



# A HOME DIALYSIS MANIFESTO

INCREASING UPTAKE OF HOME DIALYSIS TO BENEFIT  
PATIENTS AND THE NHS

## A report of the findings of the 2013 Home Dialysis Summit



Hosted by the All-Party Parliamentary Kidney Group

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## EXECUTIVE SUMMARY:

It is now ten years since NICE first recognised the benefits of home dialysis, stating that between 10-15% of patients would be on home haemodialysis if given the choice. More recently, NICE has also stated that the optimum level for peritoneal dialysis, which is also administered at home, would be 39%; a far cry from current levels. When NICE made these recommendations, few would have predicted that uptake would stagnate and, in the case of peritoneal dialysis, fall throughout the following years. However, with just 3% of patients on home haemodialysis and 15% on peritoneal dialysis, there is no doubt that home dialysis remains a most striking missed opportunity for the NHS.

Compared with centre-based haemodialysis, home dialysis and peritoneal dialysis both offer improved clinical outcomes for suitable patients. Not only is home dialysis clinically effective, it is also substantially more cost-effective than in-centre haemodialysis and can bring about a marked improvement in patients' quality of life. In the light of the current focus on moving care closer to home, as well as the QIPP programme, the disappointing rates of home dialysis appear to be the product of cultural and clinical inertia.

With this in mind, the All-Party Parliamentary Kidney Group hosted a home dialysis summit which heard evidence from patients, clinicians, commissioners and regulators. Patient representatives made clear the difficulties they had encountered in moving to home dialysis and the benefits they had experienced as a result. Other witnesses acknowledged the substantial attractions of increasing rates of home dialysis while exploring the reasons this had failed to come about.

The APPKG puts forward the following recommendations, grouped around three key themes, arising from the day's proceedings with a view to removing the apparent barriers to home dialysis and unlocking the widely acknowledged clinical and financial advantages:

### **A. COMMISSIONING CONSIDERATIONS: GETTING IT RIGHT**

1. The NHSCB should consider establishing a national target for home dialysis uptake as well as a minimum baseline target for both PD and HHD which all providers should meet.
2. A mandatory CQUIN payment should be introduced to promote home dialysis. This would provide more concentrated impetus than the existing exemplar home dialysis CQUIN.

3. The tariff structure for dialysis should be reviewed to ensure that the right incentives exist for home haemodialysis and peritoneal dialysis.
4. The service specifications for renal dialysis should be streamlined and promote home dialysis as a preferred first choice modality for patients.
5. Increased rates of uptake for home haemodialysis and peritoneal dialysis should be adopted as a measure of the NHSCB's performance in relation to QIPP.

## **B. CLINICIANS AND PATIENTS: CULTURE AND INVOLVEMENT**

6. All providers should support clinical and patient champions of home dialysis; offering patients robust information and a genuine choice to be initiated on home dialysis or to switch to home dialysis where it suits their needs.
7. Patients on dialysis should be consulted and assessed at regular intervals and, if necessary, changes should be made to their mode of treatment. This should be mandated in any future iteration of the renal replacement therapy service specifications.
8. Patient Reported Outcome and Experience Measures should be prioritised and should be the principal barometer of success.

## **C. RESEARCH: BUILDING THE EVIDENCE BASE**

9. Comparative audits of home dialysis rates by renal unit should be introduced. These could be undertaken by the Renal Registry and would be published to show how well individual centres are performing in terms of their home dialysis rates and outcomes.
10. Home dialysis should be designated as a research priority for the NIHR. Investment should be focused on a select few renal centres which would gather information on the major aspects of home dialysis from a patient and a clinical perspective.

## INTRODUCTION

The All-Party Parliamentary Kidney Group (APPKG) is a coalition of Members of Parliament and Peers whose registered purpose is: “to improve understanding in parliament of kidney disease and transplant medicine and promote improvements in the health and care services that are available to improve the health of people with renal failure.” The group is co-chaired by Madeleine Moon MP and Glyn Davies MP. The secretariat is provided by the National Kidney Federation, a kidney patient charity which is run by kidney patients for kidney patients and is registered charity number 1106735.

A key area of interest for the APPKG during 2012/13 is home dialysis within the NHS, the uptake of which remains lacklustre despite its acknowledged benefits and significant policy support. With this in mind, on 31<sup>st</sup> January 2013 a summit was held to explore the impediments and opportunities which exist in the field of home dialysis. Stakeholder representation at the event was broad and testimonies heard included those from patients, clinicians, regulators and commissioners. The consensus that emerged was whole-heartedly in favour of action to improve home dialysis rates and a number of recommendations have been drawn together based on the discussions that took place.

It is hoped that the recommendations will help to drive the activity required to increase uptake of home dialysis and unlock the improved outcomes and financial savings that this would provide.

## HOME DIALYSIS BACKGROUND:

In England around 5,000 people are diagnosed with kidney failure every year and there are currently roughly 41,000 patients receiving treatment for kidney failure. In the absence of a successful kidney transplant, most of these patients will require renal replacement therapy for the rest of their lives<sup>1</sup>.

There are two main types of dialysis, both of which can be delivered at home.

- Haemodialysis (HD) involves inserting needles, which are attached by a tube to a dialysis machine, into a blood vessel. Blood is transferred from the patient's body into the machine, which filters out waste products and excess fluids. The filtered blood is then passed back into the body.
- During peritoneal dialysis a permanent catheter is inserted into the abdomen and a dialysis fluid flows into the space that surrounds the peritoneum (the peritoneal cavity). As blood moves through the peritoneum, waste products and excess fluid are moved out of the blood and into the dialysis fluid. The dialysis fluid is then drained from the cavity.

Currently as many as eight out of ten dialysis patients are treated with in-centre haemodialysis which requires three hospital visits per week, lasting roughly four hours each<sup>2</sup>.

The regular hospital visits associated with in-centre dialysis can place strain on a patient's family and social life, as well as preventing them from working normal hours. One summit attendee described feelings of depression as a result of these thrice-weekly visits which were universally seen as an inconvenience. In contrast, home dialysis allows patients to fit their dialysis schedule around their professional and social commitments, with minimal disruption to their day-to-day routine.

In addition to the demonstrable improvement in patient quality of life, greater uptake of home dialysis could bring about significant financial savings for the NHS. In-centre renal dialysis involves significant direct and indirect costs; in 52 hospitals in England which offer dialysis services, up to 50% of their patient transport service costs are accounted for by dialysis<sup>3</sup> and in 2009/10 £49.5 million of NHS expenditure was attributed to dialysis transport costs<sup>4</sup>. In the context of the drive to achieve QIPP, it is perhaps surprising that home dialysis has not been prioritised.

<sup>1</sup> NHS Choices <http://www.nhs.uk/conditions/Dialysis/Pages/Introduction.aspx>

<sup>2</sup> NHS Choices <http://www.nhs.uk/conditions/Dialysis/Pages/Introduction.aspx>

<sup>3</sup> Why Home Dialysis? National Kidney Federation, 11 March 2010

<sup>4</sup> Chronic Kidney Disease in England: The Human and Financial Cost, Marion Kerr, Insight Health Economics, 2012.

It is widely anticipated that the renal patient population will grow in the coming years. However, any capacity issues could be effectively counteracted by an increased focus on home dialysis rather than a growth in the number of dialysis centres, many of which already report patient vacancies<sup>5</sup>.

The barriers to home dialysis are varied, however none are insurmountable. The summit revealed that the principle obstacles were: clinical bias against home dialysis; the lack of patient awareness of the availability and advantages of home dialysis and the absence of a coordinated national approach to home dialysis. Research conducted by the NKF<sup>6</sup> in the lead up to the summit provides further insight into the patient barriers contributing to low uptakes of home haemodialysis, suggesting that practical concerns around lack of space are compounded by fears of the ability to cope with dialysis without the presence of a medical team.

In the reformed NHS, the NHS Commissioning Board will be able to effect national change and introduce greater consistency in specialised services through the policy levers at its disposal. In the case of renal services, the NHSCB has the opportunity to produce an improvement in home dialysis rates so that they come to reflect patient experience.

The proposals outlined in the following document seek to address some of the barriers to home dialysis uptake and, in so doing, to create an environment which recognises and prioritises the clinical, financial and social benefits of home dialysis.

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<sup>5</sup> Dialysis Capacity Survey, NHS Kidney Care, October 2011.

<sup>6</sup> Summary of NKF research has been reproduced in Appendix 2

## BARRIERS & RECOMMENDATIONS:

### A. COMMISSIONING CONSIDERATIONS: GETTING IT RIGHT

Despite significant policy support and pockets of best practice, attempts to increase home dialysis rates have made little progress. Powerful policy levers are now needed to drive uptake uniformly across the country.

➤ **BARRIER: Many of the existing policy levers have produced minimal change in clinical and commissioning practice.**

The policy levers currently in place to boost home dialysis rates include NICE guidance, best practice tariffs and exemplar CQUINS; however uptake remains at a disappointingly low level. The NHSCB has the potential to produce substantial improvements in national consistency and uptake of innovation; improving home dialysis rates would be an achievable and cost-effective objective for it to undertake.

➤ **RECOMMENDATION 1: The NHSCB should consider establishing a national target for home dialysis uptake as well as a minimum baseline target for both PD and HHD which all providers should meet.**

Where the superior clinical evidence, patient outcomes and financial savings are so widely recognised and supported, as is the case with home dialysis, there may be justification for national targets to ensure that prevailing inaction is transformed into results. During the summit, consensus formed amongst commissioners, clinicians and patients around the idea of the NHSCB implementing a national target for home dialysis.

➤ **BARRIER: Despite significant policy support for home dialysis, existing incentives are optional and have thus far been unsuccessful in boosting the uptake of home dialysis.**

Where clinicians profess a personal preference for in-centre dialysis or a prejudice against home dialysis, national policy levers are required to incentivise the use of home dialysis. This should be nationally consistent in order to avoid perpetuating the postcode lottery which currently exists in this field. Home dialysis is covered by the NHSCB's exemplar CQUINs, however these are not mandatory and are merely a resource for local commissioners. In addition, the existing CQUIN is not sufficiently forceful around the rate of home dialysis that providers are expected to achieve.

- **RECOMMENDATION 2: A mandatory CQUIN payment should be introduced to promote home dialysis. This would provide more concentrated impetus than the existing exemplar home dialysis CQUIN.**

The home dialysis CQUIN should be adopted by local commissioners for introduction in all renal centres and should clearly define what 'good' looks like in the field of home dialysis. This would go some way to addressing unfounded institutional and clinical bias against home dialysis.

Although national consistency is a priority for dialysis services, the differences in local geographies and demographics should not be entirely overlooked. However, where local variation does arise it should not be unwarranted and should not be a Trojan horse for postcode prescribing. Consideration should also be given to establishing a minimum baseline target of the percentage of patients on PD and HHD for all providers to help reduce unacceptable variations.

- **BARRIER: Perverse incentives may exist within the financial reimbursement structures of the NHS which inhibit wider home dialysis uptake.**

The 2012/13 payment by results best practice tariff (BPT) package stated that it intended to 'incentivise home therapies' through the renal dialysis BPT. The draft tariff for 2013/14 was released for road testing in December 2012 and claimed to maintain these objectives. However, in the draft tariff that is currently being road tested, the tariffs for home dialysis have fallen to a greater extent than those for in-centre dialysis, creating a systemic barrier to their usage. In addition, there seems to be a lack of consistency in the dialysis tariff structures, with some forms of dialysis being directly incentivised and others being purely reimbursed in a way which does not reflect their clinical and social benefits. This is particularly true in the case of peritoneal dialysis which is purely reimbursed, and at a diminishing price, despite its clinical benefits.

- **RECOMMENDATION 3: The tariff structure for dialysis should be reviewed to ensure that the right incentives exist for home haemodialysis and peritoneal dialysis.**

The improved clinical and personal outcomes home dialysis offers should be reflected in its tariff price. The falling price of peritoneal dialysis is a disincentive which does not reflect clinical evidence or patient outcomes. Currently, some aspects of the dialysis tariff are designed to direct behaviour and others purely reimburse costs; this mix seems somewhat arbitrary and lacks clinical motivation. In addition, annual tariff reviews are not conducive to effective planning; a multi-year tariff should be considered to encourage stability and allow for longer term planning to be conducted. A review should

be carried out to consider how the tariff structure can better reflect clinical evidence and patient experience.

- **RECOMMENDATION 4: The service specifications for renal dialysis should be streamlined and promote home dialysis as a preferred first choice modality for patients.**

The NHSCB has the opportunity to implement national improvement and consistency through the introduction of service specifications for specialised services. In the case of renal dialysis, the NHSCB could effect change by proposing a more streamlined patient pathway with home dialysis prioritised as the first choice modality. Currently, there are four separate service specifications for renal dialysis, a model which could perpetuate fragmentation and limit patient choice.

- **RECOMMENDATION 5: Increased rates of uptake for home haemodialysis and peritoneal dialysis should be adopted as a measure of the NHSCB's performance in relation to QIPP.**

Home dialysis has the potential to unlock substantial financial savings in line with the QIPP programme's objectives. Its inclusion in this programme would drive home dialysis uptake as well as representing an efficiency saving with clinical and patient support.

## **B. CLINICIANS AND PATIENTS: CULTURE AND INVOLVEMENT**

In a patient-centred clinical environment, the wishes of the patient would be prioritised over the personal preferences of the clinician or any institutional bias. Decisions about patients' mode of treatment should be taken after a collaborative consultation which takes full account of the relative benefits in terms of patient quality of life.

- **BARRIER: There is a lack of awareness of the benefits of home dialysis.**

Clinicians' personal preferences can be highly significant in determining individual centres' home dialysis rates, both in a positive and a negative sense. Where clinicians are more supportive of in-centre treatments, patients can feel anxious about initiating home dialysis, despite its equivalent or even improved clinical effectiveness. Patients also express fears about the cost of installing dialysis equipment in their home and about the changes that would need to be made in order to install a cumbersome dialysis machine, which may not even be a requirement depending on the modality of dialysis needed. Peritoneal dialysis does not require any capital investment and advances in technology are dramatically reducing the space required for

home haemodialysis. These fears could be allayed easily through an open discussion with a clinical or patient champion.

Many dialysis patients who attended the summit reported that they only became aware of the availability of home dialysis services through interactions with home dialysis advocates, clinical or otherwise. However, these promoters of home dialysis seem to be deployed on an ad hoc basis by individual hospitals, without national consistency. If patient choice is to be a guiding principle for the modern NHS, as is mandated by 'no decision about me without me', patients should be informed about all dialysis options at the earliest possible opportunity.

- **RECOMMENDATION 6: All providers should support clinical and patient champions of home dialysis; offering patients robust information and a genuine choice to be initiated on home dialysis or to switch to home dialysis where it suits their needs.**

All dialysis providers should identify and appoint clinical and patient champions of home dialysis who should be encouraged to engage with patients to enable them to make informed decisions about their care. These champions would also be responsible for educating and updating the clinical team with the aim of ensuring that the information provided to patients was comprehensive and balanced. Patients will interact with clinical teams at many points throughout the care pathway, so there is a need for a strong understanding of home therapies across the multiprofessional workforce; in the wards, the renal units, outpatient departments and the community teams.

In the case of clinical champions, the requirement to inform patients about the benefits of home dialysis should be included in their job descriptions and feed into appraisals to monitor their progress in improving home dialysis rates. In addition to this, there is a lack of emphasis in clinical training on home therapies. Home dialysis should receive greater prioritisation in the curriculum for medical students in order to ensure its uptake increases in the future. A set of resources should be produced to encourage this.

The NHSCB has said that it would like clinical champions to become a standard feature of dialysis centres, we would agree with this objective and urge the NHSCB to implement effective policy levers to ensure its realisation.

- **BARRIER: Regular reassessment of the appropriateness of a patient's dialysis modality can be limited despite the changing needs and circumstances of dialysis patients.**

In-centre haemodialysis is frequently the default treatment for patients starting dialysis, particularly those who present late or who start dialysis in an

unplanned way. Whilst this is not a clinical requirement and urgent start peritoneal dialysis offers a viable alternative (especially when assisted peritoneal dialysis is used), in many centres it has become the status quo. In addition, patients who attended the summit reported that they were not given the option to change their form of dialysis after initiating in-centre treatment. This can result in patients remaining on in-centre haemodialysis when home haemodialysis or peritoneal dialysis may be a more effective modality.

- **RECOMMENDATION 7: Patients on dialysis should be consulted and assessed at regular intervals and, if necessary, changes should be made to their mode of treatment. This should be mandated in any future iteration of the renal replacement therapy service specifications.**

Regular reassessment of the relative benefits of a patient's dialysis modality should be incorporated in the patient pathway. Both physical and lifestyle changes should be considered alongside cost-effectiveness and a judgment should be reached in collaboration with the patient and the patient's carer.

As one clinician noted during the summit, patient priorities may differ from those of the attending clinician and the latter should not override the former. Patients' quality of life is often affected by regular hospital visits, to the detriment of their personal and professional lives and this should be an influential factor in selecting a treatment method. The explicit requirement to reassess is not currently a component of the patient pathway in the renal replacement therapy service specifications, however it should be considered for inclusion when these are updated in the future.

Ideally, a care plan would be drawn up, with the patient's involvement, to mandate for timely re-evaluation of clinical outcomes and to assess the suitability of the patient's dialysis method. When patients move from one mode of dialysis to another, the pathway should be fully integrated to provide a seamless transition from one renal replacement therapy to another, which would include self-care, in-centre models and moving from home to centre when indicated.

- **BARRIER: Patient benefits do not receive sufficient prioritisation.**

The current system is too heavily weighted towards clinical outcomes; patients who attended the summit reported feeling that their experience was not given sufficient consideration.

Where clinical efficacy and cost-effectiveness are equivalent or improved, as is the case with home haemodialysis compared to in-centre dialysis, patient preference should be considered within the commissioning framework.

➤ **RECOMMENDATION 8: Patient Reported Outcome and Experience Measures should be prioritised and should be the principal barometer of success.**

Wider usage of Patient Reported Outcomes Measures (PROMs) and Patient Reported Experience Measures (PREMs) would reflect the social benefits of home dialysis and would align with the NHS's current focus on patient-centred care and decision making. Patients should be involved in designing and selecting the measures that are used in order to ensure these are fully reflective of patient experience.

Whilst clinicians' assessment of a patient's progress might be based on serum creatinine levels or other objective measurements, patients may prioritise their ability to work normal hours or their wellbeing more broadly. A system which measures its success by clinical outcomes rather than patient experience cannot be responsive to patient need. Patient perspective should be given greater importance throughout the renal services pathway and should be the definitive barometer of success.

### C. RESEARCH: BUILDING THE EVIDENCE BASE

The data on renal replacement therapy does not provide sufficient detail on home dialysis to allow a complete understanding of the service and the outcomes it delivers from a clinical or patient perspective. Increasing the scope of data collection would provide the evidence base required to drive continued improvements in the quality of care delivered to patients.

➤ **BARRIER: Home dialysis rates vary between centres. This makes national assessment complex and amounts to a postcode lottery for patients. Centres are often unaware of how they compare to other centres nationally and, as such, have no incentive to improve home dialysis rates.**

Home dialysis rates are often the victim of ingrained cultural practice and this can result in unwarranted disparities between centres. A 2011 Renal Registry audit revealed an 18 fold variation between PCTs with some reporting home dialysis uptake of as much as 66% compared to 0% in other regions. This variation is often attributed to geographical differences; however this is not borne out by the evidence and is frequently used to justify unwarranted variation. In fact, physician enthusiasm appears to be high on the list of factors influencing centres' differing rates.

- **RECOMMENDATION 9: Comparative audits of home dialysis rates by renal unit should be introduced. These could be undertaken by the Renal Registry and would be published to show how well individual centres are performing in terms of their home dialysis rates and outcomes.**

Comparative audits of dialysis centres were frequently mentioned by summit attendees as potential drivers of home dialysis uptake. It was felt that centres with disappointing home dialysis rates may be unaware of their status as poor-performers and that uptake was unlikely to improve as long as there was no barometer against which centres could self-assess. The Renal Registry publishes renal replacement therapy data annually and many attendees, including Renal Registry representatives, felt that it would be a logical step if it were to assume responsibility for the compilation of these comparative audits. It was also felt that the information included in the audits should be broadened to include detail on the frequency and duration of dialysis, allowing more nuanced assessments to be made. This improved data collection would also allow for more effective planning for dialysis treatment. Failure to tackle the low rates of home dialysis has led to overestimation of the need to increase in-centre capacity, something that could be addressed through improved collection and understanding of data.

- **RECOMMENDATION 10: Home dialysis should be designated as a research priority for the NIHR. Investment should be focused on a select few renal centres which would gather information on the major aspects of home dialysis from a patient and a clinical perspective.**

The low rate of home dialysis is a major theme in renal care but current data does not provide a complete picture of the service delivered or the outcomes achieved. More information should be gathered on all aspects of home dialysis, marshalled by the NIHR but conducted through a small number of renal centres that should explore all aspects of home dialysis, from service design to clinical advantages and patient outcomes.

## APPENDIX 1: SUMMIT SESSION OVERVIEW:

Session Number	Session Chair	Witness 1	Witness 2	Witness 3	Witness 4	Witness 5	Witness 6
1	Madeleine Moon MP	Nick Palmer Head of Advocacy National Kidney Federation	Ron Cullen Director, Renal Registry	Damian Fogarty Chair, Renal Registry	Andrew Samuel HHD Patient	Mr Gordon Pearce PD Patient	Michael Abbott Carer / Husband
2	Neil Carmichael MP	Richard Fluck Chair, Kidney Alliance Consultant Renal Physician	Fiona Loud Director, Kidney Alliance	Roger Greenwood Consultant Nephrologist, East & North Herts NHS Foundation Trust			
3	Duncan Hames MP	Donal O'Donoghue National Clinical Director for Renal Services	Mark Baker Centre for Clinical Practice Director, NICE	Ann Jarvis Acute Portfolio Director (Specialised Commissioning), NHS CB	Sam Alderson Department of Health, PBR team, responsible for renal		
4	John Murray (JMC)	Charles Newstead CRG Lead	Jonathan Howell CRG Public Health Lead	Fiona Loud Director, Kidney Alliance			

**APPENDIX 2: SUMMIT ATTENDEES:**

#	Name	Comments
1	Frank Howarth	NKF
2	George Brown	NKF
3	Kirit Modi	NKF
4	Michael Abbott	Witness
5	Denny Abbott	Patient
6	Mick Walker	NKF
7	Raymond Mackey	NKF
8	Tim Statham	NKF
9	William Beale	NKF
10	Angela Beale	NKF
11	John Mullen	NX Stage
12	Janet Wild	Baxter
13	Siobhan Gladding	NX Stage
14	Nick Palmer	Witness
15	Andrew Samuel	Witness
16	Damian Fogarty	Witness
17	Ron Cullen	Witness
18	Gordon Pearce	Witness
19	Roger Greenwood	Witness
20	Fiona Loud	Witness
21	Richard Fluck	Witness
22	Donal O' Donaghue	Witness
23	Ann Jarvis	Witness
24	Mark Baker	Witness
25	Sam Alderson	Witness
26	Charles Newstead	Witness
27	Jonathan Howell	Witness
28	John Murray	JMC Partners
29	Sarah Fisher	JMC Partners
30	Alice Briceno	JMC Partners
31	Ian Newton	Department of Health
32	David Campbell	Baxter
33	Kate Brownlow	Baxter
34	Kieron O'Neil	Baxter
35	Luella Tricket	Baxter

### APPENDIX 3: NATIONAL KIDNEY FEDERATION RESEARCH:

The NKF conducted a Home Dialysis Questionnaire in December 2012. The questionnaire was distributed to 75 Hospitals across England, Wales, Scotland and Northern Ireland. 25 hospitals responded, representing a 33.3% response rate. There was no response from Wales, two responses from Scotland and one from Northern Ireland, the remainder from England. Out of the 52 Renal Centres identified by the Atlas of Variation, 22 responded representing 42.3%.

The results revealed significant variation between centres, with some reporting home dialysis rates as high as 32% whilst a minority (8% of respondents) were unable to offer all forms of home dialysis. The hospitals also reported the reasons patients gave for not wanting to dialyse at home and these often cited a lack of confidence as a decisive factor. Centres also acknowledged the need to “re-educate centre staff on the benefits of home therapies” in order to improve uptake. As one unit noted: “usually as [patients] become more educated and we build up relationships with them, they realise they will be well supported and this helps to get them over [the] barriers”.

#### Key Patient Barriers to Home Dialysis:

- No space at home (HHD)
- Lack of support or keen not to burden family (HHD / PD)
- Lack of confidence – like reassurance of being in a clinical environment (HHD / PD)
- Like coming to the unit and keeping treatment and home life separate (HHD / PD)
- Home dialysis perceived to be too technical and demanding (HHD / PD)
- Language barriers (HHD / PD)
- Not as easy to travel and take holidays (HHD)
- Perception that dialysis at home might impact government benefits (HHD / PD)
- Lack of clarity around reimbursements for additional costs associated with home dialysis, such as gas, electricity and water (HHD)

## APPENDIX 4: GLOSSARY OF TERMS:

**Commissioning for Quality and Innovation Payments (CQUINs):** The CQUIN payment framework enables commissioners to reward good practice by linking a proportion of providers' income to the achievement of local quality improvement goals. These goals are agreed between commissioners and providers and reflect local priorities. The NHSCB releases exemplar CQUINs which can be adopted as local commissioners see fit.

**The Quality, Innovation, Productivity and Prevention (QIPP) Programme:** QIPP is a national, regional and local programme of work that looks at how the NHS can improve quality whilst making efficiency savings. There are twelve national QIPP workstreams designed to guide local and regional decision-making.

**Patient Reported Outcomes Measures (PROMs):** PROMs are a means of collecting information on the effects of NHS care on patients' quality of life as perceived by the patients themselves. This information is gathered through questionnaires completed by the patient before and after treatment.

**Patient Reported Experience Measures (PREMs):** PREMs collect data on patients' experiences of NHS care, also through questionnaires.

## APPENDIX 5: CONTACTS:

### **The All Party Parliamentary Kidney Group (APPKG)**

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An electronic version of this document may be viewed at [www.kidney.org.uk](http://www.kidney.org.uk)

The National Kidney Federation supplies the Secretarial Services and financial support necessary to run the APPKG. The NKF receives financial sponsorship from 15 renal industries including all the pharmaceutical companies that produce transplant medication. The NKF is a patient charity that adopted the following policy :-

#### **PHARMACEUTICAL COMPANIES**

The National Kidney Federation (NKF) has a working relationship with many pharmaceutical companies and this works to great advantage. The nature of the support that an industry partner may give can vary, but essentially it usually comprises of an annual donation to assist with the costs of our core activity, office and staffing, plus assistance either practical or financial with a particular project that will assist kidney patients.

The NKF always likes to establish a close working relationship with these industry partners and in particular likes to encourage the relationships to be long term. It is of prime importance to the NKF that its commercial neutrality is scrupulously preserved so that the interests on one company over another are not advanced by the NKF, or the interests of an industry partner are not put before the interests of kidney patients or carers. The independence of the National Kidney Federation is one of its most important assets, and is one reason why Government is prepared to listen to the NKF over and above commercial bodies. This independence will never be sacrificed in return for financial support.

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