

Improving the Visualisation of Renal Blood Test Results to Enhance Patient – Clinician Communication

Abstract: Dialysis patients in the UK usually undergo routine monthly blood tests which support the medical team in assessing their ongoing condition. Based on these results, clinicians then advise the patients on appropriate changes to diet and/or medication to improve their health. Whilst the results of these blood tests can be made available to the patient via an online patient portal, their presentation is primarily numerical. While this style is applicable to medical professionals who are able to interpret such results, it is less accessible to patients, restricting their ability to readily engage with their own results. This research presents a collaborative design approach aimed to produce alternative ways of visualising blood test results that meet both the needs of clinicians and the patient with the aim of enabling patients to be more actively involved in managing their own condition.

Keywords: Renal dialysis, wellbeing, design, blood results, data visualisation, patient empowerment.

1. Introduction

As part of the ongoing monitoring for dialysis patients in the UK, routine blood tests are usually carried out on a monthly basis. When the blood tests results are known, the patient's medical team, consisting of a doctor, dietitian and nurses, reviews each patient's blood test results and determines if any action is required. The appropriate team member, for example the dietitian, then discusses the blood results with the patient and suggests changes to diet, medication or lifestyle to help the patient optimize the management of their condition. An example of this process is taken from our research at The Westmorland General Hospital in Kendal, Cumbria, UK, where the dietitian prints out a spreadsheet with all the patients' data for that month (Figure 1).

1	Name	NHS	CCG	Date	K	NA	Pre Urea	Post Urea	Cre	Phos	CCa	BIC	TP	Alk-Ph	New PTH	Albumin	Chol	HbA1c	Hb	Ferritin	HCT	URR
2				07.01.15	3.7	127	13.3	3.7	748	1.24	2.19	25	64	121		29			111		0.341	
3				08.01.15	4.7	136	17	3	711	1.12	2.26	26.9	61	68		37			108		0.305	
4				08.01.15	4.7	138	17.8	4.8	592	1.34	2.21	28.4	75	112		38		57	106		0.315	
5				08.01.15	4.3	134	11.7	4.3	743	1.2	2.4	31.3	59	70	12.8	30			88		0.264	
6				08.01.15	4.6	137	12.6	2.4	506	2.2	2.55	28.2	62	156		33			93		0.268	
7				06.01.15	4.2	143	32.2	4.4	572	1.6	2.29	28.2	56	76		35			81		0.238	
8				08.01.15	4.5	137	12.2	3.4	369	1.07	2.55	29.9	64	187		28			135		0.417	
9				08.01.15	4.1	135	16.8	4.1	722	1.11	2.28	24.6	72	75		39		84	114		0.331	
10				07.01.15	4.1	133	10.7	2.6	573	1.44	2.27	26.9	67	80		32		51	138		0.431	

Figure 1. Extract from the medical practitioner's spreadsheet used on the ward. Due to privacy concerns, the names of all patients have been removed.

Any patients with blood results outside the acceptable ranges (based on the national UK renal guidelines) is then prioritized and seen individually to discuss their results; the dietitian will make suggestions to help the patient improve their medical condition and subsequently optimize their future results. Due to privacy and confidentiality of other patients' data, the patient is not shown the data on the spreadsheet. For a new patient, unfamiliar with the terminology, too ill or with little knowledge of how blood test results should be read, reliance on the medical practitioner to act as a translator could provide a barrier with the understanding of their own blood results in situations where the representative of the medical team is not present. As such, the process of empowering the patient (Bridges, et al, 2008), where the knowledge held by the medical practitioner is interpreted, transposed, and finally passed onto the patient, can be undermined by the complexity of the data presentation. This can lead to the patient becoming a passive consumer of own generated data until knowledge is acquired and agency of data passed to the patient which could in turn limit the patient's learning, comprehension and understanding of the analysis and finally their treatment. The importance of patient involvement in managing health conditions, particularly in relation to chronic long term conditions including Chronic Kidney Disease (CKD) has been recognised by the National Institute for Health and Care Excellence. Clinical Guideline 182 (CG182, 2014) highlighted that patients with CKD should be supported and encouraged in self-management with regards to accessing their test results and medical data.

Over the past decade different research projects (Munir, et al, 2000; Ueckert, et al, 2003; Wensing, 2000) have highlighted the direct relationship between patient treatment and access to medical information and the need to provide patients with online access to an Electronic Healthcare System (EHS). Patient View¹ is the UK online system implemented and supported by the National Health Service (NHS) where, amongst other useful information, the patient can access their blood test results. It employs a card style web visualisation (Figure 2), where each card displays the name of the nutrient or waste product eg. phosphate, potassium, urea (and sometimes only the shortened name), its numerical value on the day of the analysis, the day and location of when and where the analysis was performed and an arrow to indicate where more information can be found.

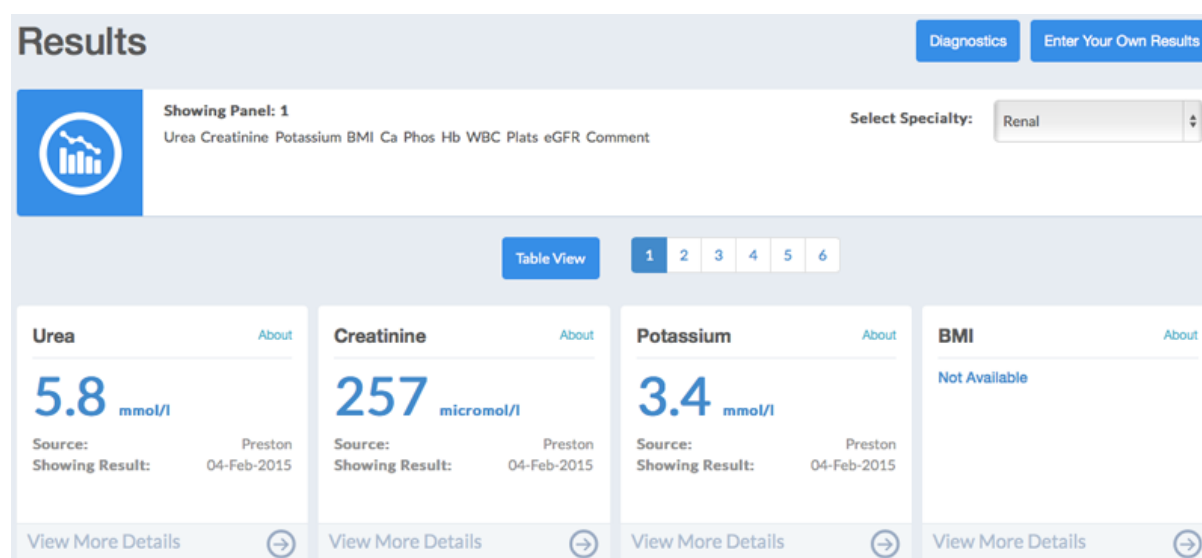


Figure 2. Patient View extract from a patient's data.

¹ <https://www.patientview.org/>

Each waste product or nutrient also has an 'accepted' range, based on current UK guidelines, which allows the patient to view the evolution of their health. Unfortunately, this range is located on the back of the card, which requires the patient to interact with the card visualisation making the whole process cumbersome and the understanding of the information difficult. Whilst the Patient View platform provides the patients with access to their information it also requires them to have a high level of numerical and health literacy skills² to determine the relevant information and comprehend its meaning. Cavanaugh et al. showed that limited health literacy is common in some haemodialysis³ patients (Cavanaugh, et al, 2010) whilst Abdel-Kader et al. suggest that:

“clinicians caring for patients with kidney disease should consider using tools to enhance communication and overcome limited numeracy skills” (Abdel-Kader, et al, 2010). “Although health literacy appears to be an important predicament of poor health behaviours and outcomes, addressing health literacy is not the responsibility of patients but rather that of the multidisciplinary system of health care delivery.” (Cavanaugh, et al, 2010). Lastly, “we need to recognize that the target of this information [test results], should not be the doctor, should not be the insurance company. It should be the patient. It’s the person who actually, in the end, is going to be having to change their lives and then start adopting new behaviours. Ordinary people are capable of understanding this information, if we only go to the effort of presenting it to them in a form that they can engage with.” (Goetz, 2010).

Unfortunately, Patient View was designed to be accessed solely by patients, thus the medical team cannot enable the patient’s understanding of this data whilst on the ward. This creates a disconnection between what information is available and how it is understood by the patient. Whilst the final aim of the medical team is to create a shared language with their patients, because of the current practices and the way in which the relevant information can be accessed, the medical team is forced to rely on different approaches to achieve their goals.

To help medical teams encourage patient-clinician communication on the ward and in the clinic by empowering the patients with the required knowledge to become active participants in the management of their own health, whilst overcoming the limited health and numeracy skills experienced by some renal patients, an emphasis on the presentation of information could be of benefit. To this end, this research focuses on how design practices and especially information design can help patients in the understanding of their blood results with the final aim of providing the patient with more independence in the decision-making process with respect to their well-being. To achieve this goal, the medical team needs a tool which can be shared with the patient during consultations to present the blood result data to their patients, in such ways that both communication with and independence from the medical practitioner is achieved. The proposed solution takes the shape of a web application with a clear focus on the presentation of data by removing the attention from its numerical aspect and switching it to the visual emphasis of the relationship between the nutrient or waste product and their accepted range according to national standards.

² “ability to obtain, process, and understand basic health information to make appropriate health decisions about one’s health and medical care” (Nielsen-Bohlman, et al, 2004)

³ Haemodialysis is the most common type of dialysis performed today and consists of a tube being attached to a needle and inserted into the patient’s arm via a fistula or neckline. Blood flows from the patient into the dialysis machine where it is filtered through a dialyser which clears the blood of harmful toxins in a similar way to a functioning kidney. The blood is then passed back to the patient through the use of a different needle. Each haemodialysis treatment takes approximately four hours and it is usually done for three days a week.

2. Background

2.1. Inception

The initial inspiration for the project arose from Jeremy Davenport's (co-author) experience as a renal "crash-lander"⁴ which led him to Ward 25 at Preston Royal Hospital (February 2014), where he was diagnosed with chronic kidney disease (CKD) requiring on-going dialysis at the Kendal Dialysis Unit (3 x 4 hours per week). While initially too ill to pay attention to blood test results, over the coming weeks and months, access to monthly blood tests played an important role in catalysing learning and understanding about CKD and its impact on the body. Regular consultations with Heather Hill (dietitian at the Kendal Dialysis Unit, Kendal, UK and co-author) provided the development of a shared plan of action (changing diet, medication, etc.) and the initial seed for this research. The following subsections describe the scope and design considerations of the project and its outcomes.

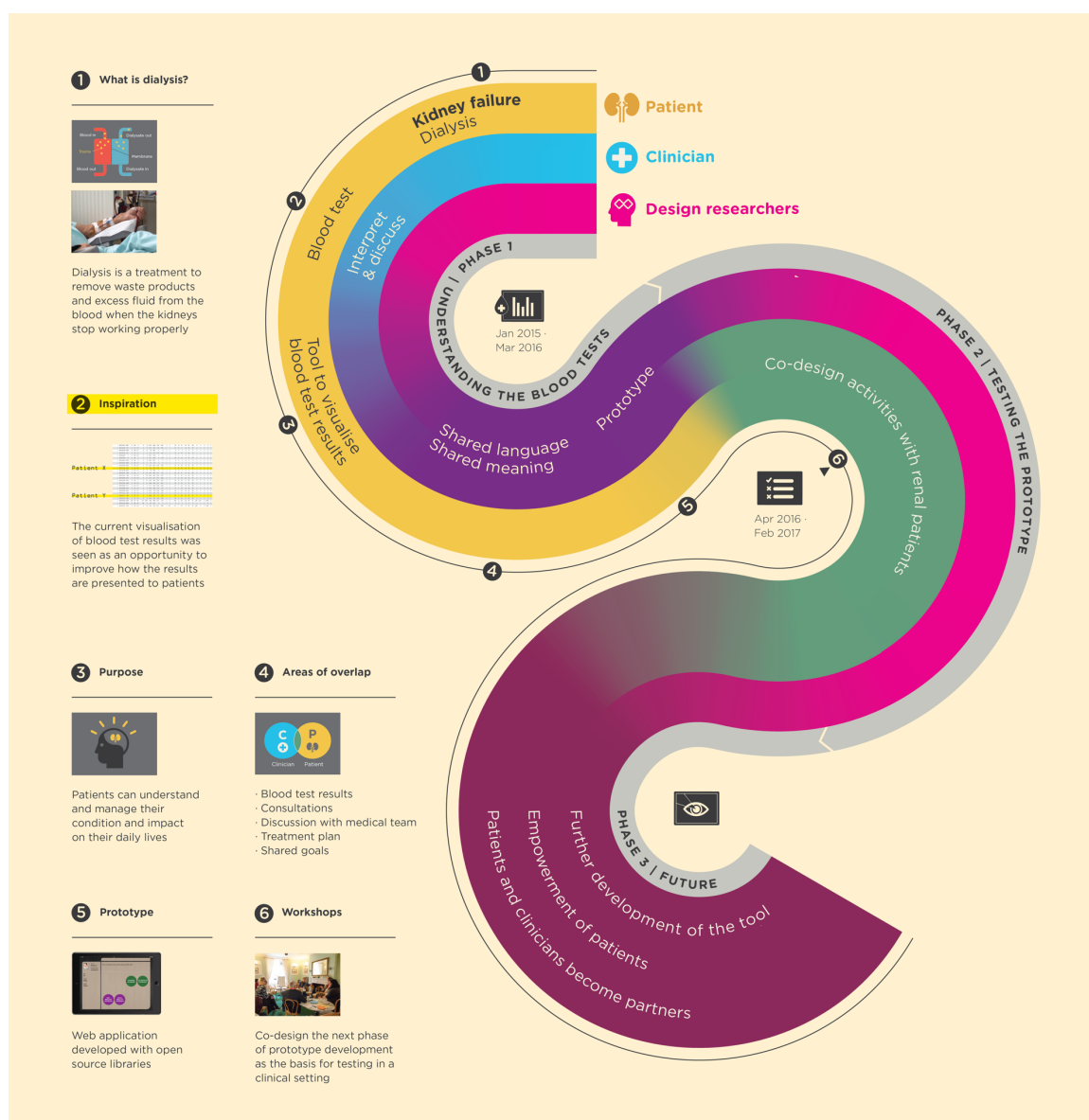


Figure 3. Project journey visualisation

⁴ Crash-landing is the nontechnical expression used by clinicians to describe the very quick onset of severe kidney failure and subsequent need for dialysis.

2.2. Project Scope

The immediate focus of the project fell on the creation of a tool to encourage patients to take a more active role in the management of their own health, however, the overarching goal of the project was to help the renal team at Lancashire Teaching Hospitals in developing innovative approaches to strengthen patient understanding of chronic diseases such as CKD by demonstrating the value of design as a professional and research discipline. These goals have been achieved through the use of a collaborative approach by encompassing both a clinician and a patient into the research team which facilitated discussions across disciplines and resulted in knowledge being acquired and exchanged on both sides. Whilst the model of shared decision making in healthcare is not necessarily new (Charles, et al, 1997; Charles, et al, 1999) having also been recognized by the NHS (Fairlie, 2015), our approach uses participatory design methods by bringing the design decisions of both patients and clinicians together and in combination with the shared decision model proposed by Entwistle and Watt which looks at

“what patients and clinicians do and say in relation to decision-making, but also how they think and feel about their relationships with each other and their own roles, efforts and contributions relating to decision-making.” (Entwistle and Watt, 2006).

The differences in methodology and wider research paradigms were reflected in the different languages used by the professions, the different needs of the clinicians and the patients as the primary user groups and the paramount importance of embedding clinical good practice in the prototype. This method, as well as the way the team worked together to achieve the set goals, can be better visualised in Figure 3.

2.3. Design Considerations

As previously mentioned, the priority was to situate the project in respect to the needs of both the patient and the clinician.

“There is limited evidence about how best to communicate results in a manner that is not only satisfying to the patients but also assist them into incorporating the results into personal health decision making” (Elder, et al, 2012).

Therefore, the focus fell on creating a shared map of the key questions and themes associated with visualising blood results covering the views from both parties. Through iterative discussions and meetings, with different renal dietitians and medical practitioners associated with Lancashire Teaching Hospitals Trust as well as internally within the project team, a shared language was developed. This newly formed knowledge and understanding of the area led to a project being developed which was based upon the following principles that guided the development process and resultant prototype.

1. Focus on understanding and addressing the users’ needs (clinicians and patients).
2. Simplicity.
3. A prototype that is aligned with clinical guidance and evidence based practice.
4. A practical and low cost solution.
5. A tool for visualisation that will meet the varying needs of patients with different capabilities and in different contexts (e.g. on the dialysis unit, ward or clinic setting).
6. A way of presenting data that will encourage discussion between the clinician and patient and which will catalyse a better understanding of test results by the patient.

The preliminary conversations focused solely on the two nutrients which a patient can aim to control through diet (phosphate and potassium) however, to encourage conversation and enhance understanding, the final prototype extended the method to incorporate additional metrics. This extension of metrics means the prototype is applicable for use by the wider renal multidisciplinary team to facilitate exchange of knowledge, for example in anaemia management (Figure 4).

Following initial discussions with the dietitian, a key point that emerged was that for some patients their 'normal' or usual blood test results may always fall slightly outside the accepted ranges. As such, a key design feature has been the provision for clinicians to adapt the patient's ideal range to reflect their unique circumstances and thus providing a powerful tool to enable bespoke interpretations as required. To emphasise colour rather than the numeric presentation of data, the proposed prototype utilises a binary colour system to show where a given value is situated; green when the value is located within the accepted range for that nutrient or waste product and purple when the value is outside of the range. The colour scheme was chosen to accommodate people with vision disability without providing a positive or negative connotation for a particular result. By not focusing solely on the numerical value, the patient has the necessary visual means to understand the test result in relation to the accepted range (for that nutrient or waste product). The proposed system is presented as a dashboard which should make it easier to understand for patients and their families/carers. Following team discussions, it was felt that the ideal tool should encourage dialogue between the patient and the medical team during the consultation thus, the dashboard was designed for a 10" tablet (iPad) as a viable screen size for visualising data whilst being easily portable for use on the dialysis ward as well as in clinic. An active Internet connection, allows the clinicians to provide the patient with additional information as required, thus giving an enhanced experience and contributing to the assimilation of the received information.

3. The Prototype

The dashboard has three different levels of data visualisation. Each level is designed to give more insights into the data, starting from level one, with an overview of the whole data, split into four different categories (Diet Results, Bone Results, Anaemia and Clearances); level two, which shows the last analysis date for the chosen category, and finally level three where the user can access their historical data, an overall image of the last twelve analysis dates.

3.1 Overview

The first level of the dashboard (Figure 4) allows the user to visualise high level of data for the last blood test date. The view is split into two different panels: the left panel presents information about the current user which gives the dietitian context about the user (last analysis date, name, age, height and weight of the patient); and the right panel, which presents the four previously mentioned categories in form of circles. Each category contains two nutrients or waste products, relevant to the group, and the same colour scheme is used throughout; i.e. a purple circle is used when at least one of the values is outside the accepted range, whereas a green circle shows all values within the group are in their accepted ranges. To further emphasise the differentiation between the 'in range' values compared to the 'out of range' ones, the positioning of the circles dynamically changes based on the data: if all the parameters for that specific category are within their accepted ranges, the circle will be located at the top of the page, whereas, if at least one of the nutrients or waste products is outside of their allowed ranges, the circle will be situated at the bottom of the page.

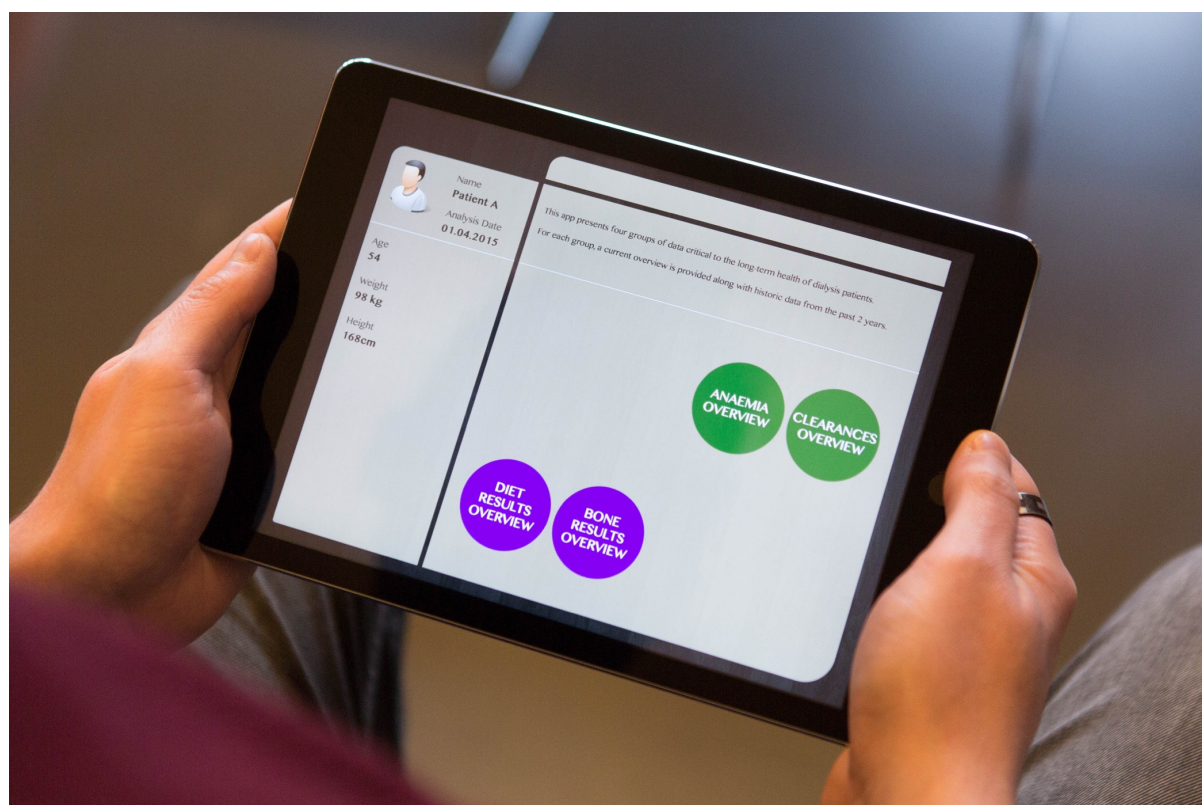


Figure 4. A live version of the prototype depicting the Overview of the prototype.

3.2 Detail View

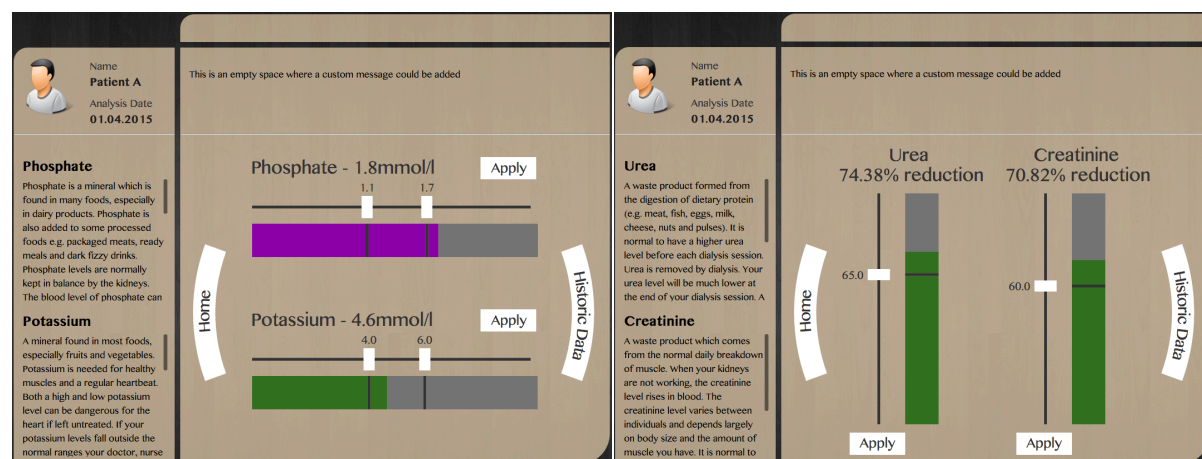


Figure 5. Detail View. Bone Results View (the same visualisation is used for both Diet Results and Anaemia Results) (left), Clearances View (right)

If the medical practitioner or patient needs further information on the patient's last results, they can tap onto the relevant circle, and the view is moved to the second level (Figure 5). Here, each nutrient or waste product is presented in detail. The same layout used on the first level is employed here as well, however, for this level, the left panel provides a short description of each nutrient or waste product, whereas the right panel presents the data in both visual and numerical format to allow for both the needs of the medical team and the patients. It displays the name of the parameter and the current value on the day of analysis, as well as their accepted range. In general, the data can be visualised by a horizontal bar with two sliders (Figure 5, left), where the sliders represent the lower and consequently the higher values of the 'accepted' range for a parameter as defined by the current

renal standards. The Clearances View (Figure 5, right) is a special case due to the uniqueness of the data displayed on this view. In this case, the medical practitioner looks at the percentage reduction calculated by the values given at the beginning and end of the dialysis procedure. As such, to better depict 'a drop' in values, a vertical bar was used with only one slider, since there's only one value the clinician can modify. The same colour scheme used on the Overview Page is used on the Detail View as well, with the same implications; if a parameter is within the 'accepted' range, the visualisation will be green whereas, if its value is above or below the range, purple will be used. The clinician can modify the 'accepted' range for a particular nutrient or waste product if required to better fit the 'normal' ranges for the patient. This decision was based on the fact that some patients' data might never fit the 'accepted' guidelines since they might be suffering from other medical conditions which will overall impair them in achieving 'perfect' dialysing results. As such, the current prototype tries to fit the data to the individual patient and their unique medical conditions and not the other way around, which seems to be the typical case when using medical information and data. Finally, the 'Home' and 'Historic Data' buttons located on each side of the panel are used to navigate between the levels of the prototype.

3.3 Historic Data View

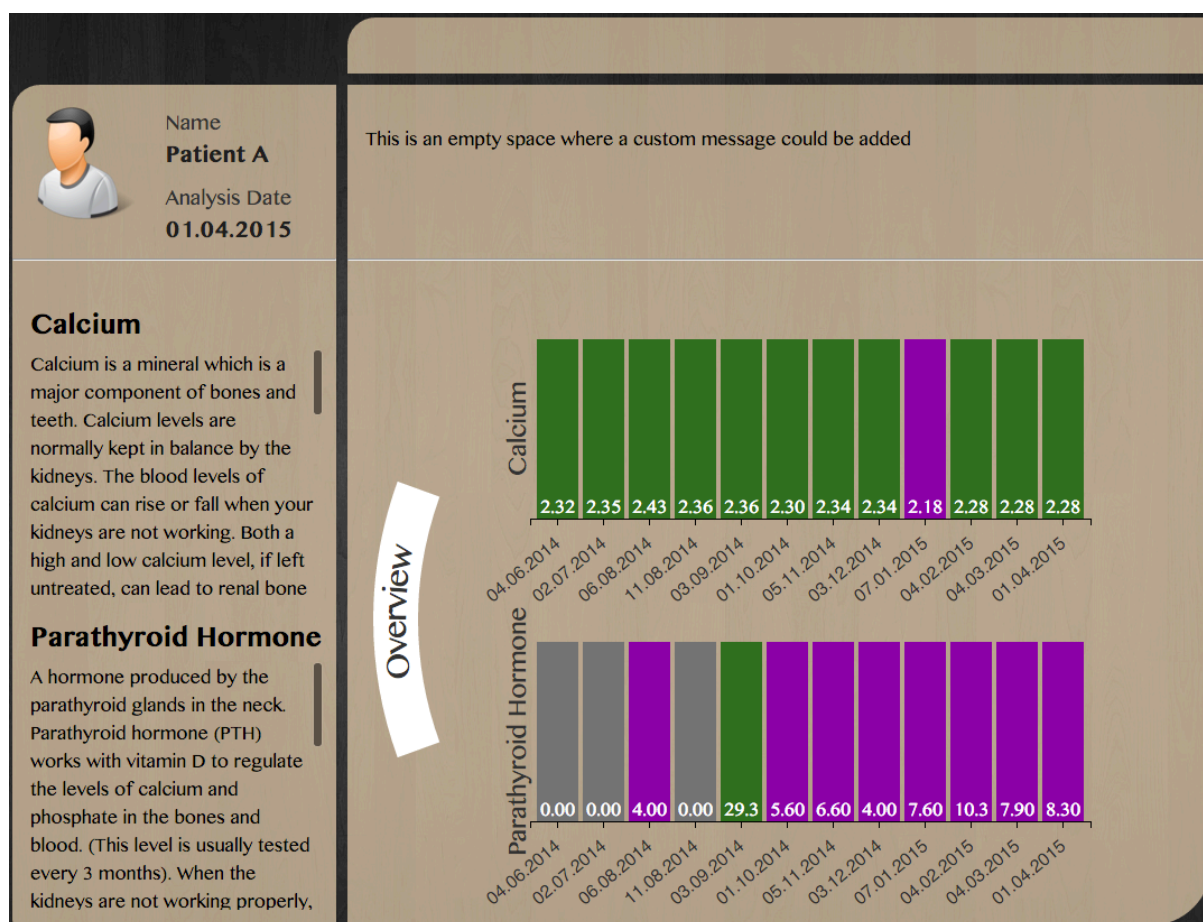


Figure 6. Historic View.

The third and final level, accessed via the "Historic Data" (Figure 6) button presents the values of the given metric over time and was introduced to visualise and help making informed decisions about the evolution of the patient. The layout is split the same way to the Detail View with a left-hand panel displaying information relating the nutrient or waste product. The right-side panel displays the

last twelve blood results data in a bar chart format. Similar to the former view, the data presented is both in numerical and visual form with the same colour scheme and meaning associated with each colour (green for in range, purple for out-of-range results). Uncharacteristically for a typical bar chart, the Historic Data View shows all bars at the same height despite their numerical value, with no explicit ranges visible. This decision was taken in order to move away from the numerical emphasis and the implicit comparison of one result to another. By having the bars at the same height, it is believed that it emphasises that it is the overall trends that are important and not the comparison of individual values.

4. Focus Group

Whilst a patient was part of this research group and his constant input shaped the final design of the prototype, a focus group was held by the research team's dietitian (in partnership with the University of Central Lancashire) to determine the overall perception of the current design and functionality of the prototype so that improvements could be made. This exercise was held at a venue outside the NHS setting and included a group consisting of patients with CKD, their carers and friends recruited through a local support group⁵ where, the research team's dietitian allowed the participants to first interact with the prototype and later on record their opinions on additionally provided materials. Although the current prototype was designed to act as a communication enabler between the medical practitioner and the patient during clinical situations where all the information would be presented by the clinician, during the focus group the participants were handed an iPad running the prototype and were encouraged to read and understand the information at their own leisure. The reasons for this approach is twofold: firstly, due to the small number of medical practitioners familiar with the prototype it would have been difficult to provide a one-to-one introduction to the visualisation tool and secondly, an overall desire from the research group to understand where the medical team will need to focus their attention in presenting the data to the patients.

The focus group consisted of a total of 7 participants: 5 patients and 2 carers. All patients were over 60 years of age and all having been diagnosed with CKD more than 5 years ago (one patient for 5 years, 4 patients for more than 10 years). All the participants found the prototype extremely useful with comments ranging from: "I am quite elderly – so actually being shown – is more than helpful", "I think even doctors in clinics would find it easier and quicker to assess results of individual patients" and "think this will help, especially to those patients who show little interest". The overall colour scheme was found easy to use, with a clear separation between 'in range' and 'out-of-range' values. None of the participants negatively complained about the chosen colour scheme and indeed one of them, suffering from colour blindness, noted that it provided an "easy colour to follow". Lastly, all participants found the size of the written information to be appropriate. On the negative side, most participants complained about the vertical display of the data for the Clearances group on the Detail View (Figure 5, right), however, all of them understood it when the focus group facilitator provided the required explanations and the reasoning behind the chosen visualisation. One participant mentioned that "a line or bar graph should show change overtime" while referring to the data displayed on the Historic view. Another participant expressed interest in showing the "good and bad results" (data) or "wider information available on Patient View". Lastly, one participant expressed their desire to see more information relating to which blood results were contained within each circular display on the home page.

⁵ Outside of and not belonging to the NHS.

4. Conclusion and Future Work

The proposed prototype concentrates on the visualisation of blood results and removes the focus from the numerical aspect of the presented data. It was designed to facilitate the conversation between the clinician and the patient by allowing the latter to visualise the blood results whilst on the dialysis machine or in clinic and thus taking a more active role in managing their own condition. By changing the focus from the numerical aspect of the data to how the data is presented, the numerical and understanding difficulties encountered by some patients could be overcome.

The current work has been developed on the basis of continuous input from both the medical practitioner and the receiving patient. It has been presented at The South Cumbria and Lancashire Renal Dietitians' meeting at Royal Preston Hospital where more than 10 dietitians provided their valuable input on the initial stages of the making of this prototype. Through her practice, Heather Hill has been in regular discussion with the renal consultants at Kendal Haemodialysis Unit, which have also shaped the design of the final prototype. The focus group held by the dietitian was deemed successful with all participants noting the importance, relevance and functionality of the proposed tool. The minor negative comments might be due to the composition and setting of the focus group and it being held in a different manner to how the prototype was designed to work. However, it is important to note that since most of the participants did not fully understand the Clearances View, it may require a re-design of this page. Additionally, the team will explore the suggestions made by participants with reference to the content of the home page.

The next stages will see the design and delivery of a clinical study to evaluate the utility of the prototype in a clinical setting at the Kendal Dialysis Unit, in order to obtain direct feedback from a wider sample of patients and clinicians. Based on the analysis of the impact and received feedback, the prototype will be presented to a board of doctors and managers and hopefully made available to all the patients receiving dialysis within Lancashire Teaching Hospitals Trust. Discussions have already taken place between the research and the renal IT team at Preston Royal Hospital regarding the required infrastructure and best practices to facilitate the use of the prototype in clinical situations. Due to information governance and strict confidentiality procedures within the NHS, the process of embedding the individual patients' data and making it accessible is likely to take time. However, we are hopeful that the added value of this research proves its usefulness to both clinicians and patients and will be adopted more widely. Finally, it is our belief that the principles we have explored are directly relevant to other conditions and clinical contexts where blood tests results are presented to patients such as GP surgery, transplant, diabetes, etc.

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About the Authors:

Adrian Gradinar is a PhD student at Lancaster University focusing on the intersection of the digital world we are surrounded by and the physical one we actually reside in by creating better experiences for everyone living and experiencing this hybrid space.

Jeremy Davenport is a PhD at Lancaster University. His research is focused upon understanding the design and delivery of complex collaborations between Universities and partner organizations specifically, at the interface between digital technology, innovation and the UK's creative industries.

Heather Hill is a Specialist Renal Dietitian at Lancashire Teaching Hospitals NHS Trust. Her main interests lie in the field of exploring new innovations to improve patient experience for those with Chronic Kidney Disease.

Paul Coulton is the Chair of Speculative and Game Design in the open and exploratory design-led research studio Imagination Lancaster. He uses a research through design approach to create novel interactive systems.

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