

Q&A Coffee Sessions

with EDGE super users

EDGE?



Super User!

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How and why did you move into clinical research?

My passion for research stems from my MSc in Psychology (specifically the Psychology of behaviour change). I have an inquisitive mind and I love reading about innovations that can improve the services provided to patients. I consider it a privilege to be in a position

where I can make a difference and I value the opportunity to bring my skills to bear to this end.

What does your role as Research Data and Information Manager at University College London Hospitals NHS FT entail daily?

I lead a team of Portfolio and Database administrators – the first points of contact into the department. Team members receive research submissions into a generic inbox, allocate studies to the appropriate teams and issue the decision to deliver e-mail to research studies once reviews are complete. They populate much of the core data on EDGE and train users across the trust on how to use EDGE. We prepare reports based on data generated from EDGE, manipulating the data in Excel.

How has your role within clinical research changed over the past

12 months?

The role has changed hugely because of COVID-19! While it's been challenging, we have adapted well and have developed skills and working practices that should serve us well long into the future. For example, rather than obtaining information from study teams via lots of convoluted e-mails, we now use MS Forms or Google Drive spreadsheets. My team then update any pertinent information onto EDGE. Rather than use shared drives on the trust network, most of our information is now held on Google Drive (with the exception of anything patient identifiable). This is more easily retrievable remotely. We have been working remotely since March 2020 and have realised the potential within Zoom and MS Teams to hold remote meetings. These will no doubt

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continue. The pandemic has been the focus of our work since March 2020. Initially we paused a large percentage of our portfolio, with only studies only allowed to continue if they related to COVID-19, urgent clinical care, or if there was no requirement for the patient to attend on site. EDGE and Epic (our electronic health record system) had to be consistent around which studies were open and which were closed. Following a mail out to study teams to extract the preliminary information, import functionality within EDGE and Epic was used to ensure consistency. We were quickly in a position to know with confidence which studies remained open, and which were paused due to COVID-19. Support departments relied on Epic statuses to know whether to prescribe drugs, process scans, etc. As lockdowns began to ease, we have been tracking our return to pre-COVID activity levels. A committee was established to review restart feasibility and EDGE workflows established to track the process.

How do you utilise EDGE in your daily role?

EDGE is the focal point of our roles! We have established an EDGE data dictionary – a huge spreadsheet outlining every data point in EDGE, what it means, where to find the information, when it should be populated and by whom. Macros have been built into the spreadsheet so that teams can click buttons to see only the fields that they need to populate. My team members input most core data points into

EDGE, as they register or approve studies.

UCLH operates a website called '[UCLH Findastudy](#)'. Driven by data within EDGE, this website allows clinicians and members of the public to search the UCLH active research portfolio. Data team members run daily 'active study' extracts from EDGE and import this data into Findastudy. We operate a process to extract patient recruitment data from Epic and import this into EDGE. This involves running some SQL code from Epic and using the EDGE 'import patients' functionality to import the patients. This process works well and UCLH has had good recruitment numbers as a result. We prepare numerous reports from EDGE, including data relating to NIHR PID and reports of BRC activity. These reports serve the needs of a diverse range of stakeholders. For example, during COVID-19 I prepared reports of studies paused / restarted by UCLH clinical divisions and tracked how we are doing in terms of returning to pre-COVID activity levels. I present this data in various forums.

You have been using EDGE for approximately 6 years now. In what ways has your use of EDGE changed and evolved over this period?

Initially, we were using EDGE as a minimum, just to satisfy LCRN requirements. A different system was used as our main business intelligence system. In 2019, coinciding with Epic go live, UCL/UCLH adopted EDGE as our main BI system. This was a

positive move. The data is cleaner than ever before. We can collaborate with other stakeholders more effectively, including the LCRN, our external research units and our support departments. The system is slicker and the reporting functionality more powerful and user friendly. We have been able to swiftly respond to evolving needs thanks to custom EDGE attribute and workflows. For example, as COVID hit we built a COVID-19 entity and used it to track, for example, reasons for studies continuing during COVID and Urgent Public Health information for COVID studies. Workflows were used to track statuses in terms of study restart – aiding regular reporting around this.

The data and information team at UCLH has been key to ensuring that EDGE can interact with other systems. This is a manual process at present, though in time we hope for automatic syncing. The data team ensure that study titles in Epic are consistent with EDGE, so there is no confusion. Information is fed from EDGE into Findastudy so that clinicians and members of the public can view the active research portfolio at UCLH. Participant recruitment data is fed from Epic into EDGE.

How can EDGE be used to help research data and information managers such as yourself?

A systematic approach to data entry by all teams can yield some powerful data that can be used for reporting purposes. The collaborative nature of EDGE means that the system can be used effectively by different stakeholders. Trust recruitment

data can be effectively monitored, though this takes a concentrated effort and awareness of NIHR data validation processes. Interaction with Power BI enables impressive data visualisation.

What magic EDGE hints or tricks (if any) do you perform during your data and information management processes?

I have set up several template spreadsheets containing various formulae, pivot tables etc. This means that simple reports from EDGE can be used to produce the initial data set, but the columns can be copied and pasted into Excel templates to produce some complex and impressive analyses. This makes it easier to delegate the production of reports. This approach has worked well in allowing us to monitor our post COVID research restart figures, breaking this down by UCLH clinical division and taking numerous variables into consideration.

What are your department's plans for using and developing EDGE over the next 12 months?

We have set up an 'EDGE Champions Group.' Consisting of cross team input, the aim is to consider what is working well with EDGE currently, and improvements /modifications that people would like to see moving forward. A MOSCOW type approach will be used to prioritise (must-haves, should-haves, could-haves, and will not have at this stage.) A priority for attention will be filing discipline,

as it can currently be difficult to find specific pieces of paperwork in the files section of EDGE. Also, the way we manage sponsorships within EDGE is likely to develop over the coming 12 months. We are keen to hear about opportunities that EDGE 3 may offer us here.

One hope for the future of EDGE and information management:

We would love to be able to import study and user information en masse without having to involve the EDGE developers. Often, we need to update large amounts of data (for example the clinical divisions of PIs). This is a time consuming, manual exercise at present – or we use separate spreadsheets which is less than ideal.

What is your "bigger picture?" That is, what do you find most fulfilling about our job?

I like to think that by supporting study teams with their data capture and information gathering, we are indirectly contributing to funding of research work that offers real potential for patient benefit.

One of your team's greatest achievements:

We have embedded a workflow to extract information from Epic and to import it into EDGE. Essentially, some SQL code, initially provided by GOSH is run to pull information from EPIC around patients enrolled in research and meeting NIHR definition of a research participant. The information is then cross mapped with EDGE data using some pre-built Excel

formulae and recruits already on EDGE are removed from the Epic extract. The Epic data is then pasted into a patient import spreadsheet and uploaded en masse to EDGE. This approach has resulted in good recruitment figures for UCLH and a less painful experience to gather the data.

One clinical research superpower that you wish you possessed:

An ability for all my 'wouldn't it be nice if ...' thoughts to magically appear, pre-populated in EDGE!

One thing that people might not know about you:

I am a keen piano player. My first job was playing the piano in a local shopping mall, and I've been known to play piano at wedding receptions.

One new personal skill that you've learned over the past year/during the pandemic:

Managing teams remotely and having confidence in remote working arrangements. This has resulted in efficiencies that will be used over the longer term.

End of interview.

By Ken Brackstone, Clinical Informatics Research Unit (CIRU)