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The Renal Group Outcome Tool – How was it developed?

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Health professionals have been encouraged for many years to capture clinical outcomes in practice, this has gained momentum since the publication of the NHS White Paper '*Liberating the NHS*'.¹ The directive to create a first class healthcare in the UK requires accountability at every level, including healthcare outcomes based on evidence-based practice, improving the patient experience, as well as capturing data to demonstrate this.

In 2012, the NHS Outcomes Framework was published to inform and direct what healthcare outcomes to achieve in practice.² This raised potential challenges for the commissioning of dietetic services. Due to the integrated care pathway model there was the potential for dietetic services to be over looked, therefore affecting funding of posts and, ultimately, patients outcomes.

The British Dietetic Association (BDA) published a guidance document to respond to this concern and provided a framework on collecting dietetic outcomes in practice.³ It was a key priority to be able to demonstrate the effectiveness of dietetic clinical practice. The Renal Nutrition Group (RNG) undertook a project with the aim to develop a simple and effective tool to demonstrate the effectiveness of dietetic interventions with chronic kidney disease patients.

Formation of a group

An email was sent through RNG listserv to invite interested parties to form the RNG subgroup in 2011. Eleven members volunteered representing a variety of units throughout the UK. The number of members allowed for balanced and valuable discussions and made it easier to delegate tasks.

Meetings were held in the BDA offices in Birmingham as this was felt central to all the units. Once a rapport was established between the group members, teleconferencing and emails proved valuable to further develop the work.

The first meeting

At the first meeting it was essential to standardise terminology (Figure 1), agree the aim of the meetings and highlight any barriers that would negate the work being undertaken.

The initial objectives were to look at five dietary interventions. These included the dietary management of potassium, phosphate, fluid and salt, weight and oral nutrition support.

Three key points were apparent from the first meeting, but also thread through subsequent meetings.

- How to capture the complexity of the diet and address external influences
- Barriers presented by dietitians on collecting outcomes
- Capturing the experience and chronic disease management of the patient.

Figure 1: Agreed Terminology and Definitions

Definition of clinical outcome:

'A change in health/health associated risks of an individual, group of people of a population which is attributable to an intervention or series of interventions.' Any outcome defined should be 'specific, patient centred and achievable, given sufficient resources.' In addition it should be recognised that other factors which influence the defined outcome should be considered.¹

Outcome:

This is the overall patient outcome; the end point following intervention. It should be measurable with a timeframe.

Goal:

A variable measurement to demonstrate the outcome had been achieved. Agree priorities with the patient. A minimum of two goals should be set.

Outcome measure:

An objective or subjective measure or tool used to measure the outcome of the goal agreed.

Plan:

This is the specific intervention provided by the renal dietitian. How you are going to achieve your outcome.

Finding the balance between encouraging and allowing individual clinical judgment, while ensuring the outcomes were evidence-based, was particularly challenging.

Like most patients with a chronic disease, renal patients very rarely fit into specific patient pathways. They usually present with multiple dietary, dialysis and medicines management issues. However, although not reflective of current practice, it was felt that focusing on each dietary intervention in isolation would allow the sub-group to improve their understanding of the rationale for dietetic intervention and consider outcome measures to prove the value of that specific intervention.

The group knew it was important to acknowledge that renal dietitians do not work independently but work as a member of a multi-professional team. Therefore, the challenge would be to capture the information required to demonstrate what part of the outcome relates specifically to the dietitians role within the team, whilst acknowledging the role the dietitian has in identifying when something is outside their remit and making an onward referral to another member of the multi-professional team. Capturing the aptitude of a dietitian to educate and empower a patient through skilled communication was felt important. It was agreed that any facilitation undertaken to help achieve an outcome should be captured in the outcomes tool.

Capturing outcomes would be challenging due to non-nutritional factors falsely affecting nutritional parameters in chronic kidney disease (CKD) patients.⁴ The sub-group felt by identifying and acknowledging these 'barriers' at the start and end of an episode of care that this would provide a broader understanding of the nutritional related outcomes.

Finding the balance between encouraging and allowing individual clinical judgement, while ensuring the outcomes were evidence-based, was particularly challenging. As with a lot of clinical practice the evidence base is often somewhat limiting. Yet to ensure this tool was embraced by not only renal dietitians but, ultimately, the wider dietetic team, being evidence-based was deemed to be pivotal to its success.

One aspect perhaps not initially discussed, was how we capture the longevity of any change achieved. If we could demonstrate a change, how could we demonstrate that this change was sustained and that it was achievable for most units in terms of the amount of dietetic time needed to achieve and sustain this change. It was therefore important to try and capture the timeframe and frequency of reviews.

Throughout the discussion, the group unanimously agreed that despite the perceived complexity of what we were trying to achieve the tool should be simple to use and had to be adaptable to both paper and electronic record cards. Without this it was felt that the usage and uptake of the tool might be affected.

Capturing patient experience is a NHS driver but something that dietitians have limited experience of. The group identified that capturing

patient experience was paramount to add validity to the results. There were few validated tools to capture this data and ideally they were to be completed anonymously. Patient experience was agreed as a goal and was included in the outcome tool. However, we now appreciate that due to its anonymity it could not be linked to an individual patient health outcome. Patient experience should be captured separately to review a service or individual dietitians performance.

Literature review

A literature search was undertaken to answer the question: *"Is there evidence to demonstrate the effectiveness of a renal dietitian in practice?"* The search identified published papers only, therefore, predisposing this review to publication bias. It is possible that renal dietitians may have conducted local service evaluations or audits that had not been shared with the wider profession. Overall there was a dearth of good quality research on which we could link positive outcomes to dietary interventions. These findings were reflective of a recent systematic literature review conducted by Ash *et al.*⁵

Guidelines on the nutritional management of a patient with CKD have been developed nationally and internationally. They provide the renal dietitian with an evidence base and offer consistencies within their practices. Along with patient values and practice-based evidence this can provide the core requirements to offer a safe and quality service. Some studies have shown that time constraints, and concerns that guidelines are outdated, have resulted in renal dietitians not implementing guidelines.^{6,7} However, measuring the outcome of a dietetic service following the implementation of guidelines has shown positive patient outcomes.⁸

Scoping national and international groups

A scoping exercise was undertaken to establish whether any renal dietetic services in the UK had started work on measuring outcomes. The BDA specialist groups and international associations were approached.

RNG members showed interest and support in the development of this work; however no developments in measuring outcomes had begun at that time. No feedback was received from international colleagues.

Diabetes Management and Education Group (DMEG) were actively looking at clinical outcome measures and had developed a tool in which they were starting to evaluate. Reflection on the RNG process was compared and contrasted with DMEGs experience. Similarities were found between the groups when discussing the concerns and barriers of collecting outcomes. The tool created by DMEG was offered as the starting framework to the outcome tool.

Developing the outcome models and tool

As there was limited guidance, the sub-group agreed to use the BDA document as the framework from which to develop the outcome models.³ An outcome model was developed for each dietary intervention and included an overall outcome; a time frame to achieve the outcome and a rationale to the dietetic intervention (Figure 2). National guidelines and best practice

evidence were referred to when deciding what goals and outcome measures could be used to demonstrate how a dietetic outcome was achieved. Each goal was coded to enable easy collection of data.

To capture this data an outcome tool was developed by adapting the DMEG tool. Following the development of the outcome models and tools the sub-group conducted a pilot study.

Figure 2: Example of Outcome Model

BDA RNG: Clinical Outcomes for Management of Serum Phosphate in Pre-Dialysis and Dialysis Patients (Haemodialysis and Peritoneal Dialysis)		
Outcome (end point)		
To achieve and maintain target serum phosphate level within nationally agreed target ranges whilst ensuring an adequate dietary protein intake		
Time Frame		
To achieve and maintain target serum phosphate level (and an adequate dietary protein intake) within ____ months (or following initial dietetic assessment and advice and ____ dietetic reviews).		
Rationale for Outcome		
High serum phosphate levels in patients with CKD lead to increased mortality through hyperparathyroidism, mineral and bone disorder, increased vascular calcification and cardiovascular events.		
Low serum phosphate levels and low dietary protein intakes in patients with CKD are associated with increased mortality and protein energy wasting.		
NICE recommends that the initial management of hyperphosphataemia should be provided by a specialist renal dietitian, who should give individualised information and advice on dietary phosphate management. It is important to ensure that the patient maintains an adequate protein intake when reducing their dietary phosphate intake. The patient needs to receive support and guidance to increase their dietary knowledge on foods high in phosphate and foods with phosphate additives. Making the appropriate food choices, along with the use of appropriate medication for phosphate control, should lead to lower incidence of hyperparathyroidism, CKD MBD and CVD.		
An adequate dietary protein intake whilst achieving a serum phosphate level within an acceptable range should reduce the risk of mortality and morbidity in patients with CKD.		
Current recommended target range for serum phosphate:		
<ul style="list-style-type: none"> CKD 3b-5 (not on dialysis) 0.9-1.5 mmol/l^{9,10} CKD 5D 1.1-1.7 mmol/l^{9,10} (measured before a 'short gap' dialysis session in HD) 		
Current recommended target range for dietary protein intake:		
<ul style="list-style-type: none"> CKD 3b-5 (not on dialysis) 0.75-1 g/kg IBW¹¹ CKD 5D 1.0 -1.2 g/kg IBW¹² 		
Plan		
The renal dietitian will provide specific intervention that is individual to the patient and will help them to achieve the outcome jointly agreed.		
Indicator	Goal	Outcome Measure
Biochemistry	<ul style="list-style-type: none"> Achieve serum phosphate within target range (G8) 	<ul style="list-style-type: none"> Serum phosphate level
Dietary Knowledge	<ul style="list-style-type: none"> Understand benefits of dietary advice (G13) Understand how to make dietary changes required (G14) 	<ul style="list-style-type: none"> Knowledge questionnaire - State 3 foods (ETDNA)
Behavioural/ Psychological	<ul style="list-style-type: none"> Empowered to make dietary changes (G17) Increase confidence (to be able) to make changes (G16) Achieve agreed dietary changes (G15) Achieve nutritional adequacy (with regard to protein intake) (G1) Improve concordance with relevant prescribed products (G18) 	<ul style="list-style-type: none"> Patient reported motivation/change in behaviour Confidence scaling Diet history or food frequency questionnaire Assessment of DPI (Dietary Phosphate intake). Patient reported taking correct dose of binders at correct time
Physical	<ul style="list-style-type: none"> Achieve stable weight (G12) 	<ul style="list-style-type: none"> Dry weight
Symptoms	<ul style="list-style-type: none"> Reduce phosphate related itching or red eyes (G5) 	<ul style="list-style-type: none"> Patient reported level of itching or red eyes
Patient Experience (essential at end of episode of care)	<ul style="list-style-type: none"> Patient feels they have had a positive experience (using locally agreed tools) (G20) 	<ul style="list-style-type: none"> PREMS questionnaire

Pilot study

The aim of the pilot study was to ensure the clinical outcome models and tools developed were functional and practical. The members of the sub-group volunteered their dietetic departments to partake in the pilot.

An 80% response rate was achieved. One hundred and ten audit tools were completed and returned for analysis. Feedback questionnaires were also completed by nineteen staff from the sub-group dietetic departments. Improvements on formatting and wording were fed back; however, it was felt that the right detail was captured.

The mean number of outcome measures used to show an overall outcome was four. As a result of the pilot study the number of goals were reduced from 40 to 20 and the outcome tool was changed from a paper copy to an excel spreadsheet (Figure 3). The tool was designed to be quick and easy to complete by using drop

down menus. The aim was to capture purposeful information at the start and the end of the episode of care only, as it was felt detail during the episode of care was surplus.

Summary

A national audit has recently taken place to evaluate current dietetic practice in a renal adult outpatient setting. Twenty three UK renal units have taken part and used the outcome models and tool to capture this data. The results will be shared in future publications.

To get to that point we have needed to go through the process of:

- Setting clear aims and objectives with appropriate time frames
- Defining and agreeing outcome terminology
- Piloting our work
- Patience to adapt and review
- Sharing of information to avoid reinventing the wheel!

Figure 3: Example of the Outcome Tool

The table in the screenshot is titled 'PLANNED CLINICAL OUTCOME OF DIETETIC TREATMENT: To achieve and maintain serum phosphate within an acceptable range'. It has the following columns: Patient No, CKD stage, Data to be added at initial consultation (Start date, Treatment Goals Set, Barriers (Start)), Data to be added at end of patient episode (Baseline Value Phosphate mmol/L, Final value Phosphate mmol/L, End date, No of times seen), Treatment Goals Set at start, Outcome for each Treatment Goal, Barriers remaining at end, Facilitators Used, Was overall outcome achieved?, and Comments eg list "other" barriers. The rows are numbered 1 to 26, representing individual patient episodes.

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