

Digital Pathology and Artificial Intelligence (AI)

Learning what matters to patients who
have undergone a kidney transplant



Foreword

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This case study showcases the value of patient involvement and engagement (PPIE) events to inform the design and delivery of a research project into the use of AI in digital pathology.

Researchers at Imperial College London - which has a strong Computer Science department with the expertise to analyse “big data”- were particularly interested in establishing a research programme focussed on using the data generated by the digital pathology conversion at North West London Pathology (NWLP) to improve the way diagnostic reporting is carried out, for the benefit of patients.

To this end, engaging with members of the public was imperative, both to understand what acceptable use of the data looked like, but also understand the pain points of the current pathway from their perspective.



We set out to create a project that not only explored patient and public perceptions of the usage of AI in kidney transplant and pathology processes, but that co-designed resources with patients and the public to share learnings within the research community and more widely.

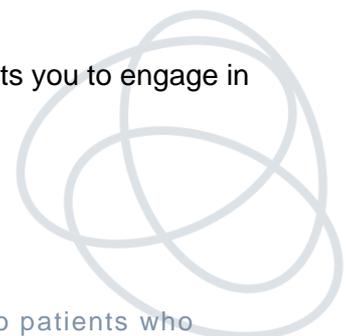


This project required additional support from a partner with more experience in PPIE. Imperial College Health Partners has a long history of PPIE, including leading deliberative workshops for OneLondon and the London Health Data Strategy, both delivered through their longstanding partnership with Ipsos UK and by their in-house team.

Through this partnership and for this project, we were able to recruit 8 patients (4 females and 4 males), from White European, White British, Black British and Asian backgrounds. Participants were aged between 30 and 65 years old, all had first-hand experience of kidney transplants and biopsy processes and were willing to support our qualitative investigations (with a commitment of 6 hours across three workshops and responding to surveys in between).

The workshops were highly informative, and we achieved all our aims, thanks to the commitment and enthusiasm of the patients involved. Below we summarise the main process of our PPIE approach, the themes which emerged from discussions throughout the workshops and the impact and outcomes for both our research and those patients we engaged.

We hope you not only find it interesting reading, but that it inspires and supports you to engage in PPIE for your next transformation project.



Context

North West London Pathology (NWLP) is one of the largest NHS pathology laboratories, hosted by Imperial College Healthcare NHS Trust, and provides diagnostic services to patients all over North West London. This includes cellular pathology services, which involves examining tissue samples down a microscope.



Many pathology services in the UK and internationally are undergoing huge transformations in the way pathologists view and analyse tissues samples, moving away from analogue reading of the samples using a microscope to digital images viewed electronically. This concept is referred to as Digital Pathology. Digital pathology converts biopsy features on the glass slide (“analogue”) into “digital” data. This generates large amounts of data that need to be securely stored. These electronic images and associated data provide opportunities for the development of tools that make work easier and potentially better for the pathologist, such as tools to make precise measurements or to mark features of interest in the tissue, or the ability to share cases easily with others for opinion. Additionally, this data can be used for research.



NWLP is due to commence this transformation to its services in early 2023. A side-effect of moving to a digitised way of working will be generation of a wealth of digital data that can be analysed and used to further improve the way pathologists work and ultimately, how disease diagnoses are made.

A key priority for us was to engage patients with this research programme from the outset, thus providing an opportunity for patients to contribute to and shape discussions relating to the use of digital pathology and artificial intelligence for research and their care.

We engaged with public and patients to:

1. Explore patient experiences (concerns and successes) in the current kidney biopsy/transplant care pathway
2. Introduce patients to the concepts of digital pathology and fundamentals of artificial intelligence (AI)/machine learning (ML), and how these may be applied to kidney transplant biopsy interpretation
3. Gather insights into patients’ understanding and perceptions of digital pathology and the use of AI in healthcare, research and in industry partnerships
4. Inform patients about the digital pathology research programme and involve them in the research design.

Workshop series

Process

Overview

Working in partnership with Imperial College Health Partners (ICHP), we held a series of three, two-hour long, virtual (online) workshops engaging a small, targeted patient advisory group (PAG) (6-8 participants). Participants were recruited from the local transplant patient population and workshops were delivered at 2-week intervals, on November 15th, November 29th, December 13th, 2022.



A small “focus-group” approach was chosen to enable a forum for in-depth, open and meaningful discussions between participants. Due to the complexity of the research topics, this format also allowed for layering of educational content and information as the sessions progressed. The workshops were hosted online, taking into account the vulnerability of the PAG, and to allow a more flexible and practical way for participants to be involved.

Most of the workshops were held as discussions in a one-room Zoom meeting. Discussions were based on invitations to share personal stories, questions about presentations of educational content and commenting on the findings from the literature on relevant topics. During the last workshop, break-out rooms were created to facilitate an activity for participants to input into the research proposal and co-design a plain English summary of the research, which had been discussed throughout the workshops.

To ensure the research concepts presented were clear and understandable, there were several brief educational talks by ICHP facilitators and members of the Imperial College research team (Cellular Pathologist Dr Candice Roufousse and Computer Scientist Dr Bernhard Kainz). These were interspersed with informal discussions on defined topics (detailed below) and comfort breaks.



Recruitment

The target audience for our event was patients with personal experience of transplantation or kidney disease. The primary method to recruit participants was via poster advertisement promoted via various channels (hard copy and online) including the West London Kidney Patient Association, Kidney Research UK, West London Transplant clinics and wards, the London Kidney Network, the Kidney Patient Involvement Network (KPIN), and Kidney Care UK.

Training

Several people on the event team had PPIE training, at various levels. PPIE experts from ICHP were involved in designing and running the event, and other members of the team, including the principal research investigator, Dr Candice Roufousse, had received previous training from the Imperial Patient Experience and Research Centre (PERC), the Imperial Clinical Trials Unit and Imperial College Societal Engagement.

Delivery (in detail)



Workshop one

Introduction and Education Part One | The first workshop introduced participants to the key terminology and concepts that would be covered in subsequent sessions. This was followed by time for patients to share their expectations of being part of the PAG for this project. Participants were then provided with educational content reviewing the kidney biopsy procedure and patient pathway.

Sample materials:

Kidney Biopsy Definition

A kidney biopsy is a procedure to remove a small piece of kidney tissue to be examined by a pathologist for signs of damage or disease or to assess how well a kidney transplant is performing.





"Patients don't know a lot but there is a lot of us that would like to and we sometimes get the feeling that consultants don't really want to tell much... it's very personal because that kidney is mine"

"I've asked questions about biopsy before and I think that doctors have been somewhat taken aback and maybe that is a place where they should explain more about the biopsy and to explain what can be gained from biopsy as well"

Discussion | Patients were then given the opportunity to share their own experiences of the kidney transplant biopsy process. Four main patient priorities emerged from this discussion:

1. "Ownership": Patients expressed that the biopsy process is often scary or painful, and that they have a strong sense of ownership of the biopsy and the results of the biopsy reading. Doctors are perceived as "gate-keepers" of the biopsy information, and do not always adequately enable patients to fully understand how their biopsy is interpreted, and what difference the biopsy made to their care.



*"It sometimes feels like theres
GATEKEEPING
around your
own Care"*



2. A quick diagnosis: This is a major concern for patients who have undergone a biopsy procedure: a quicker result “saves lives”.

3. A clear, actionable diagnosis: Patients are in favour of any changes to practice that would help get the safest, best, most complete information from the biopsy procedure.

4. “Do we need it?” Patients commented on variable transplant biopsy practice from centre to centre and variable communication on how useful the biopsy was for their care. As the biopsy is a procedure that on the whole they would prefer not to have, they are keen to have more information/data on exactly when a biopsy is needed, and to better understand how useful it was for their care.

Education Part Two | The workshop facilitators then guided participants through an explanation of what digital pathology is and how this would change current pathology workflows.



Sample materials

Kidney Biopsy Procedure: analogue vs digital

In the traditional workflow, thin slices of the biopsy are stained with dyes to identify specific cells within the tissue and laid down on glass slides, which the pathologist then examines down a microscope. In Digital pathology, an image of the glass slide is captured by a scanning machines, and the digital image is viewed on a computer screen.





Discussion | Following the educational content, patients were presented with a summary of the key potential benefits and drawbacks of digitisation in pathology based on public opinions reflected in the literature. Participants were asked to vote and comment on those that they perceived as most important and were invited to discuss their own views on the topic.

TIP

Planning and delivering the successful PPIE workshop series involved a considerable amount of organisation. Carefully designing the workshop structure and content, participant recruitment strategies and how to co-ordinate communication with all those involved (particularly patients) throughout the duration of the event should be considered from the outset. Using a variety of external channels such as patient networks, charities to promote the event offers greater opportunity to reach the desired target audience.

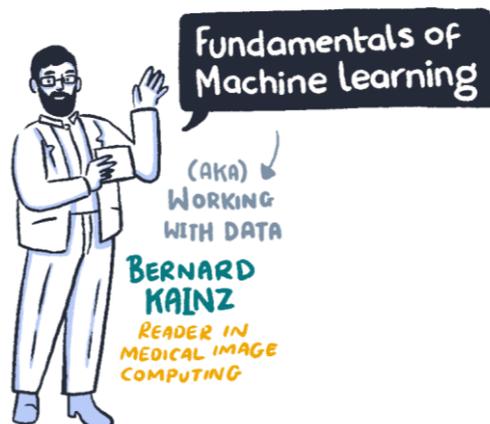
Outcomes

Participants were supportive of digitisation provided it could be demonstrated that it led to quicker, high-quality diagnosis, without compromising reliability of results.

Participants thought a key potential benefit of digitisation could be better patient education and involvement in their own care, as well as easier access to second opinions.

Participants had concerns around security of their data in a digitised form, especially if held by contracted private firms: how will long term security of their data be ensured? "Where does the responsibility for loss of data or misdiagnosis lie?"

Workshop two



Introduction and Education | The second workshop again combined a mixture of educational content to build participants' understanding on the fundamentals of Machine Learning with opportunities for patients to discuss their views on how this could be applied to biopsy interpretation. Computer scientist Dr. Bernhard Kainz provided an overview of how Machine Learning can be used for visual recognition tasks, such as those used by pathologists to reach a diagnosis when looking at a glass slide or a digital image.

Discussion | Following Dr Kainz's talk, the participants were presented with a summary (based on public opinions reflected in the literature) of the key potential benefits and drawbacks for patients and society of using ML in pathology diagnosis. When participants were asked to comment on those that they perceived as the most important benefit, the majority agreed that using AI as an objective and consistent tool to aid pathologists was the greatest benefit. When participants were asked to comment on those that they perceived as the most important drawback to be considered, nearly all selected lack of accountability and increased dependency on technology as concerns.

Outcomes

Three main themes which emerged from further discussion on this were:

1. **Time-to-result:** Patients perceive this as a potential benefit. Some are aware that AI is helping reduce time-to-result in radiology.



2. **Machine learning as a tool, not a replacement:** Patients felt strongly that human over-sight should be maintained. Although ML might make the quality of their care less dependent on the pathologist reading the slide, there was concern about completely reliance on technology. They

were unsure who would be held accountable for the diagnosis in the absence of human oversight. There was concern over rare diseases misdiagnosis by the computer.

3. **Cost to the NHS:** Patient were keen to know whether digitisation and AI would save money for the NHS. There was concern that cost-saving should not be the sole aim, as this might result in de-skilling of the human workforce that in the long term would not be beneficial.

"Anything that can help in the process – to prevent delays and misdiagnosis is good."

[Participant]

Sample materials:

Artificial intelligence (AI)/machine learning (ML) explained

Dr Kainz explained how the brain identifies things, using the illustration of images of crocodiles: we have all built up a mental image of what a “crocodile” is. When shown very different crocodile images, everyone in the room would identify each of these images as a crocodile by comparing it to a “template” crocodile in their brain.



Dr Kainz then illustrated how a computer can be trained to identify things, using the example of handwritten 0's and 8's. He explained that a digital image is a grid of points (“pixels”) each of which is given a number that represents its brightness.

If a computer is given a series of examples of images and 0's and 8's, it can use machine learning to develop its own “template” of a handwritten 0 and handwritten 8.



A machine needs a lot of examples to be able to learn, particularly if the images become complex, like a biopsy image. Machines can be very good at some tasks that humans are bad at (e.g., measuring things) but will still make mistakes, especially for rare things they may not have been trained to recognise.



Workshop three

Introduction | The final workshop was divided into two sections. The first part consisted of a focused discussion exploring how patients felt about using machine learning and AI in healthcare. The second half of the session revisited the Digital Pathology research programme and involved an interactive activity for patients to contribute their ideas to the research design and co-create a plain English summary. This section also included discussion about consent/permissions of AI in health care delivery.

Discussion | To facilitate the discussion on patient perspectives on the use of AI in health care, an example of a patient's care pathway (a case study), with and without AI, to reach a diagnosis from a transplant biopsy was used. This was a successful approach to contextualise and bring the discussion topic to life. After discussing the case, patients were directly polled in the session about their feelings on the potential benefits and drawbacks of using machine learning in health care, drawn from a



summary of the literature on the topic.

Research project design and creating a plain English summary | In Workshops 2 and 3, Dr Roufousse presented an outline of the digital pathology and machine learning research project, focusing on the research aims and the methodology (i.e., how the team planned to conduct the research).

TIP

Participants were reimbursed for their involvement and contribution for the PPIE, as part of funding from NIHR Imperial BRC, which also contributed to the commission of ICHP to assist with hosting and delivering the event. The quality of the event would have been far inferior without input from their PPIE specialists and would have diverted the resources of the research team away from their other tasks such as grant writing and data analysis.

Using two smaller break-out rooms, participants were guided through discussions using Miro virtual white board to co-design a plain English summary of the research based on their understanding of the key aspects presented. This activity provided the opportunity for participants to highlight any areas of the research which needed clarification, or which should be addressed in the overall research programme design.

TIP

Given the complexity and sensitivity of the topics discussed, a key priority for the event team was to ensure that the engagement exercise was interactive, appropriate and simple language was used and that there were diverse communication forums patients could engage with to make it more inclusive (i.e. Verbal discussions online, virtual chat, break out rooms, surveys, email). Being proactive with providing any additional information or materials/resources in advance or after workshops supported the layering of content in a digestible way.

Outcomes

Strongest benefits perceived by participants: more objective and consistent diagnosis, to confirm clinician's opinions; increased efficiency.

Strongest drawbacks perceived by participants: possible deskilling of clinicians; unclear accountability for errors.

There was a spread in opinion among participants about whether informed consent for the use of AI in a patient's care was necessary.

Overall, the majority of patients perceived greater communication and transparency on when AI was being used as being more important than consent at each stage of use of AI.

Workshop series wrap up and outputs

"I have found it educative, and it gave me plenty of insight into how my treatment is being processed and carried out. Makes me feel part of my own treatment. Made me feel more confident in explaining to people the benefits of AI."

[Participant]



What resources and opportunities were presented to participants?

The final workshop concluded with a summary of all the concepts discussed throughout the series and reflecting on the overall experience of the event.

Participants were also presented with the opportunity to participate in future research PAGs and as co-applicants for future Imperial College research grants.

Workshop presentations were shared with participants via email with any additional outputs and future communication to be disseminated to patients and the public via email, websites and cascaded via various kidney networks.

What impact did our event have on the people involved?

“I felt I learned something tangible about the way forward as without it I wouldn’t have really understood what was going on.”

[Participant]

“I really enjoyed hearing what other people thought and the questions they asked, things I might not have thought of. It was very useful to get the answers there as well.”

[Participant]

The vast majority of feedback was extremely positive, from both researchers and patients. A post event survey was circulated to participants via Survey Monkey to gather their feedback on their experience of being part of the Digital Pathology Patient Advisory Group. All participants who responded to the survey provided the highest score for overall event experience indicating the workshops were very useful, engaging, and inclusive.



What's next?



This workshop has provided initial patient involvement in design of our research programme. Engaging with the patients strengthened our research proposal by testing its relevance and expanding it to include investigating concerns that were a top priority for patients. In the next year we will be applying for funding for our research. We will have patients as co-applicants in our grant applications, and several attendees at our workshop gave us permission to contact them for this purpose. In addition, many were keen on ensuring wider dissemination of information on our research to more patients, and will help us with this during the research programme. We feel we now have a strong footing on the relevance of our research to patient benefit.



Appendix 1. Recruitment materials



We are exploring how we can get better, broader and safer use of NHS kidney patient records, through using digital images of kidney biopsies and artificial intelligence.

Help us to understand how patients feel about the potential use of this technology in their healthcare by joining our Patient Advisory Group.

Get Involved..



Being part of the Patient Advisory group will involve attending three workshops between October-December 2022.



We would like to hear from patients in North West London who have experienced a kidney biopsy or kidney transplant biopsy.

THANK
YOU

You will receive a thank you payment of £37.50 for each workshop you attend.

How do I find out more?

Email communications.engagement@imperialcollegehealthpartners.com or call on 07951 415 109 to find out more.