

UCLH

UCLH Listening Event

Patients, carers and their families; access to electronic healthcare records

12th February 2019



**University College London Hospitals NHS Foundation Trust
UCLH Listening event**

Patients, carers and their families; access to electronic healthcare records:

On the 12th February 2019, the Trust held a Listening Event. The aim of the event was to understand patients and public opinions on persons accessing their electronic healthcare records, for instance patients, carers and their families.

UCLH is going to have a single, Electronic Health Record System (EHRS) to further improve patient safety and experience. This means that our doctors, nurses and other healthcare professionals will have access to all relevant patient information at UCLH in one place. We will switch on our new system, which is called Epic, on Sunday 31st March 2019. The new system has a portal for patients and their families. Patients will be able to access their information safely and securely for patient to manage and improve their condition and communicate with the people looking after them at UCLH.

UCLH will be able to exchange data with other hospitals such as the Royal Free Hospital, and with General Practitioners (GPs), so that information can be communicated between healthcare providers. This new system will make it easier for patients to transfer to a different hospital if needed.

A total of 32 attended the event. In attendance from UCLH included the Head of Patient Experience, Head of Safeguarding Adults, Named Child Safeguarding Consultant, Paediatric nursing staff and representatives from EHRS team.

We told you:

- What is an Electronic Health Records System
- What is an Patient Portal (named by patients as My Care UCLH)
- What does proxy access to your health care records involve?

Patients and staff discussed:

- Any questions about the EHRS system or patient portal
- What are the benefits to the patient and the proxy?
- What concerns do patient have about the electronic health record system and patient portal

- What resources will be informing patients, carers and families about EHRS and the patient portal, My Care UCLH.

Access

Attendees asked whether there will be areas of the patient portal not available to patients; some felt that being open and transparent was the best approach to ensure patient safety. Other patients were concerned that the record would display information that they would rather not have access to. Patients felt that consideration must be given to the age of consent and proxy authority for parents and carers. Access to the portal via an app on a tablet or smart phone was recognised as not suitable for all patients.

Confidentiality

Patients felt concerned about who could view confidential clinical data and what they may do with it. Attendees told us they were uneasy about the transfer and usage of information, and worried that it may be shared too widely. Attendees were reassured that there is no intention for patient information to be shared with drugs companies. Information governance and data protection are of paramount importance to the Trust and patients must give consent for their information to be shared, and can opt-out if they choose.

Response from attendees

Comments received about the patient facing benefits of EHRS and My Care UCLH includes:

- 'Improved patient communication'
- 'I can self-manage my condition and view my details in one safe mobile app'
- 'Streamlining patient registering at admin check in desks and upgraded administrative tasks'
- '24-hour access to connection with my health information'
- 'Ability to help my elderly father manage his many hospital appointments'
- 'Greater focus on patient care'

The top three concerns for the attendees involved online **security and safety** including concerns about hacking into the EHRS patient portal system and will patients be able to access our clinic letters on-line securely. **Proxy**

relationships were another key topic including the procedures in place to ensure the patient is not being coerced into granting proxy access. The **processes** of signing up the My Care UCLH such as how will other systems communicate with Epic. These questions are assisting in writing patient facing 'Frequently Asked Questions' which are available on leaflets and on the UCLH website.

Proxy Access

A focus was the involvement of a patient's parents and guardians raises several questions, specifically affecting to patients in adolescence and aging into adulthood and their use of the patient portal. A proxy access refers to access to online services by somebody acting on behalf of the patient with the patient's consent.

There will be times where patients, carers and their families would find a proxy access to your health records via the patient portal beneficial.

There are different levels of access available to patients. All requests for online access will be dealt with on a patient by patient basis and suggested access will be granted within the agreed timescales. All patients must be deemed competent to be granted access to detailed data. However, some elements may be marked as sensitive or confidential and will not be shared on the online services. There are three main types of access 'classes' to the My Care UCLH patient portal which are:

- Adult to Child (Children under 16)
- Adult to Teen (16 – 18 years)
- Adult to Adult (anyone over 18)

Key questions

Questions throughout the evening event are detailed below along with the answers.

Can you close the use of a proxy user?

- A patient with access to their portal can always revoke a proxy user, as long as they are over the age 16.

What is the verification process of a proxy user?

- The verification happens in the patient's clinic appointment in person. The appropriate application form must be completed prior

to any online access being enabled. ID verification is required to ensure access is granted to patients and proxy users that have a legitimate reason to access a record. This will prevent access being granted to the incorrect person and support the Trusts to adherence to information security guidelines.

If a patient is in clinic, can a proxy be attributed to someone who is not present?

- Yes, a patient would have to consent and have at least basic information about the proxy user (name, relationship, contact details)

What are the security measures to stop people taking screen shots from mobile devices?

- This depends on the mobile device. The Apple operating system prevents screenshots being taken in the patient portal application. However this does not happen using an Android device.

How is it ensured the Proxy relationships are still valid?

- The My Care UCLH patient portal will trigger an annual review the proxy access.

Can I see who has viewed my patient portal?

- Yes, you can see the date and time the proxy access user has logged into the patient portal.

How can we be reassured that the proxy user is acting in the patients best interests?

- There are clear terms and conditions of use and what an appropriate proxy relationship should entail. A proxy user will sign up to the terms of use of the patient portal.

Can the proxy have a discussion via the messaging service without patient's knowledge?

- Currently, this would depend on the level of proxy access.

How does UCLH ensure safeguards are in place to stop online coercion? (Sharing information from their record, including login details, medical history, repeat prescription orders, GP appointment booking details and other private, personal information)

- When there is a safeguarding concern, a patient with proxy users are highlighted and safeguarding teams or other clinical users will be progressed to the 'proxy user' page in order to review and potentially suspend access. The clinical teams will be able to ensure the level of access granted to the proxy is appropriate and does not exceed what has been agreed by the patient. UCLH will consider the risk of coercion on a case by case basis as requests for access are received, and if necessary will decline access.

Volunteers

We are seeking volunteers to assist in providing a positive hospital experience to patients during and after the implementation of the new system, for example helping in waiting areas and promoting the patient portal.

Summary and next steps:

After the system 'goes live' there will be opportunity to make future improvements to the patient portal, such as, the ability to be more selective to enable patients to indicate what they can see in the portal along with proxy users. Following the meeting on accessing your electronic healthcare the suggested changes to the levels of proxy access have been considered and changes made.

The Event allowed the Trust to inform patients and members of the new developments at UCLH and to seek initial feedback on approach to the EHRS system and the portal.

Many thanks for your attendance and active discussions. Please contact us with any feedback on the patient portal My Care UCLH or otherwise.

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delivering top-quality patient
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