

## KidneyCloud: A Clinically-Codesigned Solution to Support Kidney Services with Assessing Patients for Transplantation

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### Abstract

*There is a need for IT systems that support the complex needs of data management in kidney transplantation. The KidneyCloud project aims to inform a transplant-specific digital solution by exploring patient pathways and data journeys. This paper reports on the early prototyping of the KidneyCloud clinician interface using an iterative codesign methodology. User workshops identified that for making clinical decisions and adding patients to the national waiting list transplant teams relied heavily on manual processes to access data across systems and organisations. Based on the requirements gathered, a prototype interface was designed to provide a unified view on the available patient data, which aligned with clinical workflows. Interactive prototype screens allowed users to gain hands-on experience and provide rich real-time feedback. This informed the necessary functionalities of the interface, but also helped us understand the capabilities required of the back-end solution.*

### Keywords:

User-Centered Design, Health Information Interoperability, Organ Transplantation

### Introduction

End-stage renal disease (ESRD) carries a significant global health burden.[11] A kidney transplant is the only treatment that improves quality of life and offers a sustainable cure. [9; 22] In the United Kingdom (UK), over 5,000 patients receive a kidney transplant each year and a further 4,000 new patients are added to the national waiting list.[14] Owing to the increasing demand, there is a need to streamline processes, increase donation opportunities and upscale services.[2]

The referral process for a kidney transplant is complex. Transplantation is typically delivered at large university hospitals, treating patients across a wide region and from local general hospitals. In the UK, the National Health Service (NHS) delivers kidney transplant services through 23 regional centres. Patients are commonly referred by a nephrologist at their local hospital and undergo pre-transplant assessment and investigations before attending the transplant centre for surgical evaluation and waiting list registration.[16] This means that transplant assessment involves a host of clinical appointments, investigations and patient education. These are directed by multi-disciplinary clinical teams across the multiple healthcare organisations involved. Furthermore, patients undergoing transplantation often suffer from multi-morbidity with complications from

dialysis and additional sequelae of kidney failure. The assessment pathway therefore results in large volumes of heterogeneous clinical data collected by multiple services and organisations, which requires meticulous management to prevent delays and errors.

Little previous work has been undertaken in this clinical area, and there is a scarcity of literature reporting the use of health information technology (IT) in kidney transplantation.[20] As a result, data management frequently relies on clinical and administrative staff to manually access, organise and summarise data for timely decision-making and communication. Owing to the complexity of the referral process from a clinical and data perspective, significant human resources are utilised to deliver the service. Current electronic health records (EHRs) are not able to provide a view of patient data that meets the needs of the transplant workflow.[15] There is thus a potential for digital solutions to improve the service by replacing paper-based data management, automating administration and improving data completeness and accuracy. However, this potential currently remains unharnessed.

To address this gap and develop a solution that meets the needs of kidney transplantation, we initiated the KidneyCloud project (Department of Renal and Pancreatic Transplantation, Manchester, UK). As part of the first phase of KidneyCloud, we explored the kidney transplant assessment pathway from a data management perspective and understand how IT is currently used to support the workflow. This will inform the design, functionality and, capabilities of a transplant-specific solution. The current paper reports on the early prototyping and iterative codesigning of the solution's clinician interface.

### Methods

#### Project background

By exploring patient pathways, data journeys and digital solutions, the KidneyCloud team identified that the multi-speciality and cross-centre nature of kidney transplant services required a specific solution that integrates health and social care data from community and hospital providers across the Greater Manchester region. As such we are developing an integrated clinical data repository (back-end) The front-end solution is being designed in collaboration with the Digital Health Software team at the University of Manchester. To better understand socio-technical and organisational barriers to future implementation, we undertook early prototyping of the clinician interface.

We used an iterative codesign methodology to design our prototype. We undertook repeated cycles of requirements gathering and workshops to allow users to provide input throughout the design process. A member of the research team (VS), who is also a clinician within the transplant team, acted as a clinical super user and coordinated the requirement gathering process. The super-user's domain expertise, combined with cross-over skills in health informatics, allowed them to readily engage clinical staff and effectively communicate feedback to a user experience (UX) designer (SF). Fig. 1 summarises how our approach combined patient journey modeling, requirements gathering and prototype design. We describe this approach in more detail below.

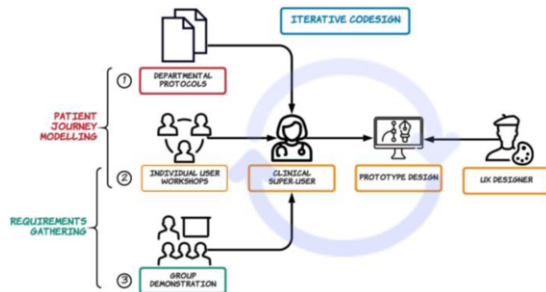


Figure 1: summary of iterative codesign approach

### Patient journey modelling

To establish the scope of the clinical pathway, we used customer journey modelling language (CJML), an established swimlane-based methodology to map the patient journey.[5] It visualises complex pathways as well as the actors, clinical touchpoints (appointments, investigations, correspondence, etc) and transitions between specialities/organisations. CJML allowed us to centre the project around the patient journey and design a prototype that accurately supported the clinical workflow. In particular, we were interested to identify how clinicians accessed, organised and communicated data as patients progressed along the pathway.

We reviewed departmental protocols and guidelines to gain a basic understanding of the pathway from initial referral to registration on the national transplant waiting list. To complement the review, we conducted and took notes at individual user workshops with four patients and six healthcare professionals. Sessions lasted 30 minutes and we presented participants with a draft swimlane diagram of three key clinical touchpoints: nephrology review, transplant surgery review and registration, prompting them to identify additional actions, actors and transitions on the pathway.

### Initial interface design

Based on our improved understanding of the patient journey, we designed a prototype clinician interface for desktop screen size using Adobe XD, part of the Adobe Creative Cloud© suite. Patient journey modeling had revealed that as part of the pathway workflow, members of the clinical team must manually complete a 10-page paper proforma. We used this as the basis for the first iteration of the proposed clinician interface. We created screens that mapped onto steps in the pathway workflow, with each screen presenting users with fields for data entry relevant to that particular step. Five screens were created that followed the clinical pathway starting at nephrology review and ending at multi-disciplinary decision to register the patient on the waiting list.

The main functionality of the interface was for data fields to autopopulate once the user entered a patient identifier (NHS number) on the first screen at the start of the workflow. Additionally, we identified that several data fields on the paper form were dependent on answers to previous fields. In our interface, we were thus able to hide fields until indicated and reduce the initial number of visible fields.

The interface was designed following the Web Content Accessibility Guidelines (WCAG 2.1 AA) (<https://www.w3.org/TR/WCAG21/>). The design framework was derived from the NHS service manual (<https://service-manual.nhs.uk/service-standard>). The typeface used throughout was Helvetica Neue, a versatile sans serif font that is optimised for digital legibility. By complying with international guidelines and NHS design standards we aimed to reduce future barriers to implementation.

We subsequently imported the user interface screens into MarvelApp (Marvel Prototyping Ltd.), a collaborative design platform for prototyping and user testing. This would enable us to employ a rapid prototyping methodology, where we could quickly turn ideas and corresponding feedback into tangible and interactive high-fidelity prototypes that could easily be shared with participants via a web link. Additionally, MarvelApp allowed us to design a prototype without the need to code reducing the development cost.

### Iterative codesign process

Having established the scope and initial interface, we undertook repeated cycles of requirements gathering to drive the clinical co-design process. Codesign, a form of user-centric design, allows expertise from multiple stakeholders to organically contribute to a solution, moving from designing *for* users to designing *with* users. It relies on participatory creativity, experience and feedback throughout the entire design process. [6; 18]

Requirements were gathered through repeated cycles involving individual user workshops and a group demonstration. This allowed an iterative and incremental increase in prototype design and functionality. In both formats, we used Microsoft® Teams to share our screen allowing participants to view the design, interact with the prototype and provide real-time input. Observations and participant feedback were recorded as written notes.

For the eight individual user workshops, we set up virtual meetings with two transplant coordinators, two nephrologists, two transplant surgeons and, two administrative staff. We presented a single-slide summary of the project to provide background information. We subsequently opened the prototype in a web browser and shared our screen to give participants control of the prototype. We allowed them to freely click through the different screens and experience the functionalities. We asked them to complete tasks such as navigate to the homepage or review a test result. We observed their user journeys and allowed them to verbalise their experiences. After each workshop, the super-user met with the UX designer to incorporate feedback into the prototype.

Following the individual user workshops, we set up a virtual meeting for a group demonstration with the multi-disciplinary transplant team, which was attended by 14 participants (four transplant consultants, three transplant registrars, six transplant coordinators and, one outpatient department sister). We presented the patient journey model, the current paper form and, our prototype. The contextual functionality of our solution was shared through demonstration of its role in the clinical workflow.

## Results

### Kidney transplant patient journey

The patient journey model confirmed the complexity and regional multi-speciality nature of the transplant pathway. As summarised in Fig. 2, we identified that patients had a minimum of 53 clinical touchpoints along the assessment pathway and interacted with at least 12 different clinical actors. At each touchpoint, there was a need to retrieve existing or store new clinical data in electronic or paper format. There were five different IT systems involved in the management of data and these were unable to share information between them. Currently, six modes of communication (email, telephone, SMS, post, fax and, face-to-face) were used to relay information amongst clinical team members and to patients. A total of five organisations were involved in the patient journey including three hospital providers, general practice and, the national organ transplant body (NHS Blood and Transplant). Fig. 3 demonstrates an illustrative segment from the overall model. Interviews with clinical staff highlighted a lack of interoperability of IT systems within, and across, the involved organisations. This resulted in significant time spent on manual data administration. Staff had devised heuristic solutions to manage transplant data, such as the use of individual paper packs for each patient stored alphabetically in filing cabinets on the hospital ward.

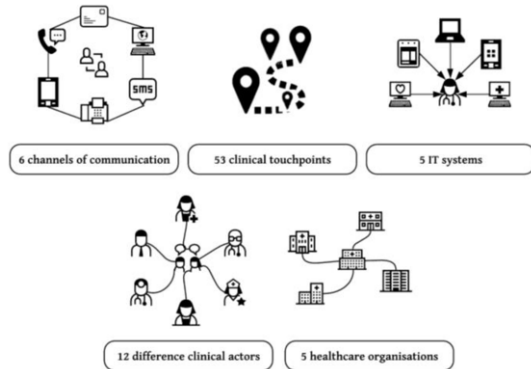


Figure 2: summary of results from patient journey modeling

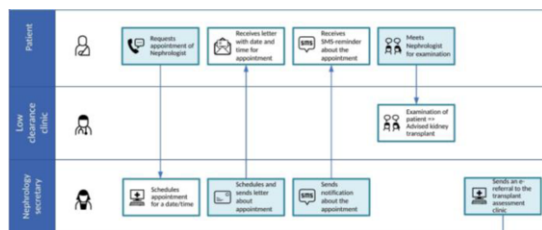


Figure 3: extract of patient journey swimlane model

### KidneyCloud user interface

The initial prototype design focussed on simplicity to transform the user experience from completing an onerous paper proforma to an intuitive web-based interface. The paper form included a total of 247 data fields that needed to be completed. Most fields (148) were free text such as address, past medical history and, medications. A further 78 were 'yes/no' fields, such as smoker, allergies and, previous surgery. 58 out of 78 'yes/no' fields required further free text data depending on the initial answer. The use of dropdown menus and collapsible

fields reduced the initially visible fields from 247 to 134 and allowed us to shorten the 10-pages of the paper proforma into five screens.

The autopopulate functionality aimed to transform the workflow experience of completing the proforma, replacing a time-consuming hand-written task with automated data visualisation. The user could now focus on confirmation of data accuracy and completeness, rather than manual data input. (Figure 4)

Figure 4: initial user interface showing autopopulation of data for a fictional patient across screens following entry of NHS number

### Iterative prototyping

Participants reacted positively to the initial user interface, particularly commenting on the clear layout of the screens. User feedback revealed that besides the form view, a summary view would add a useful snapshot of clinical data for decision-making (Figure 5). When using the paper form it was not possible to know which clinician was responsible for the completion of the data fields. We thus introduced a log-in page at the start of the prototype and displayed a user profile with a name and photo of the current user at the right top corner of the screen. We further added a progress bar, including green and amber ticks, allowing the user to track which parts of the form had been completed and which still required input.

A participant (transplant coordinator) raised the point that the current paper proforma is frequently incomplete with missing data fields. An administrator further highlighted that, as several members of the clinical team interact with the proforma, it is common for multiple versions to be created, resulting in duplication of work. They reported that these data management challenges lead to delays in the patient journey and additional resources spent on manual data completion. As a result, we introduced mandatory completion of fields before the form may be rendered complete. A central clinician interface that all users can access would prevent multiple versions. We added a save function to the interface which meant that several users could complete parts of the workflow without replacing work undertaken by other team members.

An additionally identified workflow constraint was the inability to view the various pre-transplant investigations within one digital solution. As the proposed prototype was designed to provide a view from an integrated clinical data repository we could demonstrate how this may be addressed in the prototype through buttons to investigation results and pop-up boxes within the interface.

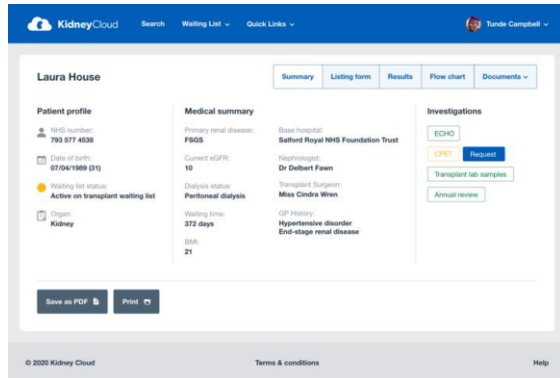


Figure 5: prototype summary screen following user workshops

## Discussion

### Summary of findings and comparison to existing literature

This study designed a transplant-specific user interface that met the needs and requirements of the clinical workflow. Specific requirements revolved around a need to view clinical data in a single solution and automating completion of data fields to reduce dependence on manual input. Our solution demonstrated to transplant clinicians how complex data collection can be more efficient, accurate and complete by using information technology. This will align expectations of intended benefits between the clinical and informatics teams and reduce resistance to future adoption.

Little published work on clinical workflow and data management in transplantation exists. An experimental study using bussiness process management in paediatric transplantation by Andelline et al demonstrated how the technology may improve resource optimisation and quality improvement.[1] A recent systematic review identified a further 17 studies on the use of health information technology in transplantation. However, none of those described the design of solutions, or discussed usability barriers to clinical implementation.[20]

The literature suggests that digital health interventions must embrace design as a key component to achieve widespread adoption.[21] However, a study of eleven EHR providers in the USA showed that only four vendors had well-developed user-centered design processes.[17] A lack of usability continues to limit the effectiveness, efficiency and, user satisfaction of clinical IT systems.[13; 19] A recent review of EHRs in emergency departments in the UK showed that no current system achieved the minimally acceptable systems usability scale score (SUSS).[3]

### Implications for practice and research

#### Design and usability

A strength of the overall KidneyCloud project, as reported in this paper, is the involvement of end users in the design process from the outset. Early feedback on layout, clarity and, user experience allowed the design of a prototype to suit a wide user group. Repeated workshops, with a diverse range of clinical and non-clinical staff, led to a rich contextual understanding of the workflow, which informed meaningful on-screen functionalities. The methodology laid out in this paper has the potential to be applied to other clinical areas undergoing digital transformation. It is however dependent on a high degree of flexibility

of the proposed solution. Though current of the shelf EHRs allow customisation, particularly during the implementation phase, they currently do not meet specific workflow requirements in a way our prototype was able to.

### Interoperability

To effectively support the workflow, clinical system must centralise large volumes of heterogeneous data and present a view that is intuitive, comprehensive, and minimises user input. Transplantation is not unique in this, with areas such as clinical genetics, oncology and neurology, operating with similar regional service models.[7] A suitable software design concept that supports this requirement is the model-view-controller pattern. It includes a data model that includes all possible data points, a controller that actions requests/responses, and a view that displays the data to the user (Figure 6).[10]

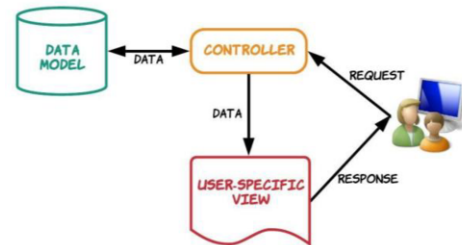


Figure 6: model-view-controller design pattern

Separating data from the application layer is being recognised internationally as a key priority to health IT infrastructure improvement.[8] The findings of this study further supported this and demonstrated the need for regionally managed data models that allow services to develop user-specific views that meet specific workflow requirements.

To operationalise such concepts Health Level 7 Fast Healthcare Interoperability Resources (FHIR) may be used to create standards-based messaging and allow independent application programming interface (API) development. An example of this is Boston Children's Hospital where an interoperable medical apps platform was build based on FHIR profiles.[12] In addition, open data standards such as OpenEHR can also realise EHR platforms based on openly available data models allowing a market of vendors to compete based on flexibility and functionalities.[4]

### Future work

Future work should include further analysis of usability, such as task-based user testing. This may provide quantitative measures of user journeys, such as time taken to navigate through screens or the number of misclicks. To judge the potential acceptance of our designs we conducted an early written survey amongst the 14 participants at the group demonstration. Survey respondents strongly agreed with the following statements: "improving IT systems to support my work and release time is important to me" (93%) and "ease-of-use of IT systems is important to me" (93%). All respondents agreed with the phrase "a system like KidneyCloud would be useful for me". In the current workflow, data collected manually on the paper proforma served no other purpose. However, the prototype solution offered the opportunity to reuse transplant patient data for audit and research. KidneyCloud has the potential to be accepted as a novel clinical solution and create additional value from routinely collected electronic health data.

## Conclusions

We successfully designed an interactive prototype for kidney transplant referrals using an iterative codesign methodology. Continuous user input provided the necessary feedback to inform interface functionality and back-end capabilities. Early prototyping added value to the overall project and will inform the further development and implementation of the solution.

General take aways for practice include the need to access data across organisational boundaries (interoperability) and provide views of data that complement workflow (UX). Moving towards regional EHR platforms, enabled by FHIR profiles or OpenEHR standards, will allow an ecosystem of digital health vendors to emerge that can meet this challenge.

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