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# **SUPPORTING SCIENCE STUDIES FOR CHILDREN WITH LONG TERM HEALTH PROBLEMS USING NEFREDUCA**

Denise Whitelock\*, Roser Pintó, Marcel.la Saez

\*The Open University, [d.m.whitelock@open.ac.uk](mailto:d.m.whitelock@open.ac.uk)

## **ABSTRACT**

Children with long term health problems cannot always maintain their schooling and keep up with the curriculum (Prevatt et al., 2000; McDougall et al., 2004). They also spend prolonged periods in hospital where access to science teaching is very limited (Sobrino, Lizasoain & Ochoa, 2001). In order to address this problem, the Nefreduca project was designed to develop a short science curriculum for children in Spain with chronic kidney disease. The Nefreduca project was designed to develop a series of open source science inquiry based web learning materials for children with chronic kidney disease. In this paper the learning design strategies employed to build the Nefreduca platform are described, together with how the students' conceptions of the Kidney's role in the nutrition process were extended whilst trialling the Nefreduca materials. The students' notions of the kidney also changed after using the Nefreduca programme. Their answers illustrated a deeper understanding of the urine production process, its constituency; and its connection to the blood filtration that occurs in the kidney. These findings suggest that the Nefreduca activities could serve as appropriate teaching material for scaffolding the students' mental models of the kidney.

## **KEYWORDS**

Science concepts, Biology, chronically ill students, hospital school, open source

## **INTRODUCTION**

Even though medical advances are facilitating a longer and better quality of life for children with long term health problems, they are still recurrently hospitalised. This means it is difficult for these children to keep up with the school curriculum and maintain the normal rhythm of the annual education cycle, (Sobrino, Lizasoain & Ochoa, 2001; Prevatt et al., 2000; McDougall et al., 2004). Unfortunately missing lessons can generate lower science literacy in children who receive science enriched information from medical staff, throughout the course of their illness. Therefore, they may not be able to fully comprehend the full extent of their illness which in turn can impede compliance with their treatment and recommendations for their future lifestyle and diet. Furthermore, regardless of whether a place in a hospital school is available for them the children's access to a science curriculum is still reduced, due to the usual lack of science teachers and the appropriate resources for teaching-learning science topics. To deal with these problems we have been working since 2007 on the Nefreduca Project, which has focused upon the design and implementation of a science based-web teaching and learning sequence about nutrition and kidney function, for hospitalised lower secondary school students with chronic kidney disease.

This paper describes the learning design strategies employed to build the Nefreduca platform and how the students' conceptions of the key biological principles concerned with the kidney have been elucidated while trialling the Nefreduca materials.

## BACKGROUND

There are a large number of learning theories which can guide the design of learning activities. These have been well documented by Mayes & De Freitas (2007) who identify three clusters of theories which are grouped together with respect to their assumptions about the nature of knowledge. These include:

- the associationist perspective
- the cognitive perspective
- the situative perspective

With respect to e-learning they argue that an associationist perspective describes the activities and outcomes from these activities that an individual learner will become engaged in. The cognitive perspective looks at these activities in more detail and describes the processes that underpin individual performance whereas the situative perspective looks at groups of learners and describes the group systems and activities which are used by individual learners. We concur that each of these three perspectives play an important role in learning and as we were designing e-learning materials which in the early stages might only be used by individual children learning science in hospital schools, we still needed to bear in mind the situative perspective since ideally we would like our platform to accommodate online collaborative learning features. Therefore these three perspectives provided an over-arching framework for the long term design objectives for Nefreduca which would then have the potential to include a rich variety of ICT tools that could be used to support the e-learning delivery.

There are a number of taxonomies that have been developed to assist with the definition of all the components involved in a learning activity (see Conole and Fill, 2005; Bailey et al, 2006) and we have drawn upon Conole's (2007) main features of a learning activity which she describes as:

- The **context** for the activity
- The **pedagogy** i.e. the learning and teaching approaches
- The **task** itself which would include any tools or resources and types of interaction that are associated with the learning activity

These were important guiding principles as although Whitelock and Pintó have designed and built science simulations in the past, we had not constructed e-learning materials for chronically ill children who had received a disrupted education due to their medical condition. In order to substantiate the more general frameworks mentioned above we also referred to the developmental research framework of Lijnse (1995). A model-based learning-teaching approach (Buckley, 2000) together with work from the biology education literature about students' nutrition misconceptions (Clément, 2003; Carvalho, 2004; Arcà, 2005) were the stimulus for selecting, elaborating and scheduling the domain-specific (Biology) content and the activities for the target audience. The pacing of the activities and together with the introduction of new concepts and their assessment was guided by the "Tell, Explore, Check" model developed by Whitelock (1999) when building scientific interactive electronic teaching materials for the Open University's Science Foundation Course. See Figure 1 below

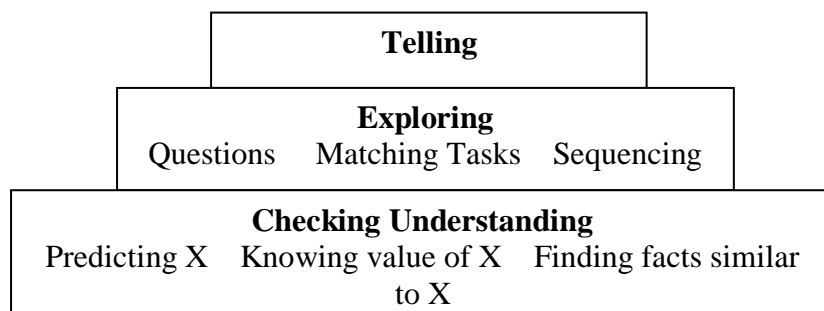


Figure 1. Tell Explore Check Model (T.E.C.)

Therefore an agile methodological approach was adopted rather than a plan driven methodology for the development of the software and the user evaluation since the former supports adaptation rather than prediction. Agile methods are less risky than a plan driven approach where it can be hard to adapt to necessary changes in project emphasis as the programme of work progresses. The agile process consists of five main phases as shown in Figure 2 below.

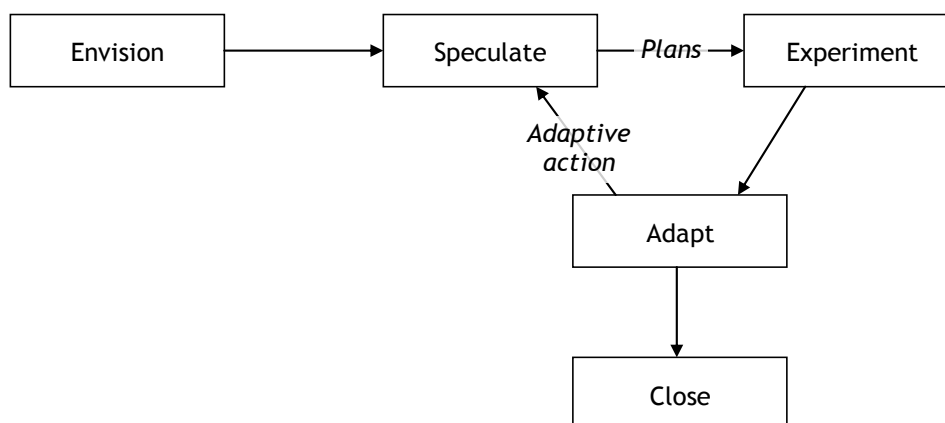


Figure 2. Adapted agile process

We adopted this methodology as good software production always involves refinements after user testing has taken place and makes this element of the process explicit. It has also been used by Whitelock & Watt (2008) in the production of the Open Comment system.

## NEFREDUCA MATERIALS

The Nefreduca materials were delivered through a virtual open-source platform and were divided into two separate blocks (see figures 3a, 3b). The first block of materials consisted of *The Introduction and Informatics management block* which presented the learning objectives for the whole series of activities, together with the instructions about how to use the program with its variety of teaching resources, and an *Initial questionnaire* to ascertain students' prior knowledge of the science before they worked through the program. This was followed by *The Science content block* that separated the content into four major themes which included: a) Food digestion and nutrient absorption; b) Blood transport of nutrients and waste products; c) Kidney excretion of waste products; d) Kidney dysfunction and the role of dialysis.



Figure 3a. Initial screen of the Nefreduca



Figure 3b. Initial questionnaire screen and List of themes templates and activities

Every theme followed the same format (see figure 4): the introduction of a set of discreet scientific concepts with text, the use of images and/or flash animations and a series of activities which addressed the given concepts.

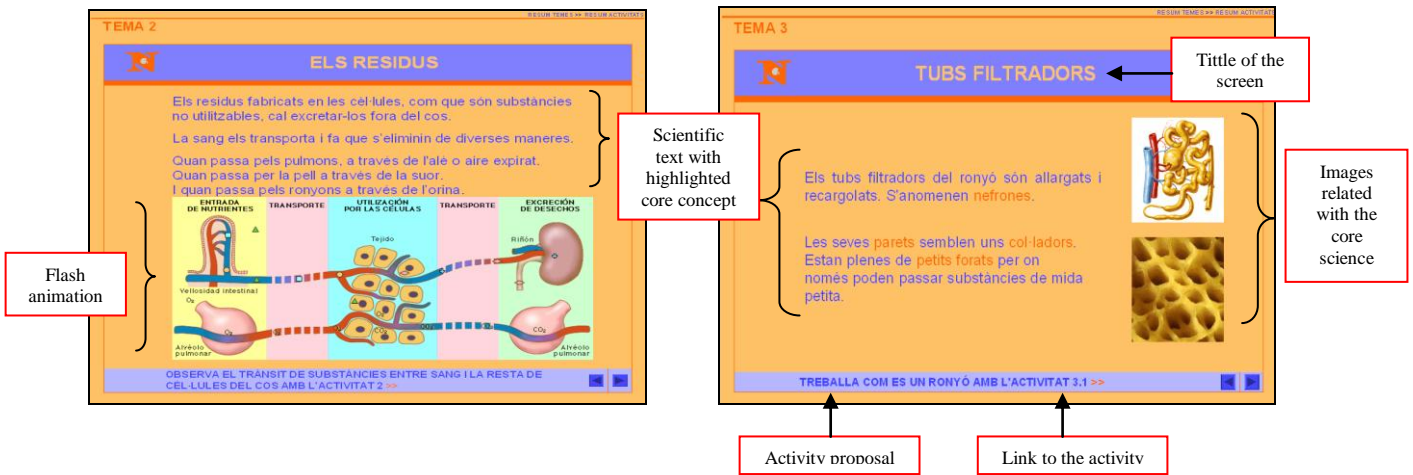
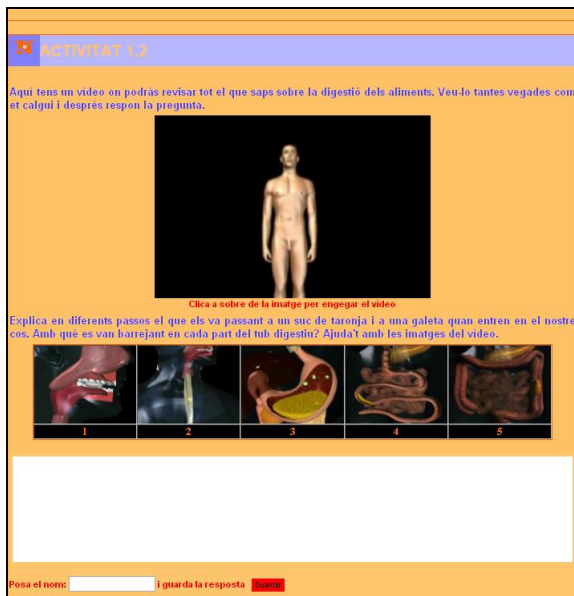
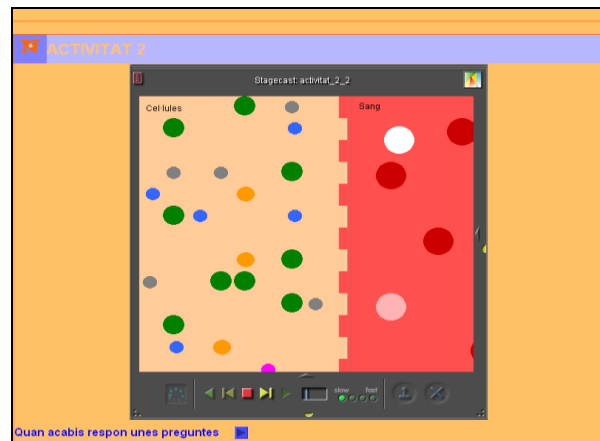


Figure 4. Examples of theme screens

Several types of ICT resources were available to support the activities. These included on-line questionnaires, animations, on-line image editors, videos and images (see figure 5).



Video



Animation



On-line image editor



Figure 5. Examples of activities with different ICT resources

In the selection of biology concepts and the design of the materials, emphasis was given to the understanding of the origin and function of the nutrients in the body cells, their transition from different “compartments” of the body and the waste which is produced from the body’s use of these same nutrients. Finally the kidney function has been described as the organ responsible for the excretion of metabolic waste products and water from the body (the urine components). In order to understand the workings of a dysfunctional kidney and its common treatment we used the analogy of an artificial kidney. We didn’t deal with the kidney function of secretor of several hormones.

The following sections of the paper focus on the evaluation of these virtual materials with respect to the hospitalized students’ understandings of the role of the kidney in waste production which sits holistically with the whole nutrition processes. The following research questions were addressed in this study:

- 1) What were the hospitalized students’ initial ideas of the normal biological kidney function?
- 2) How do the students understand the role of the kidney in relation to urine and blood?
- 3) What are the students’ initial ideas of the normal urine content? How do they explain alterations to normal urine content?
- 4) What are their explanations of the urine changes seen and blood alterations which are caused by kidney dysfunction?

## METHODOLOGY

The Nefreduca materials were developed (following the agile methods approach, see Figure 2) in collaboration with the five hospital school teachers from a major Paediatric Hospital in Barcelona. During the pilot study 32 chronically ill children (between the ages of 10-16 years) worked with the Nefreduca materials. The sessions took place either in the hospital school or the children’s’ hospital rooms or in the dialysis suite. All sessions lasted between 1-1h30min. Most of the children were able to finish the complete set of activities during this period.

The majority of the pupils who used the Nefreduca program, were patients in the Nephrology (12 students) and Oncology-Haematology departments (8 students). The others were patients in the general paediatrics ward of the Hospital (6 students), in the Cardiology department (3 students), in the Pneumology department (1 student) or the Surgical ward (2 students).

All the student log-ins to the Nefreduca platform were registered and their answers to the activities collected by the informatics system and delivered to the researchers on-line. This data was then analyzed and classified according to the categories shown below (see table 1). The students' answers to the initial questionnaire were compared with the answers to the activities in the theme 3 (Kidney Excretion of waste products) and theme 4 (Kidney Excretion of waste products; Kidney Dysfunction) (See annex A).

Table 1. Category analysis

Analysis categories	Data collected in the following students answers
The kidney function related with the urine production	Question 1 of the initial questionnaire
	Question 3 of the 3a activity
The kidney function related with the blood filtering	Question 1 of the initial questionnaire
	Questions 2 & 3 of the 3a activity
The urine content	Question 2 of the initial questionnaire
	Question 3 of the 3a activity
Consequences of kidney dysfunction in the urine	Question 2 of the initial questionnaire
	Question 1 of the 4a activity
Consequences of kidney dysfunction in the blood	Question 2 of the 4a activity

## RESULTS

The students' ideas about the kidney per se were analyzed. The Nefreduca program was set up to capture the students' initial understandings of the biological functions of the kidney before they started working with the Nefreduca program. These are called the initial conceptions as shown in Table 2 below. The program also recorded the students' answers to the questions posed after the activities and are recorded as final conceptions in Table 2 below. At the end of the Nefreduca sessions, a total of twenty-two students completed the activities associated with the working of a normal kidney together with kidney dysfunction and the role of dialysis.

Table 2. Initial and final kidney models

		Initial	Final
<b>MODEL I</b>	<b>Kidney as urine eliminator</b> (i.e. "it gets out of the body a useless liquid"; "it makes you urinate")	9/32	-
<b>MODEL II</b>	<b>Kidney as a waste cleaner (from the blood or the body fluids)</b> (i.e. "it cleans the blood", "it purifies the body fluids")	14/32	-
<b>MODEL III</b>	<b>Kidney as urine eliminator + waste cleaner (from the blood or the body fluids)</b> (i.e. "it cleans the blood and makes me urinate; "it is used to not retaining body fluids and to eliminate all the useless things of the body")	9/32	-
<b>MODEL IV</b>	<b>Kidney as urine producer + blood waste eliminator</b> (i.e. "The kidney eliminate the metabolism waste products of the blood")	-	4/22



<b>MODEL V</b>	<b>Kidney as urine producer + blood filter</b> (i.e. "it filters the waste products of the blood and produce the urine")	<b>1/32</b>	<b>17/22</b>
<b>No answer</b>		<b>-</b>	<b>11/32</b>

Our analysis revealed that the students held a number of different models of the kidney's function as shown in Table 2. From the qualitative analysis of the students' initial answers, we found that most of them attributed only one function to the Kidney (22/32; model I and II). We see that the kidney is therefore envisaged as an organ which only eliminates urine or it can be viewed as an active organ that cleans the blood. Some of the students focused their explanations on the role of urine elimination (model I). They believed that the kidney is "responsible for making them urinate", so they assigned to it the role of other parts of the urinary tract. Students also confounded the relationship between the kidney and the blood. The basic notion of the kidney as a filtration system was expressed by the students only in terms of "cleaning". Less than half of the students (10/32) connected this kidney function with the blood (in model II and model III). When students attributed two functions to the kidney (10/32; model III), they still maintained the notion of the kidney as a urine eliminator but added a cleaning role of the body fluids (6/32), rather than cleaning the blood (3/32).

Data in table 2 show that the majority of students initially explained that the urine is composed of water with some added substances (15/32). But the range of those substances varied: some students referred to them as being waste substances, others expressed the name of the regularly nephrology tested substances (i.e. urea) or mentioned the presence of mineral salt in the urine. So, it is important to note that even when the students could name certain the eliminated useless substances they initially did not relate their origin from the blood or to their filtration by the kidney.

The analysis of the students' answers from the Nefreduca activities which were designed to scaffold the construction of a biological model of the kidney; illustrated that their ideas changed. Most of all the incorrect pre-conception models (I to III) changed to model IV and V. We found just one student that maintained their complete and correct initial model (model V). Therefore after using the Nefreduca program, all the students demonstrated that they improve their understood the relationship between the kidney and the blood even though not all of them express the same comprehension level of the process of filtration after using the Nefreduca materials.

They also displayed the notions about the production of urine and its origins which were illustrated by the Nefreduca materials. The references to mineral salt content of urine or the common substances tested in the nephrology test, did not appear in the answers to the final activities, probably because the students now understood the basic functionality of the kidney. For us it was more important to focus on the process of production and filtration of waste substances rather than teaching the chemical names or properties of the waste materials. This has proved to be a good strategy as, for some of these students, although they might be suffering from a kidney disease, understood for the first time that a kidney that "works" properly is regularly removing water and metabolic waste products. (See table 3).

Table 3. Initial and final explanations of the urine content

<b>Students explanations of urine content:</b>	<b>Initial</b>	<b>Final</b>
Water	3/32	-
Liquid	5/32	-
Waste products	1/32	
Water and mineral salts	3/32	-
Water + nephrology tested substances (i.e. urea, bacteria, toxin)	3/32	
Water + waste products + mineral salts	-	1/22
Water and waste products	8/32	21/22
No answer	8/32	-

Initially most of the students were able to reference changes to the urine caused by renal dysfunction (see Table 4). Their initial reasoning focused around several observations of their own urine production. The majority of them emphasized the alteration to the quantity of pee that they produced (i.e. “*When you have kidney problems you make less pee*”, “*The pee is retained in the body and you have a kidney disease*”). We found other students who paid more attention to the alterations in the colour or smell of their urine (i.e. “*The pee is different, it has a darker colour and a more intense smell*”, “*The pee is more yellow*”). The alterations to the quality of the urine were also mentioned by a few students (i.e Student A said: “*If the kidney doesn’t work properly, some blood could leave the body through the pee*”. Student B explained: “*When your kidney doesn’t work well, you don’t make pee or your pee has a bad quality*”).

After working with the Nefreduca program they were able to relate kidney dysfunction to measurable changes not only in the content of the urine but also in the blood (i.e. “*The pee of a hospital patient could contain substances that the body needs and have come out, because the kidney hasn’t made a good filtration*”, “*I think that if a hospital patient has more waste products than normal in their blood, it could be caused by kidney problems. If the waste products haven’t been ejected by the pee they have gone to the blood*”). Here we can see a greater understanding of the lack of functionality of a diseased kidney. The science was also beginning to make sense for them in terms of the dialysis that some of them regularly had to undergo.

Table 4. Initial and final explanations of urine alterations caused by a kidney dysfunction

<b>Students explanations of urine alterations caused by a kidney dysfunction:</b>	<b>Initial</b>	<b>Final</b>
Alterations in the content or quality of the urine	4/32	22/22
Alterations in the quantity of the urine	12/32	-
Alterations in the colour or smell of the urine	6/32	-

## CONCLUSIONS

Our results illustrate that initially the students were not able to relate the functionality of the kidney with the body’s transport system i.e. the blood. Even though some of them expressed an initial idea of the “filtering” action of the kidney, naming it as “cleaning”, just few related it with the blood. However, most of the students were able to relate the kidney with the process of urine production. They considered the kidney as a “urine eliminator/ejector”.

When starting with the Nefreduca materials, just half of the students were able to explain that the urine is composed of water with some other waste substances, but they did not mention the relationship of these substances in the blood or with the kidney filtration process. Many of the students however, recognised the changes that they could see for themselves to their own urine which was caused by a kidney dysfunction, but they could not explain these changes to the colour or concentration of urine produced by a malfunctioning kidney. At the end of using the Nefreduca programme of study, the students’ answers illustrated a deeper understanding of the urine production process, together with more capability to express the content as waste product and water. We found that all the students were, at the end able to relate a kidney dysfunction with an alteration to the content of their urine. Also all the students’ that finished studying the Nefreduca system were also able to associate the kidney with the accompanying process of blood filtration.

These findings suggest that the Nefreduca sequence could serve as a teaching material for scaffolding the construction of the students modelling of the kidney, allowing children who suffer from a kidney dysfunction to see for the first time the big picture. The findings also have implications for the general design of teaching materials for these biological topics. This is because a number of misconceptions were identified by the “pre-test” administered to students at the beginning of the Nefreduca program. Addressing students’ misconceptions has played a large role in the science education literature over the past 20 years. The Nefreduca model has started to change students’ misconceptions and the introduction of an automatic feedback system could also scaffold this change. This addition is being considered for the next phase of development of the Nefreduca program.

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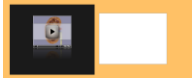


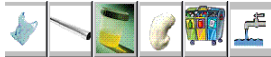
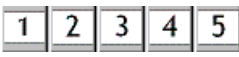
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**Annex A:** Questions in the Initial Questionnaire and theme 3 and 4 activities

<p><b>Initial Questionnaire:</b></p> <p>1) Explain with your own words what do you think the kidney does?</p> <p>2) What are the urine components? What happens to the urine when the kidney doesn't work properly?</p>	
<p><b>Activity 3a from theme 3:</b></p> <p>We study now, how the filtration process is produced by the kidney. We want you to watch a video and an animation, and after that answer some questions.</p> <p>1) Click the button  to switch on the video. Which element appears on it?</p> <p style="text-align: center;"></p> <p>2) Look the animation to understand more about the filtration process. Click on the button  to switch on</p> <p style="text-align: center;"></p> <p>3) After using the animation, answer the following questions:</p> <p>a) Which elements or substances go out from the blood to the kidney (Filtering tubes and renal pelvis)? Which does not?</p> <p>b) Why can some elements or substances be filtered and others not? Think about how the structure of the filtering tubes</p>	
<p><b>Activity 3b from theme 3:</b></p> <p>Complete the sentences about the excretory-system filling in the gaps ..... with the icons that you think are necessary, and then put the sentences into a correct order than explains the full process.</p> <p></p> <p style="text-align: right;"></p> <p>The ureter connects the.....with the bladder.</p> <p>The .....comes out of the..... through a ..... called the ureter.</p> <p>The .....filters..... and ..... from the blood and forms the .....</p> <p>The bladder works as .....where the.....,is stored</p> <p>When the bladder is full, the.....goes out outside the body through a.....called the urethra.</p>	
<p><b>Activity 4a from theme 4:</b></p> <p>Imagine that you're in charge of analyzing a sample of pee and blood of a hospital patient. The first test result is that the pee contains substances the body needs and have come out.</p> <p>1) Explain how those substances might have arrived to the pee and why.</p> <p>You know yet that the blood circulates to all parts of the body and gains and loss substances. So, if you suspect that a hospital patient has kidney problems, you could think that she/he might have more quantity of certain type of substances.</p> <p>2) Do you know which substances could be? Why it could be possible?</p>	
	