# Improving patient understanding of phosphate binders: a bony challenge

Susana San Miguel, Mirella Curtale, Deborah Knagge, Chi Nhan and Josephine Chow

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**Abstract**

Clinical evidence shows that phosphate control in renal patients is suboptimal despite patients being prescribed phosphate binding medication. Education deficits and confusion exists as some of these medications are used for their phosphate-binding action as well as for other indications.

**Aim:** The objectives of this project were to identify and assess deficits in patient education relating to phosphate binders and to implement strategies to promote better understanding of phosphate control, thereby improving patients' adherence.

**Methodology**: Using a prospective descriptive quality project conducted over 12 months, a need analysis survey was distributed to 52 renal patients at a tertiary hospital. A patient information leaflet based on the result of the need analysis was developed and distributed to 100 renal patients. Another survey was conducted to assess the efficacy of the patient information leaflet.

**Results**: Results showed that patients have a good understanding of dietary control of their phosphate level. However, the term 'phosphate binder' was unfamiliar to many patients (69%). Results from the pre and post surveys revealed an increase from 31% to 69% in identifying phosphate binders, and an increase from 48% to 69% of patients identifying correct usage or dosage.

**Conclusion**: This project has supported the importance of information distribution to patients. It is paramount that health professionals ensure that renal patients are aware and understand the reasons for taking phosphate binders. Continuous education and the provision of educational materials (published in different languages) are fundamental in enhancing patient adherence in taking their medications.

**Key Words**

End stage renal disease, Calcium phosphate management, Dialysis, Phosphate binders

## Background

One of the functions of the kidneys is to maintain calcium and phosphate balance. Phosphate and calcium homeostasis is mainly maintained by the kidneys, gastrointestinal tract (GIT), and bones (Yucha & Dungan, 2004; Yucha & Guthrie, 2003). The net amount of phosphate that is absorbed in the GIT is directly proportion to the amount that is consumed. Phosphate is released and reabsorbed from the bone and is identical to calcium homeostasis, that is, a drop in serum calcium causes release of phosphate and calcium into the extracellular fluid (ECF), and a rise in serum calcium causes withdrawing of calcium and phosphate from ECF (Yucha & Guthrie, 2003). Both the bones and the GIT have no specific way of regulating phosphate balance as compared to the kidneys (Yucha & Dungan, 2004). The kidneys performed this function by the secretion of hormone, dihydroxycholecalciferol (1,25(OH)2D3), an active form of Vitamin D, and through the interaction of this hormone with parathyroid hormone (PTH) (Moe, 2001).

In chronic kidney disease (CKD), the phosphate and calcium homeostasis is severely altered and results in abnormal mineral and bone metabolism. Calcium and phosphate imbalance has its onset early in the disease process (CKD Stage 3), when the glomerular filtration rate (GFR) falls below 60ml/min (Benavente, et al., 2008) and continue to progress as renal function declines (Smith & Smelt, 2009). As a consequence, patients with Stage 5 CKD (end-stage renal disease [ESRD]) further develop other co-morbid conditions such as, secondary hyperparathyroidism, soft tissue calcifications, coronary artery calcifications, and bone remodelling and turn-over (Alleman, et al., 2008; Moe, 2001), contributing to increased mortality risk for this patient population

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(Canaud, Morena, Leray-Moragues, Chalabi & Cristol, 2006; Moe, 2001; Smith & Smelt, 2009). Several studies have concluded that patients with CKD or ESRD who have hyperphosphataemia, elevated calcium-phosphate product, elevated serum PTH, and excess calcium load are at an increased risk of developing cardiovascular disease (Bro, 2003).

In Australia, only 31-77% of haemodialysis (HD) patients and 24-72% of peritoneal dialysis (PD) patients meet the Caring for Australians with Renal Impairment (CARI) guideline for serum phosphate level of 0.8-1.6mmol/L. Similarly in New Zealand, 18-50% of HD patients and 19-59% of PD patients are reported as meeting the phosphate target (Polkinghorne, McDonald, Excell, Livingston, & Dent, 2008). While some of these data report on patients within the target range, it is those patients who are above 1.8mmol/L that are of greatest concern. Serum phosphate levels in Australia have been stable over the past few years with little difference between haemodialysis patients and peritoneal dialysis patients. In 2007, 39% of PD patients and 36% of HD patients had serum phosphate levels >1.8mmol/L . In New Zealand the trend over the past few years has improved with HD patients (48%) having the higher proportion with serum phosphate >1.8mmol/L as compared to PD patients (40%) (Polkinghorne et al., 2008).

## Strategies for Phosphate Control

Phosphate control can be achieved through dietary restrictions, use of phosphate binders (Sherman, 2007), and dialysis (Hutchison, 2007). Phosphate is in most foods and if patients restrict what they eat in terms of food high in phosphate, optimum phosphate control should be able to be achieved. Unfortunately, dietary restrictions is very difficult to achieve by some patients as a wide variety of food contains phosphate (Hutchison, 2007), and patients are already restricted in other types of food that they could eat, so dietary adherence is often an on-going issue. In addition, restricting phosphate-rich food inadvertently results in reduction of protein intake, leading to malnutrition (Sherman, 2007).

## Dialysis phosphate removal

The mechanism of phosphate removal through HD is complex and not completely understood. During HD, phosphate is removed from both the intracellular and extracellular fluid compartments. Although the removal could level-off 1-2 hours into the treatment, it has been reported that the serum phosphate level could rebound after HD (Leypold, 2005, cited in Hutchison, 2007), indicating poor phosphate removal through HD. Hutchison (2007) further suggested that it is possible that the major obstacle in phosphate removal in dialysis is the "limited transfer of phosphate between the fluid compartments" (p.S29). In addition, 5-10% of serum phosphate is protein-bound (Yucha & Dungan, 2004), so a substantial amount of phosphate are unable to be removed during HD, as dialyser membranes are designed for large molecules (such as protein) not to pass through. Some theories suggest that increasing the time and frequency of haemodialysis may lead to better phosphate removal (Hutchison, 2007). Prolonged nocturnal haemodialysis has been proven to be highly effective in phosphate removal, necessitating addition of phosphate into the dialysate solution (Sherman, 2007). Other studies suggest that an increase in frequency and time of haemodiafiltration (HDF), together with the use of oral phosphate binders can increase phosphate removal (Canaud, et al., 2006).

## Phosphate binders

Treatment of hyperphosphataemia begins with a protein-restricted diet, and this is particularly applicable in patients with CKD as it can slow down the progression of the disease. However, in many patients with CKD or ESRD, and patients on maintenance dialysis, the administration of phosphate binding medications are almost always required to limit the absorption of dietary phosphate in the GIT (Cronin, Berns & Post, 2009). There are a few available phosphate binding medications in the market, such as Aluminium hydroxide (Alutab™), Calcium salts (e.g. Caltrate™), magnesium-containing antacids (e.g. Mylanta™), Sevelamer hydrochloride, and most recently, Lanthanum carbonate. Some of these medications are used and are marketed for other indications which can cause confusion for some patients. For example, Calcium salts, such as Caltrate™ is also used to prevent osteoporosis, and should be taken separately from meals (that is, not with food) to enhanced Calcium absorption. Others are used for indigestion such as Magnesium-containing antacids (e.g. Mylanta™), and are usually taken before food to be effective. On the contrary, medications prescribed as phosphate binders must be taken with the first mouthful of food for it to be effective.

## Medication adherence

Research on adherence in patients with ESRD dates back to the 1960's but evidence to support the most effective strategies to achieve adherence remains inconclusive (Christensen, 2004). Various methods and tools have been utilised to monitor and optimise patient compliance in the intake of medication such as phosphate binders. Devices such as the medication events monitoring systems (MEMS), an electronic timing and record cap on medication bottles, has been used for some patients in an attempt to improve adherence (Sellares & Ramirez, 2004). However, phosphate binders appear to be the medication that causes the most issues with adherence

in patients with ESRD (Chiu et al., 2008). Adherence to phosphate binding medication plays a vital role in reducing serum phosphorus and associated cardiovascular risk (Karamanidou, Clatworthy, Weinman & Horne, 2008). This poses a challenge for patients as the regimen is often complex and there may be no noticeable impact of adherence on symptoms. There is a need to increase the understanding of adherence with phosphate binding medication in renal patients and identify the factors associated with it.

A cross-sectional study of maintenance dialysis patients (HD and PD), aimed at determining the relationship between pill burden and adherence, serum phosphate levels, and quality of life, found that phosphate binding medications are the largest contributor to daily pill burden (Chiu et al., 2008). Pill burden was described as the total amount of pills taken by the patient is a single day. This study also found that patients with higher total pill burden from phosphate binders was an independent predictor of higher serum phosphate levels, higher serum PTH, and lower mental component of quality of life. Similarly, Tomasello, Dhupar, and Sherman (2002) reported the same result in their study of assessing patient's adherence with their phosphate binder prescription. This study involved interviews of 188 chronic dialysis patients (129 on HD and 59 on PD). The overall prescribed pill burden was found to be 8.3 pills/day, tending to be higher in HD than in PD patients (8.80 vs. 7.46 pills/day, $p = 0.07$). Patients acknowledged that non-adherence has resulted in the omission of 16.1% of prescribed doses; 37.8% of patients took <80% of their phosphate binders. Only 11 of the 188 patients (5.9%) were within the recommended target ranges for serum calcium, phosphate, calcium supplementation, and PTH as defined by the Kidney Disease Outcomes Quality Initiative (KDOQI) (National Kidney Foundation, 2006).

Non-adherence to phosphate binding medication appears to be prevalent in ESRD. Several potentially modifiable psychosocial factors were identified as predictors of non-adherence including patients' beliefs about their treatment and their perceived social support. There is a need for further, high-quality research to explore these factors in more detail, with the aim of informing the design of an intervention to facilitate adherence (Tomasello et al., 2002).

Unintentional non-adherence (knowledge deficit) needs to be addressed or explored. As previously discussed clinical evidence shows that phosphate control in Australian patients with ESRD is suboptimal. Education deficits and confusion may exist as some medications are used for their phosphate binding action as well as for other indications. This paper presents the results of a project which sought to explore some of the above issues and the strategies implemented to improve patients' adherence with phosphate binders.

## Objectives

The objectives of the project were to:

- Identify and assess knowledge deficits in patient education relating to phosphate binders
- Implement strategies to promote better understanding of phosphate control thereby improving adherence
- Improve patient outcomes.

## Methods

This was a prospective descriptive quality project conducted over 12 months (October 2006-October 2007) within the renal service of a tertiary hospital in New South Wales. It involved two phases. Phase one involved an educational needs analysis and development of a phosphate education leaflet, and phase two evaluated the changes in patient knowledge about phosphate control and adherence. Subjects included a convenience sample of patients with ESRD who were either receiving haemodialysis or peritoneal dialysis, or patients were immediately pre-dialysis. A total of 52 patients were selected: 25 on HD, 22 on PD, and 5 patients were pre-dialysis (admitted in the renal ward at time of recruitment). A working group was formed, which included representatives from the renal ward, the PD and HD unit, pre-dialysis case manager, dialysis Clinical Nurse Consultant and Renal Anaemia Coordinator. After discussion with the Cardiovascular Stream Manager, Renal Research Manager, and Renal Unit Director, it was decided that this is a quality project and therefore did not require ethics approval.

## Process

*Phase 1: Educational need analysis*

A six-item survey was developed and distributed to the patients. The survey consisted of close-ended questions, that is, either yes or no, and multiple choice (3 choices only), for ease of patient understanding. The aim of this survey was to assess knowledge deficits in regards to phosphate management and control amongst this patient population (e.g. phosphate binders, diet), and to determine ways of improving adherence (e.g. development of patient information leaflet, poster and education sessions).

Fifty two patients received the survey whilst they were either receiving HD, or an in-patient on the renal ward or during an outpatient clinic visit (i.e. pre-dialysis and PD clinic). A response rate of 100% was achieved because the surveys were distributed and collected by staff well known to the patients. The results showed that 38 (73%)

patients had a good understanding of dietary control of their phosphate level but that the term 'phosphate binder' was unfamiliar to 69% of the patients. Thirty two (61%) patients reported poor understanding of phosphate binders and would like to receive written information, such as a leaflet, that could be easily read and understand. At the time the project commenced, there was no readily available patient education material on phosphate binders hence the development of a leaflet was highly essential.

*Development of the patient leaflet*

Based on the specific knowledge deficits found from the needs analysis survey, a patient information leaflet was developed and distributed. This was a collaborative approach involving dieticians, and nurses working within the renal service. The leaflet was designed and written in lay terms explaining the purpose and action of phosphate binding medication (Figure 1). Information on the leaflet included: what are phosphate binders (including samples of commonly used phosphate binding medications), when they should be taken, and the importance of taking them. The leaflet only briefly touched on dietary sources of phosphate, as results of the survey revealed that most patients were well informed about phosphate dietary restrictions. The leaflet also contained useful contact numbers such as the dialysis units, renal research unit and pre-dialysis case manager.

A sample of the leaflet was given to 10 patients and carers to confirm its content and readability. The responses were positive:

- "Very well explained and easy to understand";
- "My brother read it and said it was easy to understand.

Finally the leaflet was reviewed and endorsed by the Area Director of Renal Services and the Cardiovascular Stream Manager. This was then distributed to a random sample group of patients on HD and PD. The pre-dialysis patients were not included in this group due to the limited number of pre-dialysis patients admitted in the renal ward and the difficulty of assessing the efficacy of the leaflet through a follow-up survey.

*Phase 2: Evaluation of knowledge and information gained*

The group of patients that were provided with the leaflet were then surveyed in regards to information and knowledge gained from the leaflet. This was done one month after receiving the leaflet. A total of 100 leaflets were distributed, with 65 patients completing the survey. The primary aim of this second survey was to assess the efficacy of the developed patient leaflet in improving patient's knowledge in regards to phosphate binders. The survey also reviewed how much of this information dialysis patients knew and where they got their information from.

## Results

*Post implementation of patient leaflet*

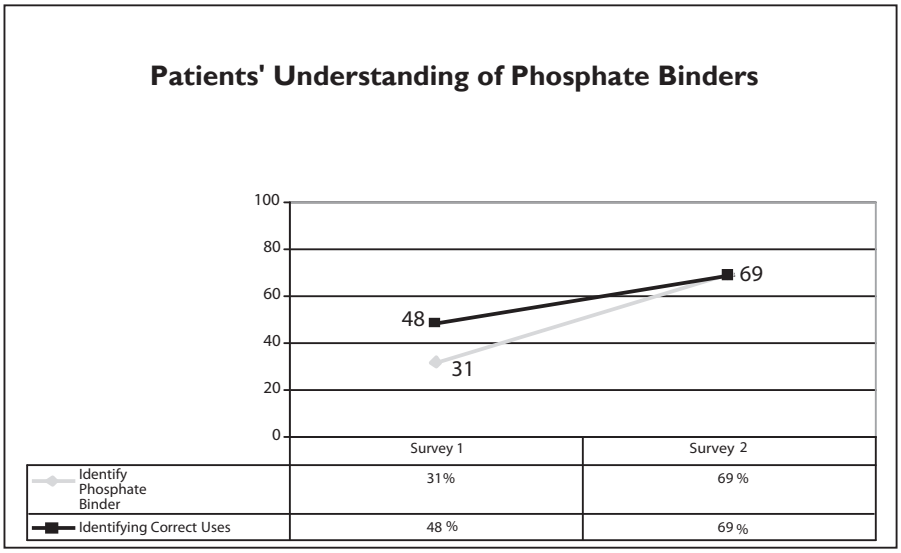
Comparing the results from the need analysis survey and the post implementation of patient leaflet survey, it showed an increase from 31% to 69% in a patient's ability to identify which medications were phosphate binders (Graph 1). Similarly, there was an increase from 48% to 69% of patients who could identify the correct use of phosphate binding medication. Looking at the data which is summarised into a flow chart (Chart 1), it was evident that the education leaflet had been utilised as an educational tool in teaching the patients the value of phosphate binders and how important these medications are. Forty eight patients reported that they found the leaflet to be a useful source of information, whilst 15 patients did not respond to this question. The majority of respondents (n=44) knew what phosphate binders were, 39 reported taking them, and 36 were able to identify the phosphate binder that they were currently prescribed. 32 patients correctly identified when to take phosphate binding medications (that is, with meals). A small proportion of respondent (n=13) did not know what phosphate binders were. Although 6 responded that they do take these medications once they found out the name of phosphate binding medication, for example Caltrate™, Mylanta™, Magmin™, etc. This was asked on the succeeding question.

It is important for a patient to understand the indications for their medications. Some individuals believed that they were taking Mylanta™ for indigestion whilst others believed they were taking Caltrate™ for their calcium levels. Medication such as Mylanta™ is a commercial product, which is marketed and targets population groups with indigestion. However better communication and more education is needed between clinicians and patients to improve levels of understanding as to why the patient is taking their recommended medication. Lastly, a substantial number of patients (n=42) knew what foods were high in phosphate. This was regardless of receiving information or not. It appeared to be a common understanding amongst all patients.

## Discussion

Communication is a major problem in the management of patients. The utilisation of printed material such as an educational pamphlet and brochure has been widely used in public health and clinical services. Turner and Pryse-

**Graph 1** – Survey results on patients' understanding of phosphate binders, Results of the need analysis survey (Survey 1) VS the post implementation of leafet survey (survey 2)




Phillips (1999) reported on a study where posters and patient information pamphlets were used to promote identification of chronic headache sufferers and to facilitate early referral to medical officers for further treatment. Previous studies (Partin, Nelson, Flood, Friedemann-Sánchez & Wilt, 2006; Vallance, Courneya, Plotnikoff, Yasui & Mackey, 2007; Whelan et al., 1998) have also reported the usefulness of printed material for educational or determination of treatment effects in patients with a chronic illness or with cancer.

Additional strategies in promoting education in patient may not always successful. Both self-help print materials and telephone-assisted counselling have generally proved useful strategies to increase physical activity. A randomised study of 399 patients examined their effectiveness in an intervention aimed specifically at promoting walking for specific purposes. However the outcome of this study indicated that the addition of brief telephone support was successful in focusing participants' attention on the print materials, but did not result in any additional increase in walking (Humpel, Marshall, Iverson, Leslie & Owen, 2004).

Miscommunication occurs frequently in populations with low-reading skills, but illiteracy does not completely account for the observed low rates of recall of communicated information. Transmission of the message also plays an important role. Successful strategies to improve communication with patients include the use of videotapes, videotape modelling or cartoon illustrations. Current and future strategies include the utilisation of Internet, chat room and computer-tailored self-help materials (Gilbert, Nazareth & Sutton 2007; Rhodes, 2004).

## Limitations

Although this project has been proven beneficial in developing strategies in improving patients' understanding of phosphate binders, it is only a small quality project designed to address the immediate need of our renal service. In addition, this project only sought to determine patients' knowledge deficit in regards to phosphate binders. It is difficult to ascertain whether this had any impact on the serum phosphate level as this was not measured before and after the implementation of the patient information leaflets. Further, larger studies exploring this aspect would be beneficial in managing calcium and phosphate balance in both CKD and ESRD population.

## Conclusion

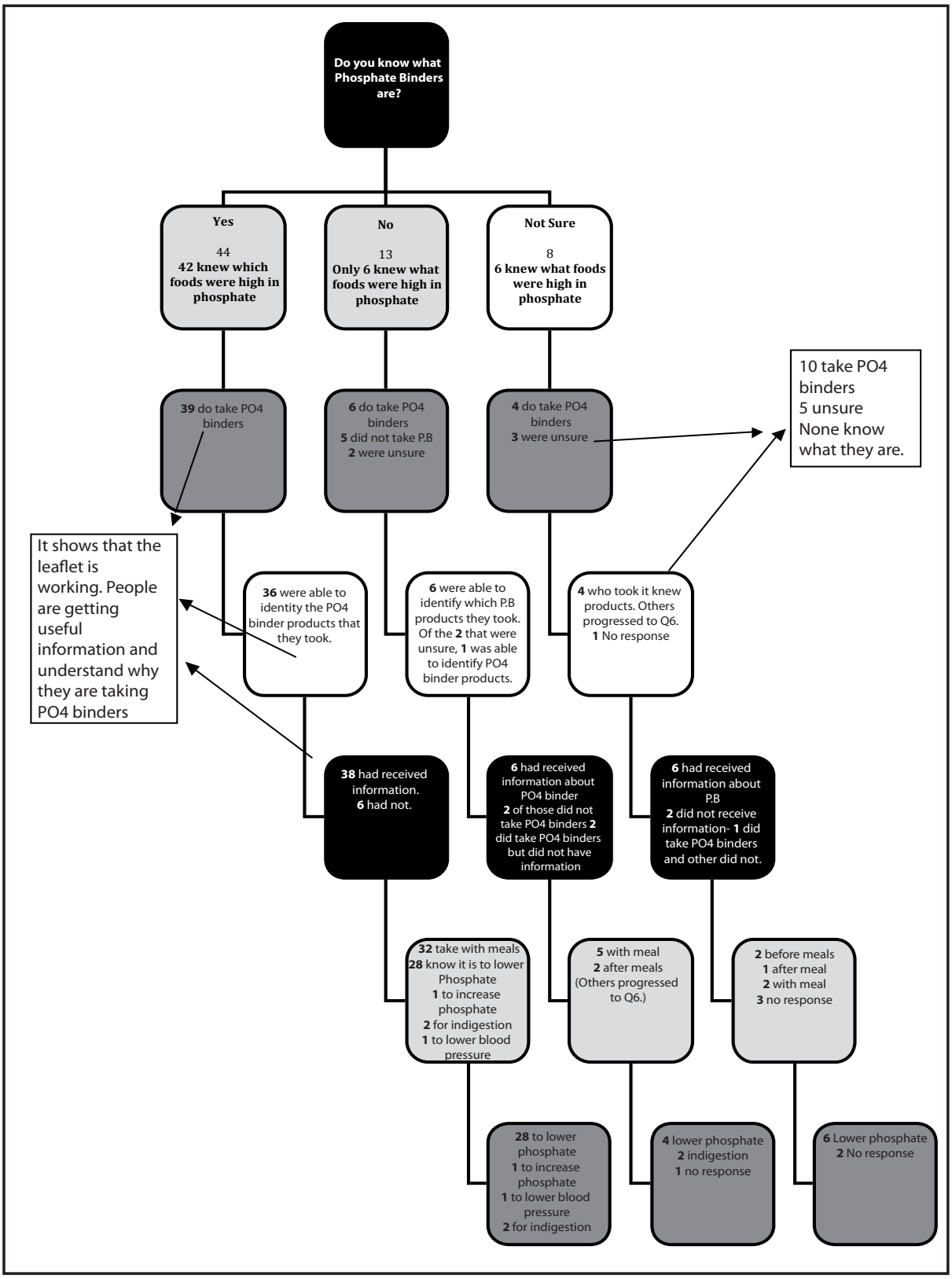
This project has confirmed that a knowledge deficit existed in this group of patients who were prescribed phosphate binders. Using a leaflet was found to be a simple educational intervention for patients to increase their understanding of the role and importance of phosphate binding medication. It is important for health professionals in the area of CKD management to ensure that patients are aware and understand the reasons for their different treatments including medications.

Ongoing patient seminars and educational sessions in calcium and phosphate management are in the planning phase. There is a proposal for the development of the patient information leaflets in different languages, as there is a large number of patients whose first language is not English in South West of Sydney. Further educational strategies are also planned: a poster on calcium and phosphate management will be developed and displayed in all dialysis units; a slogan has been developed to enhance patient adherence with their phosphate binding medications:

> "Before you eat what's on your plate, STOP, and think about your phosphate!"

Other strategies such as podcast informational sessions and e-mail link-ups with patients for a chat and advice are also being considered. Controlling calcium and phosphate balance is crucial

**Chart 1 –** Flowchart on the Patients' Responses for the Survey



in preventing further complications in people with CKD. A combination of strategies, such as dietary restrictions, use of phosphate binders coupled with relevant patient education, and enhanced haemodialysis, should be used to achieve optimum phosphate balance.

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