuss these proposals before they are agreed.

Kirit Modi, Chairman, NKF 14th August 2014

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