

Secure Data Environment Q&A: Introduction webinar

Question	Answer
<p>We have a project, LITMUS that is a partnership between Newcastle University and NUTH, studying non-Alcoholic Fatty Liver Disease (NAFL) which is a quite a hot topic at the moment. We're looking to find an TRE to allow collaboration with NHS, academic, and external pharmaceutical partners, would this SDE be a viable option for that?</p> <p>One concern we would have would be who the data owner would be?</p>	<p>If you pop your email address in the chat and we can get in touch. We are still developing our SDE. The governance around the SDE isnt up and running yet so we still need to approach every data controller</p>
<p>Please explain how this links with the Federated Data Platform (FDP)</p>	<p>It is a separate programme, the FDP has different use cases to the SDE. SDE is for research and development projects whereas from what we have seen so far from FDP is the uses of it are more operational</p>

<p>To clarify, access to the NENC SDE would also give researchers access to the national datasets?</p>	<p>we will be working to make use of existing data where we can</p>
<p>Is this project in addition to, or likely to replace the Data Access Environment (DAE) Hospital Episode Statistics (HES) system?</p>	<p>We believe that this is currently being done via the National SDE. The NENC SNSDE is one of the 11 regional SDEs that will support this by bringing together data at a local level. Researchers will still be able to access data via the National SDE</p>
<p>Hello, Jonathan Richardson from the UK Teratology Information Service based at NUTH, we have a national remit (funded by UKHSA on behalf of all UK health departments) to perform observational research creating datasets of pregnancies with medication/vaccine exposures and their outcomes. If this would be valuable for the SDE and you would like to know more about our datasets, please let me know</p>	<p>Emailed Jonathan and query being followed up by the team</p>
<p>What is the plan for industry access to this data?</p>	<p>We need to develop the commercial model around the SDE. We do plan to engage with industry and we will set the rules and parameters around their access</p>
<p>Will the SDE include historic data or just prospective data going forward?</p>	<p>It will include historical</p>
<p>The public - are they able to truly opt-out of any of their data being held in the SDE or are you simply following the NDOO?</p>	<p>This is being looked at as part of the Section 251 application as CAG will require an opt out system but we dont know at the moment exactly how that will work. We know from engagement we have done before that there must be an opt out</p>
<p>who be commercialising this - HI NENC? Will these mean that revenue is generated and given to individual trusts?</p>	<p>The programme is being run through a collaboration between HI NENC, ICB, NECS and CNTW. The commercial model and value sharing will be developed in collaboration with all orgs. NHS E has</p>

	<p>set a Value Sharing Framework Value Sharing Framework for NHS data partnerships - The Centre for Improving Data Collaboration - NHS Transformation Directorate (england.nhs.uk)</p>
<p>So access is granted per-project? Are there plans for continued access?</p>	<p>Yes it is per project, each project would need to apply each time to the Data Access Committee. There will be a data catalogue so you will be able to see what data is available but can only access once the DAC approves.</p> <p>We need to understand the use-case for any potential continued access</p>
<p>Securing funding before application was on the process slide - would there be a fee to use the SDE to host and access? (in a similar way to how we can pay to access national HES data now?)</p>	<p>Yes there will be a fee to access</p> <p>We will develop a pricing model this year, NHSE aim to have a common pricing model across the national network and we'll work with them on that. We can provide interim pricing based on current practice</p>
<p>Is there an intention to keep the results of any research eg analytics meta data etc on the platform. Funders typically expect deposition of 'research data' but don't provide anywhere to put it!</p>	<p>providing the governance is in place if there are things that would help build our data repository and could be used by others it would be good to explore this</p>

<p>Where data is sought from or shared with other regional/national SDE,(s), will further approval from other DACs be necessary?</p>	
<p>Do you have a link to documentation on Axym?</p>	<p>we have a variety of draft documentation around the project process. we will look to publish this on the SNSDE website. As part of applications we can provide researchers with detail on the technical controls for example. NECS has DPST, Cyber essentials + and Iso27001 and Axym/SNSDE will undergo routine security testing</p>
<p>Using machine learning to build models can be very computationally intensive (needs a set of nodes with GPUs). What computational resources will be available for analysis?</p>	<p>As its cloud baed we can also scale to support projects that involve machine learning using Microsoft's machine learning pricing. We could support researchers via use of a Kubernetes cluster or we can set up support for running batch processes with spot VMs</p>
<p>For national studies would individual researchers have to apply to each of the sub-national SDEs, and run through this process X times? Or will there be a parallel national access process?</p>	<p>some of this is still being developed at a national level but where possible we will be looking to streamline</p>
<p>Any information on the pricing/fees would be of interest? Will there be waivers/discounts for phd students for example?</p>	<p>We will develop a pricing model this year, NHSE aim to have a common pricing model across the national network and we'll work with them on that. We can provide interim pricing based on current practice if there are details of a use case for example datasets required, size of data and number of users.</p>
<p>How are you planning to remove the reliance on S251, which is meant to be a temporary measure and effectively suspending the Common Law Duty of Confidentiality? Does the NENC public</p>	<p>Yes, A section 251 is meant for being able to temporarily lift the CLOD to allow the processing of personal data. Having said that we are working under some s. 251s which have been in place since the commissioning</p>

<p>know/understand that the basis of running this SDE and some others is for that Common Law Duty of Confidentiality to be indefinitely suspended?</p>	<p>support units were formed in 2013 eg Invoice Validation; they keep getting renewed as there is no other lawful basis. We as an SNSDE are not planning to remove the reliance on s. 251 as we have to work within the current legal framework and the common law. There is a precedent for the SNSDE s251 to span a 3-year period rather than an annual renewal (Thames Valley and Surrey SDE) which our application will also request in line with other SNSDEs currently going through their s251 applications. This position is also supported by both the national team in NHSE and HRA.</p>
<p>what role would public health data have here? Would it be part of routinely collected data or is it something that is separate that could be linked to routinely collected NHS data via SDE?</p>	<p>this is definitely something we can look to include. The SNSDE will look to include data across health and care</p>
<p>Is there a risk that every SDE will have a different 'flavour' of application so users may be faced with different requirements at each regional SDE in a similar way to the way DPIAs differ a lot between Trusts?</p>	<p>we are working through communities of practice with other regions so these align where possible to simplify the user journey but there may be areas where we need some local additions for example</p>
<p>Just some guidance on how the local SDEs will work with national processes, such as the DARS process, to access national data, which presumably will include NENC data. It will be more helpful to go through a national process once, rather than potentially 11 local processes, which will delay the commencement of any useful research.</p>	<p>Yes, the DARS process will continue as a separate approval route to offer researchers access to national level data. The local SDEs will use a similar approvals process to that which is already in operation for DARS.</p>

<p>do you plan to allow users/researchers access some scalable compute analytics platforms like Databricks on Azure?</p>	<p>Yes, we plan to include scalable aspects to facilitate different types of use cases</p>
<p>will the NENC CRN (soon to become the RDN) also be able to make requests to access the SDE?</p>	<p>Yes, provided they meet the same approval criteria that is applied to all other researchers.</p>
<p>Can you please clarify what assurances/ systems are in place to demonstrate that patients are happy for their data to be included in the system?</p>	<p>We have a comprehensive Public and Patient Involvement and Engagement strategy. Already we have recruited 16 public members who are doing more than just participating in meetings such as the steering group. They are instrumentally part of the programme. They are involved in the development and design of the Data Access Committee and we plan to have a public group who will have the ability to veto projects if they are not in agreement. In addition we are doing extensive engagement work such as surveys and focus groups to understand more about the public's views on using their data for research and development purposes. We have also budgeted for a public information campaign so that the public are aware of how their data is being used, the benefits and how to opt out if they would prefer.</p>
<p>What data variables are currently on the SDE platform</p>	<p>We are currently working with data controllers to establish data flows into the NENC SNSDE. As part of this we would look to include data items, such as demographic information</p>
<p>What is the difference going to be between data held within the regional SDE and the national SDE?</p>	<p>The National SDE will contain data on a national level that providers are mandated to submit to NHS England. The local SDEs</p>

	will offer data for their local footprint with the aim of providing more enriched datasets collected from local providers.
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