
In response to an enquiry from the developers of vCreate Neuro

vCreate Neuro for the diagnosis and management of adults and children with epilepsy and other neurological disorders (Final Report)

What were we asked to look at?

The Scottish Health Technologies Group (SHTG) was asked to assess the value of using vCreate Neuro, an asynchronous secure video messaging service, for delivering care to adults and children with epilepsy and other neurological disorders.

Why is this important?

Societal restrictions as a result of the COVID-19 pandemic had a profound effect on access to health and care, and necessitated the exploration of both synchronous and asynchronous remote consultations across Scotland. vCreate Neuro is an asynchronous service that was developed by clinicians from the Royal Hospital for Children, Glasgow (RHCG) in partnership with colleagues in other NHSScotland centres and a technology partner vCreate Ltd. vCreate Neuro enables patients or carers to send videos of seizures that have been recorded on smartphones, and associated data, to their clinical team for remote clinical interpretation and management advice.

In April 2020, the Digital Health and Care Directorate, Scottish Government funded a 6-month pilot project to test the use of vCreate Neuro in all tertiary adult and paediatric neurology services in Scotland. Based on initial positive feedback and to allow evaluation at test sites, the vCreate Neuro service was extended beyond the pilot to include all non-tertiary paediatric services. SHTG's work will help to determine the value of the vCreate Neuro for patients and NHSScotland.

What was our approach?

A rapid review of the published literature was conducted to identify evidence on the advantages and disadvantages of using an asynchronous service like vCreate Neuro in diagnosing or treating patients (adults and children) with epilepsy and other neurological disorders. A user experience survey was designed for service users and clinicians who used vCreate Neuro, and quantitative and qualitative data from the survey and interviews were analysed to help inform the value of the technology. An economic analysis was conducted using the survey responses to gauge potential resource savings for NHSScotland.

Information on our SHTG Assessment product can be found [on our webpage](#).

What next?

This SHTG Assessment will be used to inform the Scottish Government's decision making on the nationwide use of vCreate Neuro.

Further work should focus on developing the evidence base, gathering real-time resource utilisation data and gaining further insights into service users (clinicians, patients and carers) who did not use vCreate Neuro.

Key findings

vCreate Neuro may add value to the delivery of care for people (adults and children) who have epilepsy and other neurological disorders by reducing people's waiting times, more efficient triage and improving information available for diagnosis and treatment. In addition, vCreate Neuro may lead to resource savings for NHSScotland.

Rapid review of the published literature

- There is no directly applicable published evidence that evaluates the use of asynchronous video-recording services in people with neurological conditions. There is limited evidence to suggest that home-video recordings (HVRs) via smartphones are a promising and reliable complementary tool for diagnostic assessment of paroxysmal seizure like (non-epileptic) episodes.
- There is some evidence to suggest that HVRs may be useful in distinguishing epileptic seizures from non-epileptic seizures, suggesting that an asynchronous service such as vCreate Neuro can potentially speed up the process of differential diagnoses or triage based on urgency and need.

Quantitative analysis of survey responses

A quantitative analysis of responses to closed questions from clinician and service user surveys was undertaken to gauge opinion on the ease and usefulness of using vCreate Neuro, if it affected quality of care, ease of communication and how 'connected' the service user and clinician were.

- Parents and carers who used vCreate Neuro within paediatric and adult services were predominantly positive about the ease of use of vCreate Neuro, how 'connected' it made them feel to the clinical team, the impact on the quality of care, and the ease of communication with the clinical team. Being 'connected' was defined by the project team as 'having easy access to the team and a positive relationship.' 'Access' was not defined. For paediatric services users, vCreate Neuro avoided absence from school or work in approximately 20% of use cases.
- Clinicians from both paediatric and adult services were predominantly positive about the ease of use of vCreate Neuro, its usefulness in the management of patients, its usefulness in making a diagnosis or selecting treatment options, the quality of the video uploaded, the impact on quality of care and feeling connected to the patient.
- More than half of the responses from paediatric service and adult service clinicians indicated that using vCreate Neuro led to a shorter time to diagnosis and selection of treatment options.

- Both paediatric and adult service clinicians reported that the most common investigation to be avoided was an electroencephalogram (EEG).

Qualitative analysis

A qualitative analysis of 16 semi-structured interviews and the free-text comments from the clinical and service user surveys was undertaken, to explore people's experiences of using vCreate Neuro and its perceived impact on receiving and delivering care.

- Service users and clinicians indicated that vCreate Neuro provided an easy and secure method of exchanging and storing videos.
- A key theme in clinicians' interviews and survey comments was vCreate Neuro's usefulness at the time of initial diagnosis for newly referred patients and in the identification of urgent cases.
- Access to expert and peer review via vCreate Neuro was highly valued by both secondary and tertiary clinicians. Clinicians and service users valued the opportunity to carry out rapid remote review of service users' videos, using vCreate Neuro and thought that this led to more rapid diagnosis and could assist with ongoing care.
- Clinicians described the impact of vCreate Neuro on pathways of care and on shifting some clinical tasks away from scheduled appointments. The direct access to clinicians via vCreate Neuro may shift some responsibilities for ongoing management from primary to secondary/tertiary services which should be recognised in job planning.
- For service users more direct access to, and communication with, clinicians was a key benefit. The response to video sharing was perceived to be more rapid than other methods of contacting clinicians, and allows contact in-between appointments. A small number of service users were concerned that vCreate Neuro could be used to replace some face-to-face appointments rather than as an adjunct to them.
- Some service users raised the concern that they may doubt themselves or find their concerns not taken seriously without video 'evidence'.
- Service users from vulnerable groups (such as people with neurological conditions who live alone), may be unable to use vCreate Neuro, or they may require assistance with its use. A lack of access to high speed internet may make it difficult to upload videos to vCreate Neuro. People who are less able with IT may need assistance to use vCreate Neuro.
- A number of improvements were suggested by vCreate Neuro service users including the facility to upload multiple videos, a framework to guide expectations about feedback, more flexibility in responding to clinical questions, increased compatibility with different types of file and device, a more user

friendly mobile phone based application (app), and the ability to edit submissions.

- Clinicians believe that vCreate Neuro has great potential as a research and training tool, and for use in other specialities. Consent and clinical governance procedures should continue to be developed and adapted to fit the changing scale and ways in which it is used.

Economic analysis

- Economic analyses based on the paediatric clinic user survey and NHSScotland cost data illustrate that vCreate Neuro may lead to cost savings via a reduction in hospital resource use, for example fewer unnecessary clinical visits and investigations. Other benefits identified in the clinical user surveys, which could not be quantified in this economic evaluation, included potentially reduced time to diagnosis and treatment.
- The robustness of monetary findings is limited by the use of expert opinion-assumptions. In deterministic scenario analyses, findings were most sensitive to the cost and number of inpatient admissions.

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Abbreviations

CT	computerised tomography
HVR	home-video recording
EEG	electroencephalogram
GP	general practitioner
MRI	magnetic resonance imaging
NHS GGC	National Health Service Greater Glasgow and Clyde
PNES	psychogenic non-epileptic seizures
SHTG	Scottish Health Technologies Group
TEC	Technology Enabled Care

Glossary

Asynchronous means 'out of sync'. In this report it is used in reference to asynchronous communication which means communication that does not take place in real time, instead it takes place between clinician and patient at different times.

Synchronous: existing or occurring at the same time. In this report it is used in reference to communication that takes place at the same time between clinician and patient.

Costing analysis: The process of examining the cost of doing something in order to make comparisons and to plan for the future.

Neurological disorders: Diseases of the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction and muscles.

Triage: The process of selecting for care or treatment those of highest priority or, when resources are limited, those thought most likely to benefit.

Paediatric is the branch of medicine dealing with the health and medical care of infants, children and adolescents from birth up to the age of 18.

Psychogenic non-epileptic seizures (PNES) are attacks that may look like epileptic seizures but are not caused by abnormal brain electrical discharges.

Utility: In economics, utility is the amount of satisfaction you get from consuming (using) goods and products.

One-way analysis of variance test: The one-way analysis of variance is a parametric test used to determine whether there are any statistically significant differences between the means of three or more independent groups.

Thematic analysis is the process of identifying and categorising feelings, opinions and attitudes found within text documents.

Resource utilisation: The process of strategically measuring how effectively each resource is utilised against its availability or capacity. In this report, this refers to use of healthcare staff time, facilities or consumables.

Remote health pathways: the use of digital monitoring technology to enable citizens to receive, record and relay relevant information about their current health and wellbeing.

Komolgorov-Smirnov test is a goodness-of-fit test that is used to determine whether data is normally distributed or not.

Kruskal-Wallis test is a rank-based nonparametric test that can be used to determine if there are statistically significant differences between two or more groups of an independent variable on a continuous or ordinal dependent variable.

Qualitative research relies on data obtained by the researcher from first-hand observation, interviews, questionnaires, focus groups, participant observation, recordings made in natural settings, documents and artefacts. The data are generally non-numerical.

Quantitative research is referred to as the process of collecting as well as analysing numerical data. It is generally used to find patterns, averages, predictions, as well as cause-effect relationships between the variables being studied.

Seizures: A seizure is a transient occurrence of signs and or symptoms as a result of abnormal excessive or synchronous neuronal (brain cell) activity in the brain. These symptoms and signs can include abnormal movements, behaviours, sensations and states of awareness.

Introduction

Epilepsy is a common condition that affects the brain and causes frequent seizures. The International League Against Epilepsy (ILAE) task force define epilepsy as the following:

- at least two unprovoked (or reflex) seizures occurring more than 24 hours apart
- one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years
- diagnosis of an epilepsy syndrome¹

In the United Kingdom (UK), the prevalence of epilepsy is estimated to be 5–10 cases per 1000.³ Incidence varies with age, with the highest likelihood in infants and people over the age of 50 years.⁴ It is estimated that epilepsy affects more than half a million people in the UK with a prevalence of approximately 40,000 to 60,000 in Scotland.² Defining accurate figures for number of people with epilepsy is challenging because of complicating factors such as misdiagnosis rates, inconsistent reporting, variations in the definition for active epilepsy and antiepileptic drugs being prescribed for other conditions.³

Mbizvo *et al.* (2021) conducted a retrospective observational data-linkage study to investigate the trends and mechanisms of epilepsy-related deaths in Scotland. They concluded that epilepsy-related deaths are a major public health problem in Scotland, and its rate has failed to reduce over time.⁵

Digital technologies have the potential to reshape and improve health and care services, support person-centred care and improve outcomes for people in Scotland.⁶ In 2014, the Scottish Government established the Technology Enabled Care (TEC) programme, which included a series of five inter-related workstreams to drive the widespread adoption of technology to support self-management, access to care and remote management within health and social care.⁷ In 2021, the TEC programme (part of the Digital Health and Care Directorate in the Scottish Government) published the Digital Citizen Delivery Plan, which promotes the role of remote health pathways towards redesigning services for the benefit of citizen access and wellbeing.⁸ Remote health pathways involve the use of digital monitoring technology to enable citizens to receive, record and relay relevant information about their current health and wellbeing.

Telehealth, or telemedicine, is the practice of sharing information via communication technologies to diagnose and treat people with a disease or illness. This can be done in real time (synchronous communication) via a video conference, phone call or chat app, or through asynchronous platforms that involve communication between clinician and patient at times convenient to them. With asynchronous platforms, a service user can upload data, such as text, photo or a video, which is then assessed by a clinician at a later date. The clinician can then discuss with the patient treatment options or recommend further investigations, as appropriate. These interactions can also lead to urgent or scheduled face-

to-face consultations for cases that are deemed too complex or are not suitable to be diagnosed virtually.^{9, 10}

Societal restrictions as a result of the COVID-19 pandemic had a profound effect on access to health and care, and necessitated the use of remote consultations across Scotland. Synchronous platforms such as Near Me were adopted by hospital outpatient services and general practices across Scotland. Near Me is a video consulting service that enables people to attend appointments from home or wherever is convenient. The spread of asynchronous services has been much more limited, and is largely dependent on local specialty interest and limited funding to run pilot projects.¹¹ The Scottish Intercollegiate Guidelines Network (SIGN) highlight the value of and need for videos in epilepsy diagnosis stating that a secure video transfer service could have a significant impact on diagnosis and management of epilepsy.¹²

In April 2020, the Scottish Government funded a 6-month pilot project which facilitated the testing of vCreate Neuro across all tertiary adult and paediatric neurology services in Scotland. Based on initial positive feedback and to allow evaluation at test sites, the vCreate Neuro service was extended to include all other non-tertiary paediatric services as test sites. An [interim analysis](#) using a partial data set was published by SHTG in December 2021. Based on the consideration of the interim analysis, the Scottish Government agreed to a 3-year procurement of the vCreate Neuro service in Scotland (2022–2024) that includes ongoing use of the service in core paediatric and adult neurology services across NHSScotland, as well as additional test-of-change pilots in 18 services allied to neurology via open application process across NHSScotland. The service is also being used in NHS England paediatric and adult services.

Scope of work

SHTG was asked to assess the value of using vCreate Neuro in NHSScotland for delivering care to adults and children with epilepsy, suspected seizures, and other neurological disorders.

Following initial scoping, the following objectives were agreed:

- Conduct a rapid review to identify any relevant literature that discusses the costs and benefits of using vCreate Neuro or any similar asynchronous service in delivering care to adults and children with epilepsy, suspected seizures, and other neurological disorders.
- Collect and analyse survey data from clinicians, patients and carers who have used vCreate Neuro.
- Conduct qualitative interviews or focus groups with clinicians, patients and carers to further understand vCreate Neuro user experience.
- Conduct costing analyses to estimate resource and cost savings in NHSScotland as a result of using vCreate Neuro.

Health technology description

vCreate Neuro

vCreate is a cloud-based service that enables the asynchronous transfer of photographs and short recorded videos in healthcare settings. vCreate was originally conceptualised and developed by a consultant neonatologist at the RHCG in partnership with vCreate Ltd (Windsor, UK). In 2017, the first version of the technology called 'vCreate Diaries' was piloted by the Glasgow team to allow videos and photos to be sent from within neonatal intensive care units to families of babies admitted to neonatal intensive care units. The response to this technology was positive and vCreate secure video technology can be found in over 80% of neonatal units in the UK (personal communication, vCreate Ltd, October 2021).

Building on the success of vCreate Diaries, vCreate Neuro was developed by the paediatric neurology team at RHCG to be used in neurology departments. vCreate Neuro enables patients or carers to share smartphone-recorded videos and associated structured clinical data (metadata) with their clinical team for remote clinical interpretation and management advice, primarily for suspected seizures and other neurological disorders. Patients (adults and children) and carers who have had their first seizure or are already diagnosed with epileptic seizures are asked to register for this service, access the vCreate Neuro web app on an internet-enabled smart device, record a suspected seizure or seizures when it happens and then upload it to the cloud for the clinician to review and respond within a 5-day period. Patients can also share videos taken before registering for vCreate Neuro.

Intended benefits of the secure video messaging service include reductions in the number of clinic visits and investigations, more accurate diagnosis and management, and helping patients, families and clinical teams stay connected throughout the care journey.

Classification, information governance and regulatory status

According to the National Institute for Health and Care Excellence (NICE) evidence standards framework for digital health technologies, vCreate Neuro falls under the tier C category as it is intended to guide diagnosis and treatment.¹³ At present, vCreate Neuro is not CE marked or UK Conformity Assessed (UKCA) marked, but it was approved by NHS England as an 'NHS trusted app' after undergoing assessment as part of the NHS Digital Tools Library. Personal communication from vCreate Ltd (17 April 2022) states that vCreate Neuro has been deemed exempt from medical device regulation by the Medicines and Healthcare products Regulatory Agency (MHRA).

Data generated using vCreate Neuro are jointly owned by the health board and the patient, and the relevant clinical service decides how long they wish to keep each video after its use. Data collected from vCreate Neuro are stored in Microsoft Azure data centres in the UK. vCreate Neuro meets the General Data Protection Regulation (GDPR) requirements – which incorporates Data Protection Impact Assessment by complying with the GDPR checklist for data controllers (personal communication, vCreate Ltd, October 2021). The developers of vCreate Neuro received research ethics approval to store videos and associated data within a research database and for their participant consent process.

vCreate Neuro was approved through local service governance structures prior to implementation in each health board. Clinical safety accreditation for vCreate Neuro is underway and vCreate Ltd is working to comply with DCB 0129, which is a clinical risk management standard that manufacturers of health IT systems and apps need to comply with. The standard is governed by NHS Digital and compliance is mandatory under the Health and Social care Act 2012. After undertaking a formal risk assessment on the product, the company will produce three documents summarising the outcome; the Clinical Risk Management Plan, Hazard Log and Clinical Safety Case Report (personal communication, vCreate Ltd, October 2021).

Current pathway compared with new vCreate Neuro pathway

If a person has a seizure for the first time, they will be referred to a neurologist by other medical specialities for further investigation. The standard referral route to secondary care is via general practitioners (GPs) or following attendance at hospital emergency department.¹⁴⁻¹⁶ Based on NHSScotland Waiting Time guidance, a first in-person appointment with a neurologist could take up to 12 weeks from the time of referral. Once the patient has had their first appointment, they are scheduled to have an outpatient appointment at either the First Seizure Clinic or an Epilepsy Clinic. Thereafter, the patient

will have repeat appointments at one of these clinics until a provisional diagnosis and treatment plan is determined. The time taken to diagnosis and treatment can vary depending on the complexity of a case, however as per the guidance, once a diagnosis has been made, it should not take more than 18 weeks to receive treatment, counting the time from when the patient was referred to an epilepsy clinic.¹⁷ During treatment, a patient will be routinely monitored and, if needed, will continue to attend more in-person appointments for any adjustments to the ongoing treatment. In NHSScotland almost all specialist adult epilepsy care is delivered in networks linked to four tertiary centres: NHS GGC, NHS Lothian, NHS Grampian and NHS Tayside.

The vCreate Neuro pathway aims to shorten the time periods described, for example by bringing forward the first clinical interaction with the neurologist to review a patient's seizure episode alongside any relevant medical history data. Following referral to the neurology department, patients are contacted by phone followed by an email or text message requesting them or their carer to register and start using vCreate Neuro. Using a personal account, patients or carers can upload videos of any seizure episodes experienced by the patient along with answers to a set of related questions. Once uploaded, the video and the associated information is reviewed by a neurologist or an epilepsy nurse, who determines the course of action for a patient: discharge or referral to another service since the video did not show an epileptic seizure or another suspected neurological condition, or prescribe further investigations and or schedule an in-person appointment with the neurologist. The whole process from the time of referral to the neurology department until the clinical epilepsy team informing the patient about the next steps should take 8 or 9 days. The timescale accounts for the time taken for the invitation for vCreate Neuro to reach the patient or carer and the 5-day period taken by the clinical epilepsy team to respond to the patient once they have uploaded their first video. During treatment, to facilitate clinical review, a patient or carer can upload further videos of seizures.

Literature review

A rapid review of literature was undertaken in August 2021 to identify relevant papers that discuss the advantages and disadvantages of using an asynchronous video-recording service in diagnosing and treating adults and children with epilepsy and other neurological disorders. Key points from the review are as follows:

- At present, as a result of the sporadic use of HVRs in diagnosing and treating patients with epilepsy and neurological disorders, there is no direct evidence that discusses the advantages and disadvantages of using an asynchronous video-recording service like vCreate Neuro.

- There is limited evidence in terms of quantity and quality to suggest that HVRs made on smartphones are a promising and reliable complementary tool to use for diagnostic assessment of paroxysmal seizure like episodes.
- Based on the evidence of HVRs being useful in distinguishing epileptic seizures from non-epileptic seizures, an asynchronous service like vCreate Neuro could potentially speed up the process of differential diagnoses and allow epilepsy services to screen patients for electroencephalogram (EEG) or triage them based on urgency and need.

Detailed findings from this review can be found in the [Phase 1 report](#) published on the SHTG website.

Demographics of patients registered and usage of vCreate Neuro in Scotland

Between 23 April 2020 and 15 February 2022 there were 2,478 patients registered as users of the vCreate Neuro app who also supplied full demographic and post code data to facilitate analysis (the number of registered users without full data is higher). Seventy-seven percent (n=1,917) of these registered users were paediatric patients (0–5 years [n=891], 6–9 years [n=402], 10–17 years [n=624]) and 23% (n=561) were adult patients (18–24 years [n=150], 25–39 years [n=185], 40–59 years [n=156], 60–75 years [n=53], 75+ years [n=17]). The sex of registered patients was split evenly across paediatric service users, and in adult services 66% patients were registered as female.

Figure 1 shows that vCreate Neuro registration for paediatric service users was slightly skewed with most people within Scottish Index of Multiple Deprivation (SIMD) decile 1. This indicates that vCreate Neuro registration was slightly greater in more deprived areas, which may be a reflection of the burden of disease in different deciles.¹⁸

Figure 1: SIMD decile of registered paediatric service users

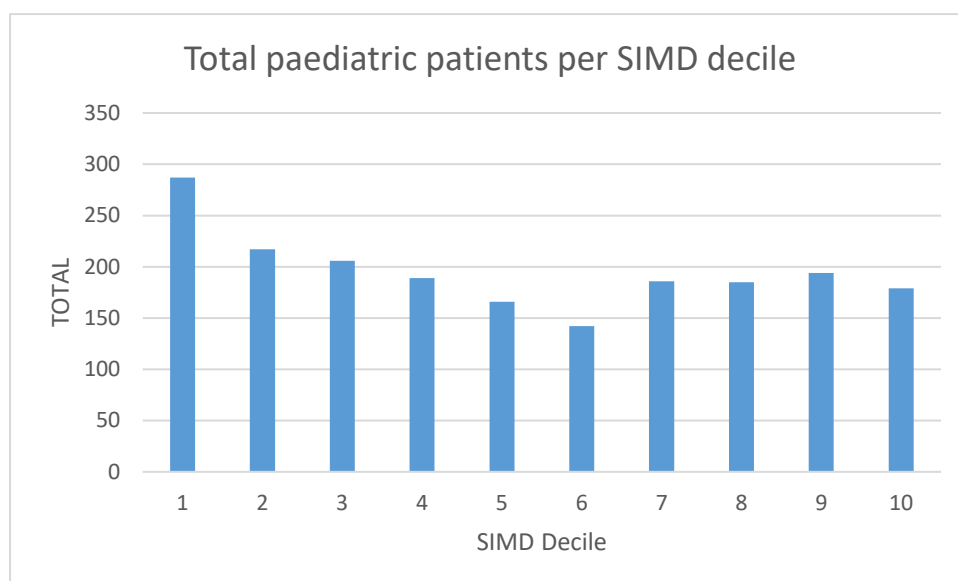
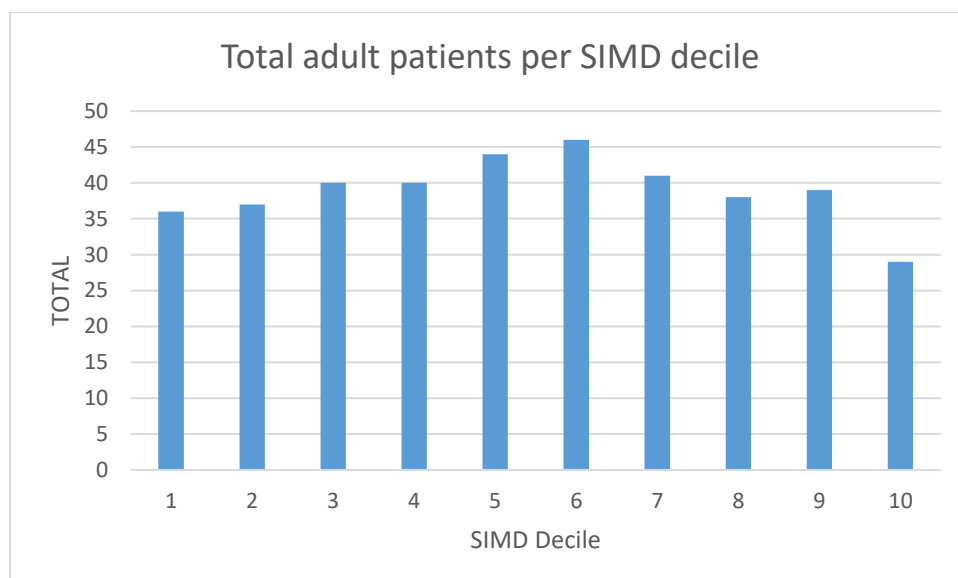


Figure 2 shows that vCreate Neuro registration for adult service users was most common among people within SIMD decile 6 followed closely by decile 5, but there was not a large difference between the most common and least common decile. This may indicate the registration of the service in the adult population was not dependent on their SIMD decile.

Figure 2: SIMD decile of registered adult service users



A total of 7,155 uploads were made to the system by service users who supplied full demographic data to allow analysis (adult service user videos, n=801, paediatric service user videos n=6,354). Twenty-one percent of adult service users and 25% of paediatric service

users uploaded a single video to the service, while multiple uploads were made by 64% of paediatric service users compared with 32% of adult service users. Paediatric service users uploaded an average of three videos whereas adult users made an average of two uploads.

Figures 3 and 4 show that the average number of logins and uploads across SIMD deciles for paediatric service and adult service users. These show that there are no clear underlying patterns determining usage for both adult and paediatric service users.

Figure 3: Average number of uploads and logins per SIMD decile of registered paediatric service users

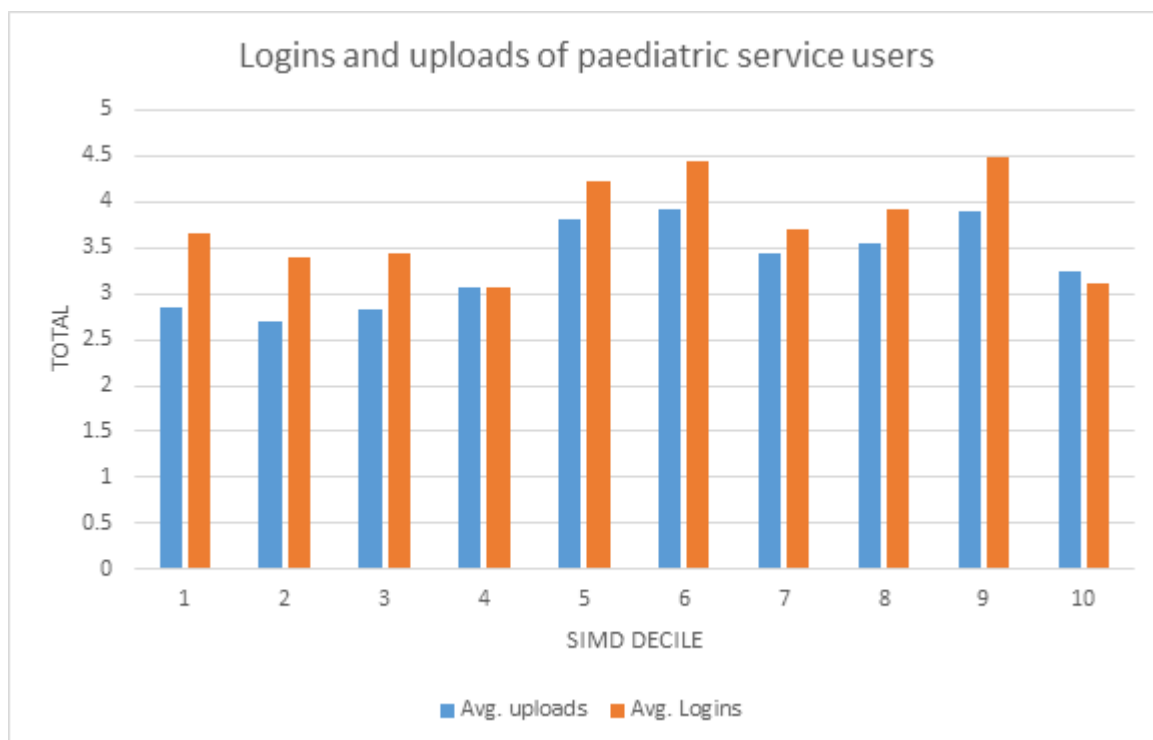
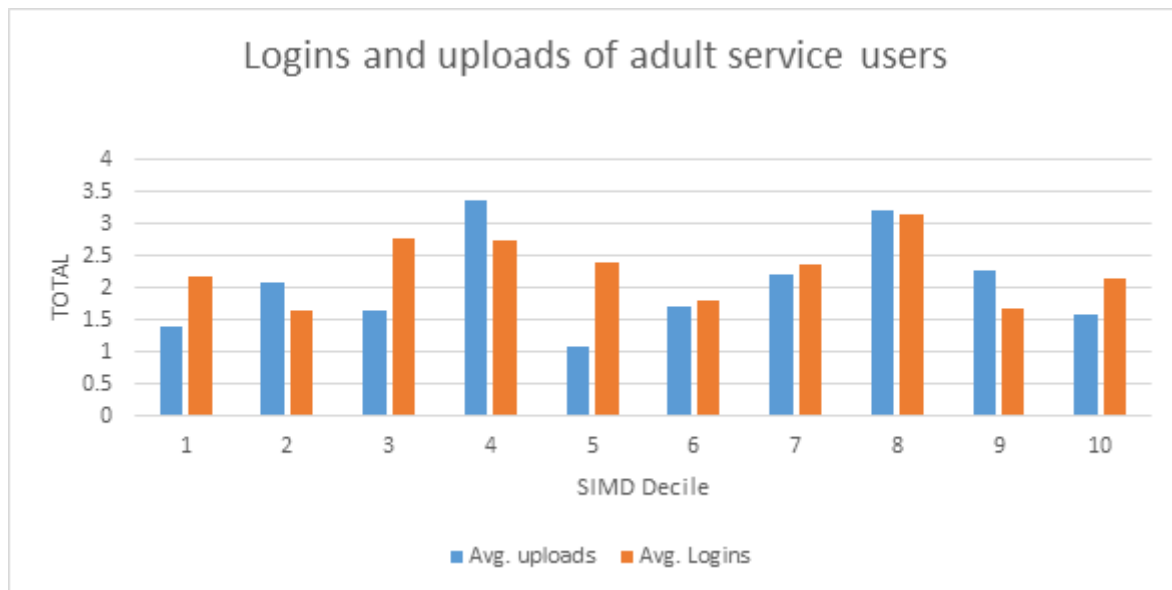


Figure 4: Average number of uploads and logins per SIMD decile of registered adult service users



Survey data analysis

In order to evaluate the use of vCreate Neuro within NHSScotland, we were asked to undertake analyses of survey data to gain insight into the opinion and experience of both the service users and clinicians who had used vCreate Neuro.

Survey design and participants

The project team collected electronic survey data from the following vCreate Neuro user groups:

- Service users
 - parents or carers of children using the paediatric neurology service via vCreate Neuro
 - adult patients or carers of adult patients using the adult neurology service via vCreate Neuro
- Clinicians
 - paediatric neurologists
 - adult neurologists

Service users were asked to complete a survey every time they uploaded a video using vCreate Neuro, while service clinicians were requested to do the same every time they classified or entered a note about an uploaded video on the system. Patients may have multiple seizures, resulting in multiple videos at different time points, and it was not possible to determine how many times each respondent (service user or clinician) completed the survey. This means that the number of responses will not equate to the number of individual service users or clinicians.

Data for all user groups were collected using surveys from October 2020, comprising open questions with free-text response and closed questions with answers that were a mix of categorical and continuous variables. As a result of concerns raised by SHTG researchers about ambiguous terms used in the closed questions and the appropriateness of measurement tools, a new survey was developed for both user groups (see *Appendix 1*). The updated survey was implemented in May 2021. The findings of the quantitative survey section are based on data gathered between May 2021 and 10 January 2022. The findings of the qualitative survey section are based on all the survey data gathered between October 2020 and 10 January 2022. An interim analysis on data up to August 2021 were presented previously in the [Phase 1 report](#).

Ethics

The evaluation was classified as a service evaluation by the project team, and therefore did not require a review by an ethics board. Respondents gave their informed consent to participate in the evaluation of the vCreate Neuro service at the time of completing the survey.

Quantitative analysis

The following research questions were set for service users - including parents or carers of paediatric patients, adult patients, or carers of adult patients (all groups referred to as 'service users' in the questions):

- How easy or difficult did service users find vCreate Neuro to use for the first time?
- How easy or difficult did service users find vCreate Neuro to use after the first time?
- Did using vCreate Neuro make service users feel more or less connected to the clinical team? (only return patients were asked as they had a point of reference)
- Did service users feel that vCreate Neuro improved the quality of care provided to them? (only return patients were asked as they had a point of reference)
- What proportion of children avoided taking time off school and was this a half day or a whole day?
- What proportion of service users avoided taking time off work and was this a whole day or a half day?
- On average how many miles of travel were avoided and what mode of transport would have been used?
- Was the avoided travel distance different depending on how connected a service user felt to the clinical team?

Research questions for the service clinicians were (clinicians delivering adult and paediatric services considered separately):

- How easy or difficult did clinicians find vCreate Neuro to use?
- What proportion of clinicians felt, to allow the video to be interpreted, the quality of the video was high, adequate, or inadequate?
- Did using vCreate Neuro make clinicians feel more or less connected to the service user or patient?
- Did clinicians feel that using vCreate Neuro improved the quality of care provided?
- Did clinicians feel that the video and information uploaded were useful or not in making a diagnosis?
- Did clinicians feel that the video and information uploaded were useful or not for choosing a therapy?
- Compared to usual care, did clinicians feel that using vCreate Neuro affected the time to diagnosis? (stratified by new and return patients to the clinical service)
- Compared to usual care, did clinicians feel that using vCreate Neuro affected the time to treatment? (stratified by new and return patients to the clinical service)
- On average how many minutes did clinicians think it took to review the video and data and respond to the patient?

- Did clinicians find vCreate Neuro useful or not in the overall management of the patient?

In the context of the above research questions 'being connected' was defined as 'having easy access to the team and a positive relationship.' 'Access' was not defined.

Results were stratified by new and return patients to the clinical service and by patients who had used and not used vCreate Neuro service previously. Komolgorov-Smirnov tests were used to test for normality and one-way analysis of variance test, with a Tukey post hoc test or Kruskal-Wallis test used to test for differences between groups where appropriate. Statistical significance was set at $p < 0.05$.

Results

Surveys were issued to paediatric service users and clinicians at 14 sites and to adult service users and clinicians at four sites (*Table 1*). In total there were 739 survey responses from paediatric service users (from 4,635 uploaded videos), 47 survey responses from adult service users (from 478 uploaded videos), 420 survey responses from paediatric service clinicians, and 26 survey responses from adult service clinicians. A breakdown of number of responses by NHS site can be seen in *Table 1*.

Table 1: Number of survey responses by NHS site

Site	Responses from paediatric service users	Responses from adult service users	Responses from paediatric service clinicians	Responses from adult service clinicians
NHS GGC	213	0 ⁺	144	11
NHS Lothian	98	13	53	3
NHS Grampian	54	33	39	30
NHS Tayside	20	1	39	2
NHS Ayrshire & Arran	26	- [^]	13	-
NHS Borders	2	-	3	-
NHS Dumfries & Galloway	12	-	4	-
NHS Fife	13	-	1	-
NHS Forth Valley	19	-	2	-
NHS Highland	20	-	1	-
NHS Lanarkshire	40	-	62	-
NHS Sheffield Children's Trust	54	-	23	-

Site	Responses from paediatric service users	Responses from adult service users	Responses from paediatric service clinicians	Responses from adult service clinicians
Evelina London Children's Hospital (Guy's and St Thomas' NHS Foundation Trust)	123	-	13	-
Great Ormond Street Hospital (NHS Foundation Trust)	45	-	23	-
Total	739	47	420	46

*The number '0' indicates where vCreate Neuro was offered as part of the service but no responses were received.

^ '-' indicates that adult neurology services not offered at these sites

*surveys were issued to and collected from adult service users and clinicians in NHS Lothian but these were not used as the wrong survey had been issued. This error has been now been corrected.

Paediatric service user survey results

From 5 May 2021–10 January 2022 the response rate to the survey across all NHS sites was 16% (739 responses from 4,635 videos uploaded. Service users were advised to complete one survey if they uploaded several videos). Eighty-eight percent of responses to the paediatric service user survey were from females, 96% were from parents of the patient, with a median age of 37 years (interquartile range (IQR) 32 to 43). Fifty-nine percent of responses were from parents or carers of patients who were previously known to the neurology service before vCreate Neuro was offered. A full description of demographics is presented in *Appendix 2 Table 16*.

Key findings from the paediatric service user survey (n=739) with results from the subgroup of Scottish sites only (n=517) presented in parenthesis:

- 88% of responses (n=453) indicated that vCreate Neuro app was either 'very easy' or 'easy' to use for the first time (Scottish sites 87%, n=303). This increased slightly to 90% (n=179) based on repeated use of the app (Scottish sites 88%, n=147).
- The majority of responses (60%, n=256) from paediatric service users indicated that vCreate Neuro made them feel more connected to the clinical team (Scottish sites 62%, n=168).
- Just over half of responses (53%, n=231) from paediatric service users indicated that vCreate Neuro increased the quality of care provided (Scottish sites 54%, n=153).

- The majority of responses (64%, n=474) from paediatric service users indicated that vCreate Neuro allowed for easier communication with the clinical team (Scottish sites 63%, n=327).
- Use of vCreate Neuro avoided what would otherwise have been a work or school absence approximately 20% of the time the app was used (Scottish sites 22%).
- The most common modes of transport avoided from using the app were car (n=561) and train (n=76).
- The median mileage of travel avoided from using the app was 17.5 miles (IQR 8 to 40 miles) (Scottish sites 15.0 miles IQR 7 to 30).
- There was no statistically significant difference in the median distance travelled dependent on how connected a parent or carer felt to the clinical team (p=0.716) (Scottish sites p=0.973).

Detailed results are presented in *Table 2* and *Tables 17 and 18 in Appendix 2*.

Table 2: Survey results for paediatric service users

Research question (n of responses)	Response categories				
	Results % (n)				
-	Very easy	easy	Neither easy or difficult	Difficult	Very difficult
Ease of first time use (all sites n=537)	44% (238)	40% (215)	11% (59)	4% (20)	1% (5)
Scottish sites n=350	46% (161)	41% (142)	11% (37)	2% (8)	<1% (2)
Ease of use after the first time (all sites n=200)	53% (105)	37% (74)	8% (16)	2% (4)	<1% (1)
Scottish sites n=166	52% (87)	36% (60)	8% (14)	2% (4)	<1% (1)
-	No or N/A	Yes	Half day	Full day	-
Avoidance of school absence (all sites n=739)	78% (577)	22% (162)	10% (71)	12% (91)	-
Scottish sites n=517	79% (406)	21% (111)	12% (60)	10% (51)	-
Avoidance of work absence (all sites n=739)	81% (602)	19% (137)	10% (75)	8% (62)	-
Scottish sites n=517	81% (420)	19% (97)	10% (54)	8% (43)	-
Mileage of travel avoided all sites n=736)	Median = 17.5, IQR 8 to 40 (KS test p<0.001)				-
Scottish sites n=516	Median = 15.0, IQR 7 to 30 (KS test p<0.001)				-
-	More connected	Neither more nor less	Less connected	Don't know/not sure	-

Research question (n of responses)	Response categories				
	Results % (n)				
Feeling more or less connected (all sites n=424)*	60% (256)	24% (102)	4% (18)	11% (48)	-
Scottish sites n=272	62% (168)	24% (65)	4% (11)	10% (28)	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/not sure	-
Quality of care (all sites n=439)*	53% (231)	22% (96)	2% (8)	24% (104)	-
Scottish sites n=282	54% (153)	22% (63)	1% (4)	22% (62)	-
-	Yes	No	Don't know/not sure	-	-
Help easily communicate with clinical team (all sites n=739)	64% (474)	5% (35)	31% (230)	-	-
Scottish sites n=517	63% (327)	5% (24)	32% (166)	-	-

*n is lower because these questions were only asked to patients already known to the service.

Adult service user survey results

From 5 May 2021–10 January 2022 the response rate to the adult service user survey across four sites in NHSScotland was 10% (47 responses from 478 videos uploaded). Of the 47 responses to the adult service user survey the mean age was 42. Twenty-nine responses were from females and 18 from males. The majority of responses were from patients (n=30) or spouses (n=10). Thirty-two responses were from service users already known to the neurology service. A full description of demographics is presented in *Appendix 2 Table 19*. As a result of the small number of responses, percentage results were not calculated.

Key findings from the adult service user survey (n=47).

- The majority of responses (n=25 out of 36) from adult service users found vCreate Neuro either 'very easy' or 'easy' to use for the first time.
- There was a relatively even spread of opinion in the responses about whether vCreate Neuro made adult service users feel more or less connected to the clinical team.
- Twelve responses were from adult service users who thought that vCreate Neuro improved the quality of care provided, 11 felt it had no effect, 11 were not sure and one felt it reduced the quality of care.
- Fifteen responses were from adult service users who thought that vCreate Neuro allowed for easier communication with the clinical team, three responses were from services users who felt it hindered communication and 13 were not sure.

- Use of vCreate Neuro avoided absence from work in three instances.
- Modes of transport that were avoided were air travel (n=3), ferry (n=2), bus (n=9), car (n=31) and taxi (n=1).
- Median mileage of travel avoided was 30 miles (IQR 5 to 66) (because of the small numbers, the distance travelled was not compared according to how connected a service user felt).

Detailed results are presented in *Table 3*.

Table 3: Survey results for adult service users

Research question (n of responses)	Response categories				
	Results (n)				
-	Very easy	easy	Neither easy or difficult	Difficult	Very difficult
Ease of use for first time (n=36)	9	16	6	3	2
Ease of use after the first time (n=11)	4	7	0	0	0
-	No or N/A	Yes	Half day	Full day	-
Avoidance of work absence (n=46)	43	3	1	2	-
Mileage of travel avoided (n=47)	Median =30, IQR 5 to 66, KS test p<0.001			-	-
-	More connected	Neither more nor less	Less connected	Don't know/not sure	-
Feeling more or less connected (n=27)^	7	6	6	8	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/not sure	-
Quality of care (n=32)^	12	11	1	11	-
-	Yes	No	Don't know/not sure	-	-
Help easily communicate with clinical team (n=31)	15	3	13	-	-

^ only patients already known to service

Paediatric service clinician results

There were a total of 420 responses from paediatric service clinicians across all NHS sites. Sixty percent (n=247) of responses were from clinicians reviewing data for return patients and 40% (n=168) were new patients. There were five entries with missing data.

Two of the vCreate Neuro project team worked in NHS sites in Scotland (NHS GGC and NHS Lothian) and completed the clinician survey. The results from these two boards are reported as a subgroup (n=197) as well as the subgroup for sites in Scotland only (n=361).

Key findings from the paediatric service clinician survey (n= 420):

- Almost all responses (96%, n=398) were from paediatric service clinicians who thought that vCreate Neuro was either 'very easy' or 'easy' to use (Scottish sites: 96%, n=342; NHS GGC and NHS Lothian: 100%, n=130). A sensitivity analysis showed that the high level of positivity was driven by the responses from clinicians in NHS GGC and NHS Lothian (which are the two largest clinical neurology test sites in NHSScotland and early adopters of vCreate Neuro). Members of the vCreate Neuro project were senior clinicians at these two sites. While these results drove the high level of positivity, even when removed the results remained positive. See *Tables 20 to 24* in Appendix 2 for more detail.
- Almost all responses (>99%, n=405) from paediatric service clinicians indicated that vCreate Neuro was either 'very useful' or 'useful' in the overall management of the patient (Scottish sites: >99%, n=349; NHS GGC and NHS Lothian: >99%, n=191).
- Almost all responses (99%, n=413) from paediatric service clinicians indicated that the video quality was either 'high quality' or of 'adequate quality' (Scottish sites: 99% n=355; NHS GGC and NHS Lothian: 99%, n=195).
- The majority of responses (92%, n=380) from paediatric service clinicians indicated that vCreate Neuro made them feel more connected to the patient (Scottish sites: 92%, n=345; NHS GGC and NHS Lothian: 99%, n=192).
- Almost all responses (97%, n=402) from paediatric service clinicians indicated that vCreate Neuro improved the quality of care provided (Scottish sites: 97%, n=345; NHS GGC and NHS Lothian: 99%, n=192).
- Almost all responses from paediatric service clinicians indicated that vCreate Neuro was either 'very useful' or 'useful' in making a diagnosis (93%, n=381) (Scottish sites: 95%, n=329; NHS GGC and NHS Lothian: 86%, n=189).
- The majority of responses from paediatric service clinicians indicated that vCreate Neuro was either 'very useful' or 'useful' for selecting a treatment (85%, n=306) (Scottish sites: 86%, n=259; NHS GGC and NHS Lothian: 96%, n=176).
- The majority of responses (76%, n=269) from paediatric service clinicians indicated that vCreate Neuro allowed for a shorter time to diagnosis (Scottish sites: 81%, n=246; NHS GGC and NHS Lothian: 91%, n=158).

- The majority of responses (73%, n=232) from paediatric service clinicians indicated that vCreate Neuro allowed for a shorter time to treatment (Scottish sites: 77%, n=215; NHS GGC and NHS Lothian: 86%, n=151).
- From the responses (n=377), a median time of 9 minutes (IQR 10 to 15, range 1 to 240) was spent by clinicians reviewing the videos and responding to the patient (Scottish sites: n=327, median 5 min, IQR 5 to 10, range 1 to 240; NHS GGC and NHS Lothian: n=182, median 5 min, IQR 5 to 10, range 1 to 240).
- From 403 responses an investigation was avoided 152 times (Scottish sites: n=137 from 347 responses; NHS GGC and NHS Lothian: n=92 from 190 responses). The most commonly avoided investigation was EEG (n=126) (Scottish sites: n=112; NHS GGC and NHS Lothian n=76). More details can be seen in *Tables 21 to 23* in Appendix 2.
- From responses the median estimated time to earlier diagnosis in both new (n=58) and return patients (n=40) was 2 weeks. These results should be interpreted with caution because of the small number of responses, the large range (<1 hour to 2 months) and that these results were driven by responses from NHS GGC and NHS Lothian where two of the project team were senior clinicians. Further details can be found in *Table 24* in Appendix 2.

Detailed results are presented in *Table 4*.

Table 4: Survey results for paediatric service clinicians

Research question (n of responses)	Response categories				
	Results % (n)				
-	Very easy	easy	Neither easy or difficult	Difficult	Very difficult
Ease of use (n=417)	78% (324)	18% (74)	4% (17)	<1% (2)	0
Scottish sites (n=358)	83% (296)	13% (46)	4% (14)	<1% (2)	0
GGC and Lothian (n=196)	95% (186)	5% (10)	% (0)	% (0)	% (0)
-	High (easy to interpret)	Moderate (interpret with effort)	Poor (unable to interpret)	-	-
Video quality (n=417)	86% (357)	13% (56)	1% (4)	-	-
Scottish sites (n=358)	87% (312)	12% (43)	1% (3)	-	-
GGC and Lothian (n=197)	91% (180)	8% (15)	1% (2)	-	-
-	More connected	Neither more nor less	Less connected	Don't know/not sure	-

Research question (n of responses)	Response categories				
	Results % (n)				
Feeling more connected to patient (n=412)	92% (380)	6% (26)	0	1% (6)	-
Scottish sites (n=353)	92% (325)	6% (22)	0	2% (6)	-
<i>GGC and Lothian (n=193)</i>	97% (188)	2% (3)	% (0)	1% (2)	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/not sure	-
Quality of care (n=415)	97% (402)	3% (13)	0	0	-
Scottish sites (n=356)	97% (345)	3% (11)	0	0	-
<i>GGC and Lothian (n=194)</i>	99% (192)	1% (2)	% (0)	% (0)	-
-	Very useful	Useful	Not useful or made no difference	Made more difficult	-
Useful for making a diagnosis (n=407)	65% (266)	28% (115)	6% (26)	0	-
Scottish sites (n=350)	67% (232)	28% (97)	6% (21)	0	-
<i>GGC and Lothian (n=193)</i>	84% (163)	13% (26)	2% (4)	% (0)	-
Useful for choosing a treatment (n=359)	58% (210)	27% (96)	14% (52)	<1% (1)	-
Scottish sites (n=304)	63% (190)	23% (69)	15% (45)	0	-
<i>GGC and Lothian (n=184)</i>	86% (158)	10% (18)	4% (8)	% (0)	-
-	Shorter than usual	Same time	Longer than usual	-	-
Time to diagnosis NP n=153, RP n=199	NP 82% (125) RP 74% (147)	NP 18% (28) RP 26% (52)	NP (0) RP (0)	-	-
Scottish sites NP n=139, RP n=165	NP 84% (117) RP 78% (129)	NP 16% (22) RP 22% (36)	NP (0) RP (0)	-	-
<i>GGC and Lothian NP n=86, RP n=88</i>	NP 90% (77) RP 92% (81)	NP 10% (9) RP 8% (7)	NP (0) RP (0)	-	-
Time to treatment	NP 76% (102)	NP 24% (32) RP 28% (52)	NP (0) <1% RP (1)	-	-

Research question (n of responses)	Response categories				
	Results % (n)				
NP n=134, RP n=183	RP 71% (130)				
Scottish sites NP n=121, RP n=158	NP 80% (97) RP 75% (118)	NP 20% (24) RP 25% (39)	NP 0 RP <1% (1)	-	-
<i>GGC and Lothian</i> NP n=84, RP n=92	NP 85% (71) RP 87% (80)	NP 15% (13) RP 13% (12)	NP (0) RP (0)	-	-
-	Very useful	Useful	Not useful	Hindered a bit	Hindered greatly
Useful for overall patient management (n=408)	73% (296)	27% (109)	<1% (3)	0	0
Scottish sites (n=351)	75% (262)	25% (87)	<1% (2)	0	0
<i>GGC and Lothian</i> (n=192)	92% (176)	8% (15)	<1% (1)	% (0)	% (0)

Abbreviations: NP: new patients, RP: return patients.

Adult service clinician results

There was a total of 46 responses from adult service clinicians across four NHS sites in Scotland, 24 were reviewing new patients and 21 were reviewing return patients (one response included missing data). As a result of the small number of responses, percentage results were not calculated.

Key findings from the adult service clinician survey (n=46).

- The majority of responses (n=39) were from adult service clinicians who thought that vCreate Neuro was either 'very easy' or 'easy' to use.
- Almost all of the responses (n=39 out of 41) were from adult service clinicians who thought that vCreate Neuro was either 'very useful' or 'useful' in the overall management of the patient.
- Almost all responses were from adult service clinicians who thought that the video quality was either high quality (n=25) or of adequate quality (n=19).
- The majority of responses (n=41) were from adult service clinicians who thought that vCreate Neuro made them feel more connected to the patient.
- The majority of responses (n=36) were from adult service clinicians who thought that vCreate Neuro improved the quality of care provided.
- Almost all responses were from adult service clinicians who thought that vCreate Neuro was either 'very useful' or 'useful' in making a diagnosis (n=35 out of 37) or selecting a treatment (n=34 out of 37).

- The majority of responses were from adult service clinicians who thought that vCreate Neuro lead to shorter time to diagnosis (n=19 out of 26) and a shorter time to treatment (n=16 out of 24).
- From the responses (n=32), a median time of 10 minutes (IQR 5 to 20, range 0 to 30) was spent by clinicians reviewing the videos and responding to the patient.
- From 28 responses an investigation was avoided 16 times. Investigations avoided were EEG (n=9), followed by inpatient EEG (n=4) and MRI (n=1).

More detailed results can be seen in *Table 5*.

Table 5: Survey results for adult service clinicians

Research question (n of responses)	Response categories				
	Results (n)				
-	Very easy	easy	Neither easy or difficult	Difficult	Very difficult
Ease of use (n=46)	25	14	5	1	1
-	High (easy to interpret)	Moderate (interpret with effort)	Poor (unable to interpret)	-	-
Video quality (n=46)	25	19	2	-	-
-	More connected	Neither more nor less	Less connected	Don't know/not sure	-
Feeling connected to patient (n=46)	31	10	0	5	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/not sure	-
Quality of care (n=46)	36	10	0	0	-
-	Very useful	Useful	Not useful or made no difference	Made more difficult	-
Useful for making a diagnosis (n=37)	14	21	2	0	-
Useful for choosing a treatment (n=37)	12	22	3	0	-
	Shorter than usual	Same time	Longer than usual	-	-
Time to diagnosis NP n=16, RP n=13	NP (11) RP (8)	NP (5) RP (5)	NP (0) RP (0)	-	-
Time to treatment NP n=13, RP n=11	NP (9) RP (7)	NP (4) RP (4)	NP (0) RP (0)	-	-

Research question (n of responses)	Response categories				
	Results (n)				
	Very useful	Useful	Not useful	Hindered a bit	Hindered greatly
Useful for overall patient management (n=41)	22	17	2	0	0

Abbreviations: NP: new patients, RP: return patients.

Summary

Summary points from the quantitative analyses are as follows:

- Parents and carers who used vCreate Neuro within paediatric and adult services were predominantly positive about the ease of use of vCreate Neuro, how 'connected' it made them feel to the clinical team, the impact on quality of care, and the ease of communication with the clinical team. For paediatric services users, vCreate Neuro avoided absence from school or work in approximately 20% of use cases.
- Clinicians from both paediatric and adult services were predominantly positive about the ease of use of vCreate Neuro, its usefulness in the management of patients, its usefulness in making a diagnosis or selecting a treatment, the quality of the video uploaded, the impact on quality of care and feeling connected to the patient.
- A sensitivity analysis showed that the high level of positivity of the responses from paediatric service clinicians was driven by responses from NHS Greater Glasgow and Clyde (GGC) and NHS Lothian (which are the two largest clinical neurology test sites in NHSScotland and early adopters of vCreate Neuro). Members of the vCreate Neuro project were senior clinicians at these two sites. When these two sites were removed, the results still remained positive. For example, when asked about ease of use, 78% of clinicians from all sites reported that vCreate Neuro was 'very easy' to use. When the responses from NHS GGC and NHS Lothian (95% of whom felt it was very easy to use) were removed, 62% of clinicians from all other sites, and 68% of clinicians from all other Scottish sites, felt vCreate Neuro was very easy to use.
- More than half of the responses from paediatric service and adult service clinicians indicated that using vCreate Neuro led to a shorter time to diagnosis and treatment selection.
- Both paediatric and adult service clinicians reported that the most common investigation to be avoided was an EEG.

Qualitative Analysis

A qualitative analysis of 16 semi-structured interviews and the free-text comments from the clinician and service user surveys was undertaken, to explore people's experiences using vCreate Neuro and its perceived impact on receiving and delivering care.

Methods

Setting and participants

Electronic survey data was collected from two groups of vCreate Neuro users. The service user survey collected comments from parents and carers of children using paediatric neurology services and adult patients (and carers of adult patients) using neurology services. The clinician survey collected free-text comments from paediatric neurologists, adult neurologists and general paediatricians. All the evaluation survey respondents, who left a free-text comment in response to the question 'Do you have any other comments?' were eligible for the qualitative analysis. For more details on the setting, timeline and method of data collection of the surveys see the survey data analysis section above.

Clinicians and service users who had used vCreate Neuro on one or more occasion, and had completed an evaluation questionnaire, were eligible for selection for interview. Staff from the local NHS board, approached the service users and clinicians to discuss participation and obtain their consent to pass their information onto the researcher from Healthcare Improvement Scotland. The researcher then contacted the potential participants by email and provided the information sheet. Participants were further contacted by telephone or email to discuss the project and arrange a video interview for those who wished to participate. We aimed to recruit 10 to 20 participants, a minimum of five clinicians and five service users, for interview. Given the focused aim, analytical approach, intended range of participants, and the use of multiple sources of qualitative data (including a relatively large number of survey comments), this number was considered sufficient to meet the aims of the evaluation.¹⁹

A quota sampling strategy was used. For the clinician interviews we aimed to recruit paediatric neurologists and adult neurologists, paediatricians, epilepsy nurse specialists, and a clinical physiologist in neurophysiology (EEG technician). We aimed to recruit clinicians based in tertiary care and secondary care. For the service user sample we aimed to recruit adult patients and carers of paediatric patients. If feasible we aimed to recruit service users from the following groups:

- patients and carers that were newly referred to the neurology service and established patients
- families living less than 10 miles from the neurology service site and more than 100 miles away from the neurology service site
- service users from the Highlands & Islands community (a remote and rural setting)

A staff member from NHS GGC selected participants for recruitment. They used a list of all active service users within the vCreate Neuro system. They selected the first then every 100th service user from an alphabetical list and reviewed each one selected for their fit with the quota sample characteristics. A second round of selection selected every 25th service user and then every 10th service user. The same member of staff identified clinicians from an alphabetical list of all active users of the vCreate Neuro system and selected the first and then every 25th clinician and then reviewed their fit with the quota sample criteria. This process was carried out iteratively until we completed interviewing.

Interviews took place between October 2021 and January 2022. The semi-structured interview questions are available in Appendix 3 and 4.

Analysis

All interviews were recorded, transcribed verbatim and imported into NVivo® 11 for analysis. Spreadsheets containing the free-text comments were imported into NVivo® 11. Thematic analysis was used to analyse the interviews and the free-text comments.²⁰

In the thematic analysis, coding was applied to meaningful chunks of entire comments at the sentence level. Where appropriate, multiple sentences were coded as one chunk. An interim analysis of the free-text comments from the first survey was carried out initially and used to inform the phase one report. The subsequent analysis applied the coding structure, and thematic structure, used in the interim analysis and developed further codes and themes as required. The thematic structure was then refined to incorporate all the data from the interviews and all the free-text comments, in an iterative process. Differences in the experiences of different clinical specialities and hospital sites were sought in the analysis and they are outlined if identified. The influence of the available demographics on the service users was also explored in the analysis process. Only one researcher was involved in the analysis process.

A researcher with experience of conducting and analysing qualitative research and no clinical or personal experience of epilepsy or the use of asynchronous video sharing platforms carried out the data collection and analysis.

Quotes are used to illustrate the findings of the thematic analysis and are selected on the basis of brevity, clarity and ability to represent the finding being illustrated. If required spelling has been corrected, so as not to distract from the meaning of the quote – but no language or meanings have been altered.

Counts are given for the number of interviews that have supported a finding. Counts are given of the number of survey comments that have supported a finding. No rates are given, this is because it can be misleading to produce a rate from answers to a question such as “do you have anything to add?” If someone does not mention experiencing a technical issue, this does not mean that they have not done so because we are not analysing their response to a question directly about this issue.

Ethics

The evaluation has been classified as a service evaluation by the project team, and therefore did not require a review by an ethics board. Respondents gave their informed consent to participate in the evaluation of the vCreate Neuro service at the time of completing the survey.

A letter of unsupervised access was issued by NHS GGC that authorised the researcher's access to all the users of the vCreate Neuro service. All participants in the qualitative interviews received an information sheet before their interview and gave recorded verbal consent to participate at the start of the interview. The participants had the opportunity to ask questions and discuss the information before they gave their consent. The participants were made aware that they could withdraw at any time and that their information would be kept confidential and any use of their data would be anonymised before publication.

Findings

Survey respondents

Thirteen NHS sites provided qualitative free-text survey comments. Two hundred and ninety service user surveys (253 from paediatric and 37 from adult service users) and 198 clinician surveys (181 from paediatric and 17 from adult clinicians) containing free-text comments were included in the analyses. In total 488 surveys containing free-text comments were included. A breakdown of the number of qualitative responses by user type and NHS site can be seen in *Table 6*. The demographics of this sample are unknown. The nature of the qualitative responses confirms that service users from a remote and rural population are represented, however the extent of their representation in the sample is unknown.

Table 6: Qualitative responses by user type and NHS site

NHS site	Qualitative comments from service user surveys ^a		Qualitative comments from clinician surveys ^b	
	Parent/carers of paediatric patients	Adult patients/carers	Paediatric clinicians	Adult clinicians
NHS GGC	86	9	79	2
NHS Lothian	51	12	39	2
NHS Grampian	29	16	14	13
NHS Tayside	11	-	27	-
NHS Ayrshire & Arran	10	-	4	-
NHS Forth Valley	8	-	4	-
NHS Highland	14	-	1	-
NHS Lanarkshire	7	-	5	-
NHS Fife	1	-	-	-
NHS Borders	-	-	1	-
Evelina Children's Hospital (Guy's and St Thomas' NHS Foundation Trust)	22	-	1	-
Great Ormond Street Hospital for Children (NHS Foundation Trust)	7	-	2	-
NHS Sheffield Children's Trust	7	-	4	-
Total	253	37	181	17
Grand total	290		198	

^a Qualitative comments were received in nearly a quarter of the total service user survey responses (n=1,215; 1,097 paediatric and 118 adult service users)

^b Qualitative comments were received in over a quarter of the total clinician survey responses (n=699; 639 paediatric and 60 adult neurologists)

Interview participants

Sixteen people took part in the interviews, ten clinicians and six service users. Of the 19 service users who initially agreed for their details to be passed on, six agreed to be interviewed, giving a participation rate of a little less than a third. Of the 10 clinicians whose details were passed on, all agreed to participate.

All interviews were video interviews using Microsoft Teams, and took place individually, except for one paired interview with two consultant paediatricians based at the same hospital.

The quota sample of clinicians covered the intended range of job roles, including consultant paediatric neurologists, a consultant neurologist, epilepsy nurse specialists, consultant paediatricians, a newly qualified consultant paediatrician and a clinical physiologist in neurophysiology (an EEG technician). The sample included clinicians working in tertiary centres and secondary care (see Table 7 below).

Table 7: clinical interview participants

Participant number	NHS site	Job role
1	NHS GGC	Clinical Physiologist in Neurophysiology
2	NHS Lothian	Consultant Neurologist
3	NHS GGC	locum consultant paediatrician (newly qualified)
4	NHS Tayside	Epilepsy Nurse Specialist
5	NHS Grampian	Epilepsy Nurse Specialist
6	NHS Lothian	Consultant paediatric Neurologist
7	NHS Grampian	Consultant paediatric Neurologist
8	NHS GGC	Consultant paediatric Neurologist
9	NHS Lanarkshire	Consultant Paediatrician
10	NHS Lanarkshire	Consultant Paediatrician

The sample did not include any adult patients or carers of adult patients. The sample recruited was geographically diverse; it included service users living in four different health board jurisdictions and service users living in deprived and affluent areas, as identified by SIMD deciles. Three of the service users interviewed were from SIMD decile 9, meaning that they lived within the 20 % least deprived zones in Scotland. One of the service users was in SIMD decile 2, meaning that they lived within the 20 % most deprived zones in Scotland. The remaining two service users interviewed were from SIMD decile 4, meaning that they live within the 40 % most deprived zones in Scotland.²¹ The maximum distance from the treatment centre recruited was 28.6 miles and no service users from remote and rural

setting were recruited for interview. *Table 8* below shows the details of the service user sample.

Table 8: service user interview participants

Participant number	NHS board of residence	Patient type	Reason for referral to use vCreate Neuro	Distance from hospital site providing care (miles)	SIMD decile
1	NHS GGC	Existing patient	Non-epileptic (>80 % certainty)	18.7	9
2	NHS Lothian	New patient in service	Epilepsy and Paroxysmal Disorders	6.3	4
3	NHS Lanarkshire	New patient in service	Epilepsy and Paroxysmal Disorders	20.9	9
4	NHS Ayrshire & Arran	Existing patient in service	Epilepsy and Paroxysmal Disorders	5.8	4
5	NHS Lanarkshire	New patient in service	Epilepsy and Paroxysmal Disorders	28.6	9
6	NHS Lothian	New patient in service	Epilepsy and Paroxysmal Disorders	6	2

Sentiment analysis (phase one report) and the influence of NHS site

A sentiment analysis conducted for the phase one report on survey data collected between October 2020 and May 2021, examined the impact of NHS site on the emotional tone of the responses. The full analysis and methods are in the [Phase 1 report](#). The percentage of positive comments from NHS GGC and Lothian based clinicians was higher than all other clinicians combined (87% positive versus 59% positive respectively). A comparison of the content of the comments in the thematic analyses did not reveal any differences in the thematic content of the positive comments. This means that the positive comments covered the same type of material in NHS GGC and NHS Lothian as the other health boards. There were more suggestions for improvements from the other health boards which is the reason for a higher proportion of negatively coded comments from those boards. However, clinicians from NHS GGC and Lothian did identify similar challenges to the use of vCreate Neuro in their survey comments and subsequent interviews as the clinicians from other health boards.

Thematic analysis

Clinicians' and service users' experiences and views were grouped under two overarching themes: the benefits and challenges of using vCreate Neuro. Under each overarching theme,

a set of subthemes are described. All the service user “stories” shared by clinicians and service users are gathered in Appendix 5 and 6.

The benefits of using vCreate Neuro

An important part of the neurology service

In the survey comments both clinicians and service users described the positive impact of asynchronous video sharing on their experience of delivering and receiving neurology care. In the service user surveys there were a large number of comments that gave generic praise to vCreate Neuro (for example *‘find it helpful’*) or specified an area of care they felt it had improved (117 service user comments). Service users described the overall beneficial impact of vCreate Neuro as the perceived ability to *‘speed up the process of care and resolution for patients...’* (service user 66, second survey). A common description of vCreate Neuro by the clinicians surveyed was that it was a *‘very helpful,’ ‘essential’* or *‘vital’* part of providing neurology services (45 clinical survey comments).

All six of the service users interviewed thought that the use of vCreate Neuro had had a positive impact on their experience of receiving care. The reasons for this will be explored in more depth in the subthemes below. Similarly, all the clinicians interviewed believed that vCreate Neuro had led to an improvement in the delivery of neurology care and that the ability to share videos asynchronously was now a part of the way that the neurology services operated:

I pretty much use it on an almost daily basis, because we very much made it a part of how our service works now, at the time the project was implemented we had quite significant restrictions on our clinical practice because of the COVID related adjustments which were made... (clinical interview 7, consultant paediatric neurologist).

The COVID-19 pandemic

The clinicians described the COVID-19 pandemic as *‘highlighting’* the need for an asynchronous video sharing platform and a tool that would *‘avoid people having to travel into hospitals’* (clinical interview 6, consultant paediatric neurologist), but they were clear that the need for this tool predates the pandemic and would continue after it (8 clinical interviews). Five of the carer interviewees also reflected on vCreate Neuro *‘coming around at a particularly good time’* (service user interview 4) given the reduction in the number of available face-to-face appointments. The impact of the pandemic in reducing the availability of face-to-face appointments and the helpfulness of vCreate Neuro in these circumstances was also mentioned in the clinical (2 Comments) and service user surveys (5 comments).

Secure transfer and storage

vCreate Neuro has provided a *‘secure place, we didn’t have before’* (clinical interview 4, epilepsy nurse specialist) to share and store videos. All the clinicians interviewed, except for

the clinical physiologist in neurophysiology (EEG technician) discussed the challenge of sharing and storing videos securely before having access to vCreate Neuro. The clinicians described relying on email, which presented difficulties because of file size and security, or on service users attending face-to-face appointments to show them videos on their phone:

...those videos would have been sent to the clinician. The clinician would have then tried to email them to us...So these are several Mega Byte videos. Often you just can't send them and you can't send them via certain hospital systems because they don't allow you to send them because they have their confidential information. So basically it makes it really, really difficult to exchange that and often you had to resort to the child having to be admitted. To come to hospital or needed a hospital transfer for us to see the child...and review videos. (clinical interview 8, consultant paediatric neurologist)

While the three consultant paediatricians described the challenge of getting the videos to the tertiary specialists prior to having access to vCreate Neuro:

...it was almost impossible to get the tertiary people to look at it securely. So I think what vCreate for me has done, over the years I've always thought 'oh I wish we had some system of getting these videos securely and being able to share them' and vCreate has just done all of that. It's just amazing. It's just like, it sounds a bit naff, but it's a bit of a dream come true. (clinical interview 9, consultant paediatrician)

Four comments in the clinical survey described the usefulness of vCreate Neuro as a secure place to receive and store videos, and one comment from a service user survey described the system as 'secure...' (Service user survey 102, second survey).

Three of the service users interviewed felt that email would not have been a viable option for sending video because of file sizes, security concerns and NHS procedures. One service user interviewed described the system as 'safe and secure' and acknowledged that because the nature of the videos who can view them should be restricted, they wouldn't want 'Tom, Dick and Harry looking at it, but....I felt fine with that side of things' (service user interview 2). None of the service users interviewed raised any concerns about the security of the system.

One clinician expressed a 'niggling fear' about the security of the storage of videos 'on the cloud' given their sensitive nature, despite 'accepting what the professionals' say about it being a secure system (clinical interview 7, consultant paediatric neurologist).

Rapid remote review and diagnosis

In the survey comments and the interviews, clinicians described vCreate Neuro as a tool that facilitates rapid remote review (101 survey comments and 10 interviews). When a video is available it can be reviewed rapidly as part of the provision of care for the clinician's own caseload or to facilitate rapid expert, or peer, review of another clinician's patient:

I work in a big tertiary centre. So lots of different colleagues have patients they may see in their outpatient clinic....so they can then send something in and say, 'oh, I've seen this patient, could you have a look at the video and see what you think.' So I can then let them know immediately when I see the video what I think it is and what I think needs to be done about...it also enables the clinician to go back to the family and say I've discussed this with an expert and they say it is this and this is what we need to do. (Clinical interviewee 6, consultant paediatric neurologist).

Tertiary neurological services that cover a wide geographical area and provide services for patients based in remote and rural locations (three clinical interviews, two service user survey comments, one clinical survey comment) may find the access to remote review and remote video sharing of additional benefit:

...we cover a very large geographic area, including Shetland and Orkney. And it's [vCreate Neuro] particularly worked well for remote and rural locations, and I think if you look at our numbers and you know the number of patients we see...a very small service is managed quite well over a very large area and a very significant patient population. (clinical interview 7, consultant paediatric neurologist)

The two general paediatricians, based in secondary care services echoed this and described the facility as 'like you're getting an immediate tertiary opinion' (clinical interview 10, consultant paediatrician). They thought that this rapid tertiary opinion 'provides a better level of care' (clinical interview 10, consultant paediatrician) for the patients and also learning opportunities for the paediatrician. All three consultant paediatricians interviewed suggested that the use of vCreate Neuro to gain rapid access to tertiary expert review had made them feel 'more reassured in my diagnosis' (clinical interview 3, locum consultant paediatrician).

A key theme in clinicians' interviews and survey comments was vCreate Neuros usefulness at the time of initial diagnosis for newly referred patients (91 clinical survey comments, 10 clinical interviews) and in the identification of urgent cases (16 clinical survey comments, 10 clinical interviews). Both clinicians and service users described how challenging it is to describe a seizure (13 interviews, 13 survey comments) and that sharing video as early as possible in the diagnostic process is beneficial for both groups:

...a lot of the descriptions that you know families give or carers give can be very similar to lots of different types of events. And actually seeing the events really, really enhanced, I think our diagnostic ability....the previous practice had been that we would see the children in clinic go through the story and then ask parents to video any paroxysmal events to send to us. Whereas here we can actually do so on the basis of the referral itself. (clinical interview 7, Consultant Paediatric Neurologist)

Five of the service users interviewed suggested that video was the only way to be sure that the clinicians would get to see the event, rather than just hear their description and this was also reflected in the survey comments (six service user survey comments):

...episodes are difficult to explain or you might doubt yourself, about what you are noticing about

your child. This makes it easier to have the conversation with clinicians as they can also see what you see. Sometimes it feels like you are imagining the episodes happening (service user 137, second survey).

The idea that service users may doubt themselves or find their concerns not taken seriously without video ‘evidence,’ was raised by two of the service users interviewed and in the service user surveys (four survey comments). It was of particular importance to the one mother interviewed whose child’s events were eventually determined to be non-epileptic. This mother had made three visits to accident and emergency (A&E) before being referred to the neurology service and being asked to use vCreate Neuro. They felt ‘reassured’ by the monitoring provided by vCreate Neuro and said that ‘*when I went to A&E it was dismissed. But vCreate allowed me to know that they were keeping an eye on our case*’ (service user interview 2). Clinicians also described the usefulness of asynchronous video sharing in identifying functional or psychologically driven disorders that are ‘*associated with great anxiety from their families*’ (clinical interview 8, consultant paediatric neurologist).

Ongoing care

Similarly both service users and clinicians described how vCreate Neuro can be used in correcting misdiagnosis and in ongoing care (32 clinical survey comments, four service user interviews, 10 clinical interviews). One example of its application in ongoing care was identifying whether new events, in a child or adult with identified epilepsy, are epileptic or not:

...I've certainly had a situation where a child who does have a diagnosis of epilepsy was having more events. The family sent the video in and in fact they were non-epileptic seizures and putting the medicine up would not have been the right thing to carry on doing. So that that's also been extremely helpful as well and you know meaning that families get correct diagnosis and access to correct, correct treatments and prognosis and management plans. (clinical interview 6, consultant paediatric neurologist).

One of the carers interviewed also described the use of vCreate Neuro for the ongoing care of her daughter who has complex needs because of a rare genetic disorder. Prior to having access to vCreate Neuro they would call the nurse to discuss any possible seizure activity with the nurse specialist ‘*and this usually that meant having to go to an appointment and hope that this behaviour happened at the appointment...*’ (SW, Service user interview). Now she feels that ‘*I'm getting good input from the consultants and the nurse and [my daughter] is, if she's needing treatment quickly, it's responded to within a couple of days.*’ (service user interview 4).

Earlier investigations and treatment

Clinicians suggested (eight clinical interviews and 21 clinical survey comments) that the rapid remote review of videos may lead to earlier access to investigations and even treatment for service users because an initial diagnosis or a judgement on the urgency of investigations can be made, on the basis of the video(s) provided. In the quote below a consultant paediatrician describes a case for which they believe vCreate Neuro led to more rapid investigation and treatment:

And you're able to look at the events and she's having a very large number of myoclonic epileptic seizures that are obviously epileptic, on the video. She had had investigations requested...but having that extra information, I had phoned the EEG department and she is having her EEG today and she's going to start her medicines this evening...I think that that's not that unusual that it's made a difference of potentially like weeks. (clinical interview 10, consultant paediatrician)

Five of the carers interviewed believed that using vCreate Neuro led to more rapid diagnosis, investigations or treatment for their child. The carer who did not discuss this had already received a diagnosis when they used vCreate Neuro and was referred to an expert neurologist to discuss the genetic component of their child's condition. One carer described her foster child's rapid diagnosis of infantile spasms:

The baby was having these irregular movements that I recorded and showed...the epilepsy Doctor and he then asked me to forward these through vCreate to the team at the sick children's Hospital...As soon as they got the EEG results, he then got started on medication. So it was all done within a day or two, which was amazing. (service user interview 3)

Time and resources

The prevention of unnecessary investigations (27 clinical survey comments), unnecessary treatment (12 clinical survey comments), unnecessary outpatient appointments (22 clinical and 11 service user survey comments), unnecessary travel (23 clinical and seven service user survey comments) and unnecessary hospital admissions (four clinical survey comments) was emphasised across the interviews and surveys. All the clinicians interviewed thought that vCreate Neuro led to ways to prioritise or reduce their workload, mainly through the reduction of in person investigations and outpatient appointments, but also through the identification of urgent cases. The three consultant paediatricians interviewed described less need to make formal referrals to tertiary specialists because of access to expert opinion via vCreate Neuro. In the case of the Clinical Physiologist in Neurophysiology (EEG technician) having access to a video prior to carrying out an EEG, helped to know what to 'look out for so that I could see exactly what type of event that child was having and then understand whether or not I've managed to capture it while doing the recording' (clinical interview 1, clinical physiologist in neurophysiology).

Clinicians described the way that access to videos of events led to a clearer picture of likely diagnosis, including a level of certainty about events being urgent, or non-epileptic and thereby reduced the need for clinical contacts and investigations:

And actually seeing the events really, really enhanced, I think our diagnostic ability...and actually pre-empted sometimes a lot of unnecessary appointments as we were able to make diagnosis just by looking at the videos and it....Avoided investigations where there wasn't required. And really, if we thought that the child needed to come for a face-to-face appointment. It helped us plan around what we've seen on the video...(clinical interview 7, consultant paediatric neurologist)

Service users valued the reduced need for, sometimes stressful, travel to outpatient appointments, they described how this can prevent the need to take time off work, or off school for their children:

...one less hospital appointment is gold to us, it's less time off school, it's less time off work. That's probably another point, another benefit—less time off school, less time off work...And so you know it, it's not interrupting his daily life, it's not interrupting ours, it's 5 minutes out of my time to upload a video and wait. (service user interview 4)

This may be of particular benefit to patients or carers of children with mobility difficulties or other conditions that can make travel challenging (three service user survey comments, two service user interviews) and those travelling from a remote and rural location (three clinical interview, two service user survey comments, one clinical survey comment):

This service saved my family and I travelling off island. The response was within the hour (thank you to the professor who called) and I was put at ease instantly. I'm no longer anxious and will sleep better tonight knowing our son is totally fine.... (service user 36, original survey)

Clinicians did also describe certain ways that vCreate Neuro can lead to an increase in workload, which will be covered in detail in the Challenges section below.

Communication

The positive impact of vCreate Neuro on communication between clinicians and service users and on building a relationship, was described by clinicians and service users (six service user interviews, nine clinical interviews, 42 clinical survey comments, 30 service user survey comments). Service users in the surveys did raise the concern that it could 'replace face-to-face appointments' (service user 39, second survey), or lead to a delay in their first outpatient appointment (13 service user survey comments). While the clinicians interviewed acknowledged the reduced number of face-to-face appointments available during the pandemic, two of them expressed the view that 'it's [vCreate Neuro] not turning appointments that would be face-to-face to remote' (clinical interview 2, consultant neurologist) and the clinical survey comments did not discuss this aspect at all.

The two aspects of communication building that were described by clinicians and service users were more direct access to clinicians via vCreate Neuro and more rapid feedback and often reassurance for service users, who do not have to wait for a face-to-face appointment

to have their videos reviewed or to provide information on changes to their clinical team:

It makes it easier to maybe access the clinical team because you can upload a video.... And they generally do watch it and phone, or a letter will come out. Whereas before it would be phoning the secretary or trying to get through your GP to contact the Doctor with your concerns. It definitely maybe makes it a bit easier to notify and show the Doctor your concerns...(service user interview 1)

Three of the service users interviewed described the use of vCreate Neuro as a more direct route back into the system and to access clinicians after discharge from the service:

And even with being discharged from neurology, they have said that if anything was to change, I could then upload, they would then get an alert and then they could get back in touch with me....It's all more accessible in the way it needs to be rather than getting a GP appointment, getting a letter, waiting lists... (service user interview 2)

The newly qualified consultant paediatrician also mentioned feeling reassured that service users who are discharged or having long periods in-between appointments, have a not been “discharged into the ether...you’ve still got a layer of connectivity back into services’ [via vCreate Neuro]” (clinical interview 3, locum consultant paediatrician).

The use of vCreate Neuro to gain a more direct way of accessing or communicating with clinicians was mentioned just one time in the clinical surveys, however, the use of vCreate Neuro to provide service users with more rapid reassurance was a strong theme across the surveys (39 clinical survey comments, 13 service user survey comments) and the interviews (five service user interviews, eight clinical interviews). The example below from the clinical survey describes the use of vCreate Neuro to provide a rapid diagnosis and reassurance for carers:

The video showed normal jittery movements when feeding. I was able to reassure the family during a video consultation and not get them back for a further consultation. I asked the mother to register during the consultation and she uploaded two videos during the consultation allowing me to make an immediate diagnosis. (comment 71, second clinical survey)

The service users (four service user interviews) and the clinicians (seven clinical interviews) described the impact of the clinician having seen the events that they were trying to describe as helpful in building a relationship with the clinician and a shared understanding:

I think having tried to kind of capture those videos actually enabled us to have a really good discussion because without those videos and just with me trying to explain it, like he wouldn't have known what I meant. And I think it's just knowing that like he didn't think it was anything to worry. (service user interview 6)

Education and research

The potential and actual benefits of vCreate Neuros use in education and research was highlighted by all the clinicians interviewed. vCreate Neuro is building a large body of videos that have been systematically classified as they are stored in the system. Service users are

asked about their consent to use the videos for training and for research purposes as they upload. Three comments in the clinical survey stated that the video had been uploaded for teaching purposes and two comments from service users mentioned being pleased that the video would be used for research or training purposes. One carer interviewed said that they *'like the idea of that it [the video] could be used for training'* that it might *'help other children with epilepsy,'* this provided an additional benefit to sharing a *'horrible video'* of their child having an epileptic seizure (service user interview 5).

The medics described using the videos for education purposes currently:

... all of our teaching are based on videos, because that's the most efficient way to teach anybody. So now that with this with vCreate...we've now thousands of videos that allow us to use that material because the patients have given their consent....We've been using it within our departmental teaching. (clinical interview 8, consultant paediatric neurologist)

The epilepsy nurse specialists and the clinical physiologist in neurophysiology (EEG technician) were not currently using vCreate Neuro for teaching purposes but felt that it had great potential in this area. One reason for not using it currently was the need for continuing development around consent and clinical governance issues, which will be discussed further in the challenges section. Similarly, its use in research was considered an area of great potential, with the proviso that further development may be required around consent and clinical governance.

The challenges of using vCreate Neuro

Access inequalities

For service users that are less familiar with the use of computers and smart devices, or do not have easy access to an email address or high speed internet, the vCreate Neuro can be challenging to use. The provision of technical support from the local clinical service, available informally on an ad hoc basis, was helpful in overcoming some of these challenges (seven service user survey comments). In the quote below one clinician describes her concerns about access inequalities related to IT access and familiarity with computers and smart devices:

...certainly there's a proportion of people that use vCreate, and then there's a proportion of people that don't upload. And when I talked to families that could be for a number of reasons to do with difficulty logging on, forgetting passwords, not managing to use the service...So they can almost miss out because if you don't put anything on it then, we don't know what we don't know...so a concern about lack of accessibility, for some families. (clinical interview 3, locum consultant paediatrician).

The two consultant paediatricians interviewed together felt that asynchronous video sharing platforms sidestep some of the access inequalities inherent in synchronous technologies like 'Near Me,' because of the relatively lower importance of a high speed internet connection for asynchronous sharing:

...vCreate because it's an asynchronous system that it is not like 'Near Me,' which is the quality of it is totally dependent on you having a decent Internet connection. If you've got the time, you can just sit and let your video creep in with your terrible 3G connection...when we've been doing virtual outpatient clinics, the quality of those appointments is definitely affected by the persons social class...But, but that's not the case for Vcreate. (clinical interview 10, consultant paediatrician)

One clinician interviewed raised the issue of inequality in health board access to systems, such as vCreate Neuro, and their concern that clinicians working outside of the 'central belt' might lose access to the system because of budget constraints:

I think it's age old thing is cost isn't it? I mean that's a huge barrier for health boards and it's [vCreate Neuro] been a real, a massive success...I personally don't work in the central belt and the rural and remote areas are often disadvantaged in access to these systems because it's going to be a low priority for our health boards to fork out money, which is not insignificant is it? So it just it makes it more of a disadvantage if there's not ongoing finance for this. (clinical interview 5, epilepsy nurse specialist)

One service user highlighted that people who live alone may be unable to capture video of a suspected epileptic event. While no other service users or clinicians raised this issue, this may be because of the low number of adult patients and carers of adult patients in the sample.

Clinical governance

Clinical governance in terms of ownership and final responsibility for the videos was discussed by four clinicians in the interviews. There was some concern expressed that, particularly if vCreate Neuro was to expand further, there would need to be clarity around who would be responsible for ensuring all videos are reviewed and acted on in a timely fashion:

...that final responsibility, the sort of the ability to have a named consultant responsible and responsibility for follow up of videos. I think if you've got junior doctors working shifts or moving jobs there be a risk to the ownership and monitoring of continuing videos, as it was wider and so that would need to be carefully thought about. (clinical interview 3, locum consultant paediatrician)

There was also some concerns expressed about the need to manage expectations around how quickly clinicians can respond to videos (two clinical survey comments, two clinical interviews). The clinicians interviewed thought that this was currently well managed (two clinical interviews) but it would need further development if the service is expanded.

...the information that they get from Vcreate is very good about setting expectations and stuff. That people haven't been expecting that, tomorrow I'll have a response to this video, which was an anxiety I think that we all had. That that once people can send these videos in they were going

to expect a telephone call about them within 30 minutes or something. (clinical interview 10, consultant paediatrician)

Education and research

The strong potential of vCreate Neuro to for research and teaching purposes was recognised by all the clinicians interviewed. However, three of the clinicians interviewed suggested that more work is necessary to develop the consent processes for teaching and research purposes. Two consultant paediatric neurologists raised the concern that videos used in teaching could appear on the internet because of talks being recorded, or shown at multiple meetings. They both suggested an additional consent was necessary, preferably at a later time point to the initial consent to share the video(s) with the clinical team, for their use in research and teaching. This would help families fully understand what they are consenting to because they can take time to consider the implications free from the initial urgency of getting their videos to the clinical team:

I think it [use for teaching] would need a specific additional consent and probably separate to the first time because actually you're so desperate to get an answer for your child's event. You don't want to be signing up to everything because you just want it to happen and it feels like it should be something that you come back to down the line when emotionally you may be feeling a little bit more able to consent to a different type of process, something for teaching is very different to something for diagnostics. (Clinical interview 6, Consultant Paediatric Neurologist)

One clinician also recognised the need to develop a clear process to 'withdraw consent for research purposes' if at some future point they do not want their videos shown beyond the immediate clinical team (clinical interview 7, consultant paediatric neurologist). One of the epilepsy nurse specialists also noted that further development of processes around consent for teaching and research may be necessary.

The surveys did not raise any concerns about consent processes.

Allocated clinical time and resources

The cost in terms of shifting clinical time to inviting service users, monitoring email notifications and reviewing videos in vCreate Neuro, which could otherwise have been used elsewhere was recognised in seven of the clinical interviews and in ten survey comments. A small number of clinicians (three comments) raised the concern that the time taken for using vCreate Neuro could be detrimental to their 'scheduled patients' and duties. The clinicians interviewed suggested that the impact of vCreate Neuro on ways of working, had not been fully appreciated prior to its adoption. Clinicians were clear that this has led to beneficial changes and more efficient ways of working, but that the time to use vCreate Neuro and the work it generates, which would previously have been associated with a clinic appointment, needs to be recognised in job planning and have allocated clinical time.

...it generates work. But that's like work, that's having a positive impact for your patients...You see these events and you're like 'well now I know what's going on so we need to act.' And it

generates other things from it...in other ways it saves work like in that in that situation where you're like, well, this is nothing to worry, you really don't need to come and see me everything is fine...I think we all have that kind of anxiety about job planning, a bit of vCreate time into our day and it's a new phenomenon for us. But the time you spend looking at those videos is probably the most efficient and valuable time that you spend for your patient. (clinical interview 10, consultant paediatrician).

One consultant paediatric neurologist raised the issue of unexpected changes to pathways of care caused by the adoption of vCreate Neuro, in terms of the shift of the *'ongoing management of the patient'* to secondary or tertiary services, from primary care. While they recognised the changes as beneficial to service users, they highlighted the potentially unexpected implications for the workload of clinicians in secondary and tertiary care.

...it sometimes leaves primary care out of the loop because you know families directly get in contact with the hospital....the primary point of contact has now shifted to hospital based clinicians...if you look at the relative resource that hospital based clinicians have versus primary care, we arguably have less numbers, and therefore it does shift the burden of care a little bit. (clinical interview 7, consultant paediatric neurologist).

Recording of useful videos

Two of the service users interviewed raised the challenge of capturing videos of the events, this can be difficult because the events can be rapid, sporadic or relatively subtle and therefore difficult to capture. A small number of survey comments (five) raised the issue that it is *'not always possible to catch an episode on video'* (service user comment 27, second survey).

The clinical interviews did not raise these issues, however a small number of clinical survey comments (seven) described video or images that *'did not help to diagnose'* (clinical survey comment 4, first survey) the events. The reasons given were that the clips were too short, were taken before or after the event, were of just one part of the body, or were photos when video was required. Echoing this a small number of service user survey comments (two) suggested uncertainty around what should be on the videos uploaded.

Technical issues and improvement suggestions

Five of the service users interviewed considered vCreate Neuro to be easy to use, although one of the service users had experienced difficulties with logging onto the system severe enough to dissuade them from uploading a second video. While 50 service users commented on how *'easy to use'* (Service user comment 27, first survey) vCreate Neuro was, technical issues and difficulties with the format of questions were the key challenges that service users described.

The technical issues experienced by service users were to do with logging on to and setting up their accounts and finding it hard to upload videos because of low internet speed,

incompatible file types/sizes and devices, or having multiple videos to upload at one time. Table 9 lists the technical issues experience by service users, with illustrative quotes

Table 9: Technical issues experienced by service users and illustrative quotes

Technical issue	Illustrative quote	Number of comments
Setting up account and logging in		
Setting up an account	<i>It's so hard to get started with it! Had password problems etc. (Service user 142, second survey)</i>	28
Logging in	<i>Find it difficult to login (Service User 79, second survey)</i>	19
Uploading videos and images		
Difficult to upload multiple videos	<i>I could not upload more than one video at a time and cannot upload a video without answering all the questions again. There should be an option to upload more than one video at a time. (Service user 140, second survey)</i>	22
Slow upload/internet speed	<i>I have a terrible time with this as the system kept timing me out while I was uploading the video, which was around 500 mb. I ended up cropping it and did eventually get it to go. This is not much use for people with poor internet connections ie where you can't get fibre. (Service user 113, first survey)</i>	18
Incompatible file type/size or device	<i>I was unable to upload my video using my phone. Following exactly the same process I could upload the video from my wife's phone. (Service user 73, first survey)</i>	14
Transfer across different devices	<i>We can only take video on the iPad. We are unable to download video footage from our phones. This makes it difficult to use quickly when an episode occurs. (Service user 63, first survey)</i>	8
Failed to upload	<i>I initially struggled to upload a video as it told me it couldn't accept the file type and I didn't know what to do about it so I gave up (Service user 55, second survey)</i>	9

Comparatively clinicians described very few technical issues, but they did describe slow video buffering (three survey comments), and some difficulties logging in and setting up accounts (three survey comment, two interviews). Seven of the clinicians interviewed, and one clinical survey comment, described the challenges experience by some service users with setting up an account and logging into the system, which can lead to clinicians and administrative staff spending time supporting them to resolve these difficulties:

I don't know how much of that it's because of IT literacy or how much it's the visibility of being able to do that. And so you're often asked where's the link? I Can't get this through to you because I've forgotten the link and then I've forgotten the passwords....I think some parents really

do struggle with all these passwords and codes. They find it very very stressful. (clinical interview 5, epilepsy nurse specialist).

Improvement suggestions

Service users suggested multiple improvements for vCreate Neuro, related to the technical issues that they had experienced (see *Table 9* in the technical issues section). They included:

- the facility to upload more than one video at a time
- the facility to delete videos
- making logging in and setting up an account easier
- making it clearer what types of file and file size are compatible with vCreate Neuro
- making it clear what type of device are compatible with vCreate Neuro
- increasing the size of file they are able to upload

There was some confusion amongst service users as to whether vCreate Neuro was available as a downloadable app, or only via a website and then which devices the web version was compatible with. Developing vCreate Neuro as an app on mobile phones was a suggested improvement (10 survey comments, two service user interviews):

The format of the questions was another area that gathered multiple suggestions for improvements and the suggestions from the surveys are summarised in *Table 10*. The inflexibility in the questions and their lack of relevance for each video and each service user led to some frustration in users and to the use of free-text fields to provide the information that they felt was relevant:

...a lot of the questions are maybe not really relevant to the episodes that we are uploading videos of...So I would just tick or select the non-applicable...I will write quite a long part, it might not even be a comment box that is supposed to be about this particular symptom, but that's the only space that there is so that is what I will fill the box with... (service user interview 1)

Table 10: Question format improvement suggestions from service users and illustrative quotes

Question format improvement suggestion	Illustrative quote	Number of comments
Ability to leave more or longer open comments	<i>The questions asked about the videos have multiple choice which I don't feel is helpful...there's also more I want to explain and say and no space to write this extra information. Like how often it happens or how long that particular episode lasted altogether or how long the episode lasted in hours before she vomited. It would be good if there was extra space to write accompanying notes. (Service user comment 89, second survey)</i>	20
Not applicable option	<i>Some questions are not applicable so would be good to have that option to select. (Service user comment 124, first survey)</i>	13
More options for answering closed questions	<i>The set questions are quite limited, for example there isn't an option for frequency of event of 'several times a week' it's either once a week or every day etc (Service User 125, second survey)</i>	7
Ability to edit or delete responses	<i>After answering the questions and uploading the video, it might be good if you could then review your answers and revise if necessary (eg if you accidentally put the wrong thing). (service user comment 75, first survey)</i>	7
Reduce the number of questions	<i>... there are too many 'generic' questions to answer before you can actually upload the video footage...If I do manage to capture some footage, it's then not great when it can be a bit of a 'drawn out' process to upload the said footage. I just want the video submitted asap for the comfort of knowing the correct people have it..(Service user comment 66, second survey)</i>	3

Service users in the surveys (30 survey comments) and the interviews (two interviews) indicated that a clear framework to guide their expectations around feedback, after submitting videos would be helpful. Although the service was praised for its speed, service users were uncertain how and when they would hear back from the neurology service about the videos that they had submitted. They did not receive any type of confirmation that the video had been received or viewed by a clinician, and were sometimes left uncertain about what would happen next. They did not know when it would be appropriate to contact the neurology department if they hadn't heard back from them:

I think if I'd had notification that it been viewed, that would have been really helpful just to be like, OK, someone's seen it. And then maybe a time frame that someone might get back to you in. So that if it's been 5 days, or longer or whatever, then you could be OK maybe it's not worked, or

you should follow up on this phone number or something. That would be really useful. (Service user interview 6)

One service user described an issue with needing to set up multiple accounts to send videos to the tertiary specialists in Glasgow because they already had an account set up with her territorial health board. This requires a different email address and they had to ‘*use my husband’s email address*’ (service user interview 3) to set up a second account to communicate with tertiary services. A consultant neurologist suggested that a “*Pan Scottish vCreate*” would help to solve this problem because despite the neurology service being provided at a national level, they have had to set up multiple accounts to view videos from other health boards (clinical interview 2, consultant neurologist).

Clinicians made less suggestions than service users, for improvements to the service. They did raise the issue of the inability of service users to submit multiple videos at one time, and noted that this leads to receiving an email for each video, having to answer the clinical questions for each video and being asked to complete an evaluation form for each video (nine survey comments, one clinical interview). All other improvements suggestions made by clinicians were shown in *Table 11*.

Table 11: Improvement suggestions from clinicians and illustrative quotes

Question format improvement suggestion	Illustrative quote	Number of comments
Facility for clinicians to download videos	<i>I think it is important for the clinicians managing their patients having access to download the videos, and hence one administrator with privileges per centre is insufficient, vCreate administration overall should be separate from privilege to download videos (each centre should be able to nominate 3-4 clinicians rather than one) (Clinician comment 88, second survey)</i>	3
Include name of patient and date in downloads	<i>It would be useful for note downloads to also include the name of the patient and date of upload of the besides the vCreate number. (clinician comment 37, first survey)</i>	2
The ability to pause service user accounts	<i>In patients with an existing diagnosis of NEA and functional neurological disorder it would be useful to be able to pause their ability to upload future videos. Otherwise, we are left having to respond to videos we no longer want diagnostically. (Clinician comment 13, second survey)</i>	1
Email alerts stating which patient the video is from	<i>The alerts do not indicate which patient the clip is in relation to so have to be reviewed acutely each time. (Clinician comment 142, second survey)</i>	1
Way of alerting a team rather than an individual	<i>Is there any way of alerting the team a video needs reviewed, when the person that invited the patient is on annual leave and are not accessing their emails? (Clinician comment 1, second survey)</i>	1

While all the clinicians interviewed had found vCreate Neuro accessible and ‘user friendly’ (clinical interview 8, consultant paediatric neurologist), two clinical survey comments mentioned needing ‘help’ or ‘advice’ to use it for the first time. One clinician interviewed suggested that extra training to develop their skills in its use would be helpful:

...another training session would be good because I think there's maybe bits that I could be doing that I don't know about it. Or I could be doing better. (clinical interview 4, epilepsy nurse specialist)

Future uses - adaptations and use in other contexts

Clinicians interviewed thought that the usefulness of vCreate Neuro would be likely to increase over time as its adoption widens and it continues to be adapted to fit different

contexts. One consultant neurologist described how they thought that the ability to store videos in vCreate Neuro would increase its usefulness over time:

...the level of the confidence in the level of diagnosis and the ability to store videos, I think it's going to be really helpful. I don't think we're really going to feel that properly until we've hopefully had this system for a number of years and be able to say, 'oh, let's go back and look at that video that you sent us in 2021.' We couldn't do that before. (clinical interview 2, consultant neurologist).

The potential for vCreate Neuro to be helpful in other specialities and to be further integrated into rehabilitation in neurology was highlighted (seven clinical interviews). The areas mentioned included movement disorders, speech and language therapy, dermatology, intensive care, neurodevelopmental assessment and reviewing EEGs. One interview described the potential for vCreate Neuro to be developed to incorporate machine learning to aid diagnosis. While the great potential for vCreate Neuro to be adapted for use in other contexts and settings was emphasised, concerns were expressed about growth and adaptations making it more unwieldy and difficult to use (four clinical interviews). The '*great research potential*' of vCreate Neuro (clinical interview 7, consultant paediatric neurologist) and the potential for expanding its use in education, was highlighted across the interviews and surveys and was discussed in more detail in the education and research sections above.

Summary

The key findings from the qualitative analyses were as follows (note that the transferability of these findings to adult service users is unclear because no interviews were completed with adult service users and their views have only been gathered in a small number (37) free-text comments).

Service users and clinicians indicated that vCreate Neuro has provided an easy and secure method of exchanging and storing videos.

A key theme in clinicians' interviews and survey comments was vCreate Neuro's usefulness at the time of initial diagnosis for newly referred patients and in the identification of urgent cases.

Access to expert and peer review via vCreate Neuro was highly valued by both secondary and tertiary clinicians. Clinicians and service users valued the opportunity to carry out rapid remote review of videos, using vCreate Neuro and think that this may lead to more rapid diagnosis and may assist with ongoing care.

By identifying what appear to be epileptic events remotely, clinicians suggest that vCreate Neuro may lead to more rapid and targeted investigations and treatment. By identifying apparently non-epileptic events remotely, clinicians suggest that vCreate Neuro may prevent unnecessary outpatient appointments, investigations, treatment and travel; and provide rapid reassurance for patients and carers.

Clinicians, across tertiary and secondary NHS sites, described the impact of vCreate Neuro on pathways of care and on shifting some clinical tasks away from scheduled appointments. The direct access to clinicians via vCreate Neuro may shift some responsibilities for ongoing management from primary to secondary or tertiary services. These changes may have a larger impact on how clinicians manage their time than was appreciated prior to the adoption of vCreate Neuro. While the benefits of vCreate Neuro for service users and at a service level (in terms of perceived reductions in unnecessary appointments or investigations and quicker diagnosis) were clearly described, clinicians experienced a change in the timeline of tasks at an individual level, that may lead to additional workload management pressures. This includes the pressure to monitor emails for vCreate Neuro alerts and respond rapidly to new information received via vCreate Neuro.

For service users more direct access to, and communication with clinicians was a key benefit. The response to video sharing was perceived to be more rapid than other methods of contacting clinicians and allows contact in-between appointments. However, a small number of service users shared their concern that vCreate Neuro could be used to replace some face-to face appointments rather than as an adjunct to them (13 service user comments).

Some service users raised the concern that they may doubt themselves or find their concerns not taken seriously without video '*evidence*'.

Service users from vulnerable groups (such as people with neurological conditions who live alone), may be unable to use vCreate Neuro, or they may require assistance with its use. The lack of access to high speed internet may make it difficult to upload videos to vCreate Neuro. People who are less able with IT may need assistance to use vCreate Neuro.

A number of improvements were suggested by vCreate Neuro service users including the facility to upload multiple videos, a framework to guide expectations about feedback, more flexibility in responding to clinical questions, increased compatibility with different types of file and device, a more user friendly mobile phone based app, and the ability to edit submissions.

Clinicians believe that vCreate Neuro has great potential as a research and training tool, and for use in other specialities. Consent and clinical governance procedures should continue to be developed and adapted to fit the changing scale and ways in which it is used.

Economic analysis

An economic analysis was undertaken as part of the service evaluation for vCreate Neuro for use in NHSScotland. The purpose of the analysis is to quantify the estimated resource utilisation associated with delivering care to patients with epilepsy and other neurological disorders. The value proposition for the service comes from expected reduction in conducted EEGs and other diagnostic tools used in neurology such as magnetic resonance imaging (MRI) and computerised tomography (CT) scans. Additionally, it is proposed that the adoption of vCreate Neuro may lead to a reduction in unnecessary outpatient appointments and hospitalisations for monitoring. The results of the analysis should be considered alongside the potential benefits indicated by patients or carers and clinicians, as discussed earlier in the quantitative and qualitative sections of this report.

Assessment methods

As a result of lack of sufficient data from the adult centres, this economic analysis was based on the data obtained from the clinical user surveys conducted over the last 15 months (1 October 2020–10 January 2022) of vCreate Neuro usage in Scottish paediatric centres. The findings in Phase 1 assessment report published in December 2021 ([link](#)) were based on data gathered between 1 October 2020 and 4 May 2021. This analysis complements the earlier findings by including follow up data gathered between 5 May 2021–10 January 2022 (361 additional responses), following a revision of the clinician and patient or carer user questionnaires. In particular, this analysis is informed by clinicians' responses to three resource-specific questions from the clinical user surveys:

- Did the uploaded data prevent the need for any of these additional investigations?
- Did using the video service on this occasion prevent an in-person review?
- How many minutes did you take to review the uploaded video and data and respond to the patient/carer?

Avoided resource use

A summary of avoided unnecessary investigations, as indicated by 580 completed paediatric clinical user surveys in a period of approximately 15 months, is displayed in *Table 12*. Estimated resource use avoidance for paediatric centres at a national level, based on the number of patients who uploaded videos, is also presented. It was assumed that the proportion of resource use avoided, reported in the paediatric clinical user surveys, would reflect that in the respective overall paediatric population across Scotland.

Table 12: Avoided resource use indicated in paediatric clinical user surveys (n=580) and scaled up nationally (n=2,453) over 15 months

Resources avoided	Number (n=580)	% clinicians' surveys	Estimated nationally (n=2,453)
Outpatient clinic appointments (face-to-face)	244	42.01%	1,030
Inpatient admission (average £ estimate)	74	12.79%	314
Electroencephalography (EEG)	168	28.97%	711
Inpatient video EEG	46	7.93%	195
MRI	14	2.41%	59
CT scan	6	1.03%	25

vCreate Neuro may reduce the need for in-person appointments. However, clinical time will still be required to review and respond to patient-uploaded video(s). Hence, the average time (approximately 10 minutes per video) spent by clinicians was estimated based on clinical user survey responses. A clinician was prompted to complete the survey after classifying or saving a comment for each video. However, an episode could comprise of a patient uploading a single video or multiple videos plus any additional data related to the same event. Therefore, it was conservatively assumed that all videos a patient uploaded, related to the same event and thus the clinician only completed one survey per episode. This assumption was explored in scenario analysis where it was assumed that a survey was filled in after each video (n=6,784).

Costs

Costs included in the analysis were obtained from various sources, predominantly the Information Services Division (ISD) cost book for Scotland, where available. These are shown in *Table 13* below. The cost of vCreate Neuro is marked as confidential. The cost of vCreate Neuro equivalent to the duration of data collection (15 months) has been included. Additionally, costs of the two individual adult centres (NHS Lothian and NHS GGC) have been excluded. It should be noted that as all available centres in Scotland are taking part in using vCreate Neuro, annual renewal costs of the service will not include a set-up fee but may include a video storage fee of ■■■.

Table 13: Costs

Unit	Cost	Source ²²⁻²⁴
EEG	£259	ISD cost book, Scotland 2021, R046
Inpatient video EEG	£2,315	NHS England reference costs, 2020, AA81Z
MRI	£191	ISD cost book, Scotland 2021, R120X
CT scan	£83	ISD cost book, Scotland 2021, R120X
In-hospital admission (average estimate)	£3,107	NHS England reference costs, 2020, PR02 B-C
In-hospital admission (low estimate)	£809	NHS England reference costs, 2020, PR02 B-C
Outpatient clinic appointment (Neurology)	£236	ISD cost book, Scotland 2021, R044X
vCreate costs (15 months)		vCreate Neuro team
Consultant (per hour)	£119	PSSRU, 2020
Consultant (per minute)	£2	PSSRU, 2020

Results

Savings associated with avoided resource use as a result of using vCreate Neuro are presented in *Table 14* below. Results were estimated for the available survey sample size (n=580) and scaled up at a national level (*Table 12*). Net savings were estimated by subtracting the estimated cost of consultant time and vCreate Neuro software. Base case results show that the introduction of vCreate Neuro service has resulted in approximately £441,000 of resource savings. Resources savings could amount to over £1.9 million, based on the extrapolation of results nationally.

Table 14: Estimated cost savings

Resources avoided (clinicians' survey paediatrics)	Cost (n=580)	Estimated cost (n=2,453)
Outpatient clinic appointments	£57,442	£242,942
Inpatient admission	£230,436	£974,587
Electroencephalography (EEG)	£43,440	£183,722
Inpatient video EEG	£106,484	£450,352
MRI	£2,681	£11,338
CT scan	£497	£2,102

Resources avoided (clinicians' survey paediatrics)	Cost (n=580)	Estimated cost (n=2,453)
Total savings (gross)	£440,980	£1,865,043
Less cost of consultant time	£10,965	£46,376
Less cost of vCreate software (15 months)	██████	██████
Net savings	██████	██████

Deterministic sensitivity analysis

Base case results were underpinned by responses from NHS GGC and NHS Lothian. Although there were limited data from other health boards across Scotland, scenario analyses were conducted where data from NHS GGC and NHS Lothian were excluded.

It is unclear from the clinical user surveys what would be the average duration of inpatient stay, for patients who avoided admission as a result of the data uploaded in vCreate Neuro. The base case estimates use an average cost of admission reported in NHS England reference costs with an average duration of 3–5 days. Patients may only require an overnight hospital stay. The cost of avoided admissions is the biggest driver of cost savings in this analysis.

Table 15: Scenario analyses

	Scenario	Base case	Total gross savings (survey based n=580)	% difference vs base case
0	Base case	-	£440,980	-
1	Exclude NHS GGC (n=362)	All clinicians' responses included	£304,422	-31%
2	Exclude NHS GGC and NHS Lothian (n=270)	All clinicians' responses included	£266,979	-39%
3	Lower estimate of cost of inpatient stay	Cost of inpatient state avoided for 3-5 nights	£270,561	-39%
4	No inpatient admissions avoided	Inpatient admissions avoided as reported by clinical service users	£104,061	-76%

NHS = National Health Service; GGC = Greater Glasgow and Clyde;

Additionally, when scaling up was conducted based on the number of videos uploaded (n=6,784) as opposed to the number of patients, who uploaded videos (n=2,453), the total

gross savings were in excess of £5 million. This estimate is associated with high levels of uncertainty.

Additional potential economic benefits associated with vCreate Neuro are reduction in time to diagnosis and treatment. The vast majority of clinicians' responses (approximately 80%) indicated that vCreate Neuro improved both outcomes. These findings indicate a potential for improved waiting times for diagnostic appointments and outpatient reviews and reduction in long term medicine costs because of a decrease in the rate of epilepsy misdiagnosis. It has not been possible to quantify these estimates in this analysis.

A reduction in work and school absenteeism – and associated economic impacts - may also be expected as a result of adopting the vCreate Neuro service as a result of the decrease in-hospital and/or clinic appointments required.

Summary

Summary points from the economic analyses are as follows:

- Base case results demonstrated that using vCreate Neuro within the existing pathway to deliver care for patients with epilepsy and other neurological disorders is likely to be resource saving and therefore cost effective for NHSScotland, with savings of £441,000. Scaled up nationally these savings equates to in excess of £1.9 million. The precise extent of cost savings remain uncertain due to the survey data upon which the analyses are based.
- Scenario analyses show that the base case result is sensitive to the finding that the use of vCreate Neuro reduces inpatient admissions. The duration (and therefore cost) of inpatient admissions is also an important driver.
- Other potential economic benefits such as improved time to diagnosis and treatment and reduction in work and school absenteeism could not be quantified in the economic analysis.

Limitations

The evidence presented in the report illustrates that vCreate Neuro has the potential to improve the delivery of care for adults and children suffering from epilepsy and other neurological disorders along with saving resources for NHSScotland. However, there were several limitations identified. They are as follows:

- Quality assessment of studies included in the literature review was not undertaken.
- Many of the papers identified in the literature review indicated the value of HVRs for differential diagnoses between epileptic and non-epileptic events, especially PNES, but there was a lack of evidence for this across all age groups. Most studies

identified in the review included adult patients, yet the findings from the quantitative analysis were primarily derived from the paediatric population.

- A video being assigned to an individual clinician could result in a delay to review if that clinician was not available or on leave. This could be rectified by assigning videos to a team account.
- The quantitative and qualitative results from the adult service user surveys and adult clinician surveys should be interpreted with caution because of the small number of responses. No adult service users or carers of adult service users were recruited for interview, so the findings of the qualitative section may not be transferable to an adult population.
- Despite effort by the project team to define 'connected' to the clinical team, the definition included the term 'access', which was not defined in the service user surveys. Access in clinical care is a multifaceted term with different applications in a care pathway.
- Although users were advised to only complete one survey when they uploaded multiple videos, it is possible that they could have done this multiple times. This meant the number of responses did not equal the number of responders. While not a limitation for a service evaluation, as it represents real world use, the results should be interpreted with this consideration in mind.
- The strength of the analyses is the triangulation of the survey data with the qualitative free-text responses and interviews that included a range of service users and clinicians. However, the sample was limited to people who have used vCreate Neuro and at present we have no information on service users and clinicians who declined to use vCreate Neuro for any reason.
- Service users from a remote and rural setting are included in the population from which the sample completing the surveys were drawn, however demographic information at that level was not available, so we do not know how well this population is represented. We were also unable to recruit service users from a remote and rural setting for the semi-structured interviews. Transferability of the results to this group is unclear.
- In the economic analyses, resource savings data were drawn from service clinician surveys and therefore the source of the data is classed as 'expert opinion' – which constitutes low-level evidence.²⁵ It is unclear if the scale of estimated resource avoidance would be seen in routine clinical practice. A randomised controlled trial or a well-matched cohort study would provide robust evidence to this effect.
- Results from the economic analyses may not be representative at a national level, since over 50% of the data came from only two health boards (NHS GGC and NHS Lothian). Nevertheless, these are the two biggest centres and sensitivity analysis excluding them from the results still demonstrated resource savings.

- The findings of this report provide limited generalisability across Scotland; adult user data was scarce and the survey sample was not representative across all health boards – it was derived mainly from the central belt. Owing to the variability in Scotland’s geographical landscape, and internet connectivity, it is possible that the findings do not reflect the experience of a patient or clinician living or working in remote or rural areas.

Conclusion

The analyses in this report showed that vCreate Neuro may add value for the delivery of care to people (adults and children) with epilepsy and other neurological disorders and implementation of vCreate Neuro may lead to hospital resource savings through the avoidance of unnecessary clinical visits and investigations.

Funding for vCreate Neuro has been approved for another 3 years, and future research work should focus on the following:

- Development of a robust effectiveness evidence base to demonstrate how using vCreate Neuro is more or equally effective in comparison to standard of care in the UK. This is important since at present, available published literature provides insufficient evidence to support the use of asynchronous services like vCreate Neuro to diagnose and treat epilepsy patients or other neurological disorders.
- Gathering real-time resource utilisation data to compare costs of epilepsy care pre and post implementation of vCreate Neuro at NHS board and Scotland level. This would help validate the cost savings projections made in this report and provide more confidence for decision makers to implement its use widely.
- Gaining more insights about patients, carers and clinicians who declined to use vCreate Neuro because of any reason, and to gather more data on adult service users. This is crucial, as it would not only identify barriers faced by service users and allow appropriate mitigation, but also increase the generalisability of the findings in this report.

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Appendices

Appendix 1: Survey questions

Service clinician questionnaire

1. **Did this video upload relate to a new patient referral OR a patient who has previously used the vCreate Neuro service?**
 - New referral
 - Existing patient in the service
 - Re-referral of patient previously discharged from service
 - Other
2. **How easy or difficult was it to use the vCreate Neuro service?**
 - Very easy
 - Easy
 - Neither easy or difficult
 - Difficult
 - Very difficult
3. **How would you rate the quality of the uploaded video?**
 - High quality, easy to interpret
 - Adequate quality, able to interpret with effort
 - Poor quality, could not be interpreted
4. **Do you think using the vCreate Neuro service makes you feel more or less connected to the patient or carer? Being connected means the patient/carers could easily access the team and you had a positive relationship with them.**
 - More connected
 - Neither more or less connected
 - Less connected
 - Don't know/Not sure
5. **In your opinion, how does the vCreate Neuro service affect the quality of care provided by your clinical care team to the patient?**
 - Improves quality of care
 - Does not affect the quality of care
 - Reduces quality of care
6. **Was the uploaded information (video and associated data) useful for making a diagnosis?**
 - Very useful
 - Useful
 - Not useful ie the uploaded information did not make any difference
 - It made making a diagnosis more difficult
 - The video failed to play/there was no video
 - N/A
7. **Was the uploaded information (video and associated data) useful for choosing a therapy (or no therapy)?**
 - Very useful
 - Useful
 - Not useful ie the uploaded information did not make any difference
 - It made choosing a therapy more difficult
 - The video failed to play/there was no video
 - N/A
8. **Compared with not having access to the vCreate Neuro service, do you think using the vCreate Neuro service affected the time to reach a diagnosis for this patient?**
 - It took a shorter time than usual
 - It took the same time as usual

- It took a longer time than usual
N/A
9. **If longer or shorter, please tell us an estimate by how much time (this could be hours, days, weeks or months)**
TEXT
10. **Compared with not having access to the vCreate Neuro service, do you think using the vCreate Neuro service affected the time to treat this patient?**
It took a shorter time than usual
It took the same time as usual
It took a longer time than usual
N/A
11. **If longer or shorter, please tell us an estimate by how much time (this could be hours, days, weeks or months)**
TEXT
12. **Did the uploaded data prevent the need for any of these additional investigations? (You can select more than one option)**
CT scan
MRI scan
EEG
Inpatient video EEG
It did not avoid an investigation
Other
13. **How many minutes did you take to review the uploaded episodes (videos and data uploaded on this occasion) and respond to the patient/carer?**
TEXT
14. **How useful was vCreate Neuro service in your overall management of this patient?**
Very useful
Useful
Not useful
It hindered the process a bit
It hindered the process greatly
15. **Do you have any other comments about the service?**
TEXT

Parent/Carer questionnaire

1. **Please state your relation to the patient:**
Patient
Parent
Carer
Grandparent
Sibling
Other
2. **Your gender:**
Male
Female
Prefer not to say
3. **Your age:** Number Text
4. **Was the patient already being seen in neurology services before the vCreate Neuro service became available?**
Yes
No
5. **Had you used the vCreate Neuro service before?**
Yes
No
6. **How did you find using the vCreate Neuro system?**

Very easy to use
Easy to use
Neither easy or difficult to use
Difficult to use
Very difficult to use

- 7. If you had to travel in person to show the video to the clinician, how many miles would you have travelled in total (to and from the clinic)**

Number text

- 8. How would you normally have travelled?**

Bus
Taxi
Walk
Bicycle
Car
Train
Air

- 9. Did using the vCreate Neuro video service prevent your child having to take time off school to attend a clinic?**

Yes – full day
Yes – half day
No or N/A

- 10. Did using the vCreate Neuro video service prevent you having to take time off work to attend a clinic?**

Yes – full day
Yes – half day
No or N/A

- 11. Do you think the vCreate Neuro service makes you feel more or less connected to the clinical team? Being connected means having easy access to the team and a positive relationship.**

More connected
Neither more nor less connected
Less connected
Don't know/not sure
Not applicable as not used neurology services previously

- 12. Do you think that the vCreate Neuro service affects the quality of care provided by the clinical team to your child?**

It improves the quality of care
It does not affect the quality of care
It reduces quality of care
Don't know/not sure

- 13. Did using the vCreate Neuro service help you easily communicate with the clinical team?**

Yes
No
Don't know/not sure

- 14. Do you have any comments on the vCreate Neuro service?**

Free text

Appendix 2: Quantitative analysis

Table 16 Demographics from responses to the paediatric service user survey

Variable	Result
Age, n=737 (missing data n=1, reported aged of parent as 3 years old, n=1)	Median 37, IQR (32, 43)
Sex, n=739	Female n=650, male n=88, prefer not to say n=1
Relationship to patient, n=738 (missing data n=1)	Parent n=705, Carer n=4, Other n=7*
Existing patient in the neurology service before vCreate Neuro was available, n=311 (missing data n=1)	Yes n=188, No n=123 missing data n=1

*Other: (aunt n=2, carer n=9, grandparent n=9, great aunt n=1, patient n=9 (reported ages of responders was 14, 15, 16, 18, 32, 35, 43, 43 years and one respondent didn't give their age), sibling n=1, 'speciality doctor of ward where she's admitted' n=1, teacher n=1)

Table 17 different types of transport that were avoided by paediatric service users

Mode of transport that was avoided	Count*
Public transport	
Bus	47
Train	76
Ferry	2
Air travel	6
Private forms of transport	
Car	561
Taxi	37
Walk	9
Patient transportation provided by hospital	4

*total is greater than number of responses (742) as a result of some responders stating that they would have used more than one type of transport.

Table 18 Comparison of distance travelled between whether a paediatric service user felt more or less connected to the clinical team

more or less connected to the clinical team				
N=182*	More connected	Neither more nor less	Less connected	Don't know/not sure
All sites				
n	254 (missing distance data n=2)	102	18	48
Distance travelled (miles)	Med: 20 IQR: 6, 39 Mean: 36.3 SD: 68.0	Med: 16 IQR: 9, 45 Mean: 39.8 SD: 52.3	Med: 21.5 IQR: 6, 52 Mean 29.7 SD 26.9	Med: 20 IQR: 6, 42 Mean 30.9 SD 32.0
Kolmogorov–Smirnov test^	p<0.001	p<0.001	p=0.006	p<0.001
Kruskal-Wallis test	p=0.716			
Scottish sites				

n	167 (missing distance data n=1)	65	11	28
Distance travelled (miles)	Med: 16 IQR: Mean: 27.8 SD: 40.0	Med: 15 IQR: Mean: 36.8 SD: 58.6	Med: 14 IQR: Mean: 32.4 SD: 31.2	Med: 17 IQR: Mean: 23.4 SD: 23.2
Kolmogorov–Smirnov test [^]	p<0.001	p<0.001	p=0.026	p<0.001
Kruskal-Wallis test	p=0.973			

[^]p<0.05 indicates that data were not normally distributed.

Table 19 Demographics from responses to the adult service user survey

Variable	Result
Age, n=47	Mean 42 (SD 15.4)
Sex, n=47	Female n=29, male n=18
Relationship to patient, n=47	Patient n=30 Partner or spouse n=10 Carer n=1 Nurse n=2 Parent n=9 Sibling n=1
Existing patient in the neurology service before vCreate Neuro was available, n=47	Yes n=32, No n=15

Table 20: Comparison of results from all NHS sites (minus sites where project staff worked), and Scottish sites (minus sites where project staff worked) to the two sites where project staff worked (NHS GGC and NHS Lothian)

Research question (n of responses)	Response categories				
	Results % (n)				
-	Very easy	easy	Neither easy or difficult	Difficult	Very difficult
Ease of use UK sites (no GGC+Lothian) (n=221)	62% (138)	29% (64)	8% (17)	1% (2)	% (0)
Scottish sites (no GGC+ Lothian) (n=162)	68% (110)	22% (36)	9% (14)	1% (2)	% (0)
GGC and Lothian (n=196)	95% (186)	5% (10)	% (0)	% (0)	% (0)
-	High (easy to interpret)	Moderate (interpret with effort)	Poor (unable to interpret)	-	-
Video quality UK sites (no GGC+Lothian) (n=220)	80% (177)	19% (41)	1% (2)	-	-

Research question (n of responses)	Response categories				
	Results % (n)				
Scottish sites (no GGC+ Lothian) (n=161)	82% (132)	17% (28)	<1% (1)	-	-
<i>GGC and Lothian</i> (n=197)	91% (180)	8% (15)	1% (2)	-	-
-	More connected	Neither more nor less	Less connected	Don't know/not sure	-
Feeling more connected to patient (no GGC+Lothian) (n=219)	88% (192)	11% (23)	% (0)	2% (4)	-
Scottish sites (no GGC+ Lothian) (n=160)	86% (137)	12% (19)	% (0)	3% (4)	-
<i>GGC and Lothian</i> (n=193)	97% (188)	2% (3)	% (0)	1% (2)	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/not sure	-
Quality of care (no GGC+Lothian) (n=221)	95% (210)	5% (11)	% (0)	% (0)	-
Scottish sites (no GGC and Lothian) (n=162)	94% (153)	6% (9)	% (0)	% (0)	-
<i>GGC and Lothian</i> (n=194)	99% (192)	1% (2)	% (0)	% (0)	-
-	Very useful	Useful	Not useful or made no difference	Made more difficult	-
Useful for making a diagnosis (no GGC+Lothian) (n=214)	48% (103)	42% (89)	10% (22)	% (0)	-
Scottish sites (no GGC and Lothian) (n=157)	44% (69)	45% (71)	11% (17)	% (0)	-
<i>GGC and Lothian</i> (n=193)	84% (163)	13% (26)	2% (4)	% (0)	-
Useful for choosing a treatment (no GGC+Lothian) (n=175)	30% (52)	45% (78)	25% (44)	% (1)	-
Scottish sites (no GGC and Lothian) (n=120)	27% (32)	43% (51)	31% (37)	% (0)	-
<i>GGC and Lothian</i> (n=184)	86% (158)	10% (18)	4% (8)	% (0)	-
-	Shorter than usual	Same time	Longer than usual	-	-

Research question (n of responses)	Response categories				
	Results % (n)				
Time to diagnosis (no GGC+Lothian) NP n=67, RP n=111	NP 72% (48) RP 59% (66)	NP 28% (19) RP 41% (45)	NP (0) RP (0)	-	-
Scottish sites (no GGC and Lothian) NP n=53, RP n=77	NP 75% (40) RP 62% (48)	NP 25% (13) RP 38% (29)	NP (0) RP (0)	-	-
<i>GGC and Lothian</i> <i>NP n=86, RP n=88</i>	NP 90% (77) RP 92% (81)	NP 10% (9) RP 8% (7)	NP (0) RP (0)	-	-
Time to treatment (no GGC+Lothian) NP n=50, RP n=91	NP 62% (31) RP 55% (50)	NP 38% (19) RP 44% (40)	NP (0) RP 1% (1)	-	-
Scottish sites (no GGC and Lothian) NP n=37, RP n=66	NP 70% (26) RP 58% (38)	NP 30% (11) RP 41% (27)	NP (0) RP 2%(1)	-	-
<i>GGC and Lothian</i> <i>NP n=84, RP n=92</i>	NP 85% (71) RP 87% (80)	NP 15% (13) RP 13% (12)	NP (0) RP (0)	-	-
-	Very useful	Useful	Not useful	Hindered a bit	Hindered greatly
Useful for overall patient management (no GGC+Lothian) (n=216)	56% (120)	44% (94)	<1% (2)	% (0)	% (0)
Scottish sites (no GGC and Lothian) (n=159)	54% (86)	45% (72)	<1% (1)	% (0)	% (0)
<i>GGC and Lothian</i> <i>(n=192)</i>	92% (176)	8% (15)	<1% (1)	% (0)	% (0)

Abbreviations: NP: new patients, RP: return patients.

UK sites without NHS GGC and NHS Lothian n=223, Scottish sites without NHS GGC and NHS Lothian n=164.

Reported investigations avoided by paediatric service clinicians

Paediatric service clinicians across all sites reported (n=403) that there were 152 instances of an investigation being avoided and 251 instances where an investigation was not avoided. The most common investigation that was avoided was an EEG (n=126) (*Table 21*).

Table 21 Investigations avoided across all NHS sites

Investigation avoided (n=342)	n*
CT scan	6
EEG	126
Inpatient EEG	41
MRI	12
Ambulatory EEG	1

Total n > n of responses as multiple investigations were often avoided.

Paediatric service clinicians across Scottish sites reported (n=347) that there were 137 instances of an investigation being avoided and 210 instances where an investigation was not avoided. The most common investigation avoided was an EEG (n=112) (*Table 22*).

Table 22 Investigations avoided across Scottish NHS sites

Investigation avoided (n=286)	n*
CT scan	5
EEG	112
Inpatient EEG	35
MRI	9
Ambulatory EEG	1

Total n > n of responses as multiple investigations were often avoided.

Paediatric service clinicians from NHS GGC and NHS Lothian reported (n=190) that there were 92 instances of an investigation being avoided and 98 instances where an investigation was not avoided. The most common investigation avoided was an EEG (n=76) (*Table 23*).

Table 23 Investigations avoided NHS GGC and NHS Lothian only

Investigation avoided (n=190)	n*
CT scan	1
EEG	76
Inpatient EEG	17
MRI	4

Total n > n of responses as multiple investigations were often avoided.

Estimated time to sooner diagnosis and treatment by paediatric service clinicians

The median time to earlier diagnosis in both new patients and return patients by paediatric service clinicians was 2 weeks. These results were driven by the data from clinicians in NHS GGC and NHS Lothian (*Table 24*).

Table 24 Estimated time by paediatric service clinicians to earlier diagnosis in return and new patients

Sites	Estimated time to earlier diagnosis in return patients	Estimated time to earlier diagnosis in new patients
All sites	n=58 Med: 2 weeks IQR 2 weeks Range: <1 hour to 2 months	n=40 Med: 2weeks IQR: 5 weeks Range: 1 hour to 2 months
Scottish sites	n=53 Median 2 weeks	n=38 Med: 2 weeks

	IQR 3.5 weeks Range: <1 hour to 2 months	IQR: 4 weeks Range: 1 hour to 2 months
NHS GGC and NHS Lothian	n=48 Median 15 days and 4 hours IQR 2 weeks Range: <1 hour to 2 months	n=33 Med: 2 weeks IQR:4 weeks Range: 1 hour to 2 months

The data for estimated earlier time to treatment was not processed because the number of responses was so low both new patients (n=8) and return patients (n=9).

The data for estimated earlier time to diagnosis and time to treatment from responses from adult service clinicians were not processed because of the small number of responses.

Appendix 3: Clinical interview questions

1. Tell me about a time that you have used vCreate Neuro and its impact.
 - Why have you used vCreate?
2. Did vCreate change the way you work?
 - The way you work with your colleagues and team, peer review
 - Any concerns about changes to ways of working?
3. Did vCreate change the way you interacted with service users?
 - your relationship with service users
 - distance vs face-to-face
4. Do you think it had any impact on the treatment you gave?
 - How did it change the treatment you gave? Diagnosis? Medication/prescribing? Investigations
5. What benefits do you see from the use of vCreateNeuro?
 - Has vCreate had any impact on service delivery eg quality of care?
6. If it is useful, when and how is it most useful?
 - What stage inpatient journey?
 - Education/training/teaching?
7. Were there any challenges/harms in using vCreate Neuro?
 - was there anything that was difficult or could be improved?
 - did you find it reliable? Did you experience any technical issues?
 - did you have any difficulty accessing or using vCreate?
8. How do you think vCreate Neuro could be used in the future?
 - Do you see any challenges with it being used more widely?
9. Anything to add?

Appendix 4: Service user interview questions

1. Tell me about a time that you used vCreate Neuro?
 - Why have you used vCreate Neuro?
 - Stage inpatient journey – diagnosis or accessing ongoing care.
2. Did vCreate change the way you accessed the clinical team?
 - Did vCreate change the way you have experienced the clinical service?
3. Did it change your relationship with clinicians at all?
4. How did it affect the care you received?
5. What do you see as the main benefits of vCreate Neuro?
 - Did it have any effect on your family life?
6. Do you think there are any problems with using vCreate Neuro?
7. How did you find using vCreate Neuro?
 - Was there anything that was difficult or could be improved?
 - Did you find it reliable?
8. Did you have any difficulty accessing vCreate Neuro?
 - Internet access, finding it...
9. Would you use it again in the future?
10. Anything to add?

Appendix 5: Patient Stories from clinician interviews

Diagnosis

Story 1: Consultant Paediatric Neurologist

I was asked by a clinician in Dumfries, who wanted an opinion on a child with a movement disorder, with unusual features. So we get quite often requests from outside, you know Glasgow to give opinions. And in the past what would have happened is that, I would have asked this child to come across to Glasgow so that we can actually see what's happening with the child. And now I've been able to look at the video and I've immediately identified what the diagnosis of this child is. This child has tics, so this child has a tic disorder. And I was able to diagnose that on the video and I emailed my colleague back and said 'thank you for sending me the video via vCreate, I had a look at this and these are tic disorders. There's nothing else that needs to be done for this child.' And this clinician can now manage this child within their own remit. So that is an illustration of how using vCreate, in this one patient, has been able to diagnosis this patient remotely so that my colleague can now manage this patient without the need of coming to [tertiary specialist centre], being assessed and having further tests. So that's a good illustration of how efficient this is.

Story 2: Consultant Paediatric Neurologist

I have had a patient that's been referred to the service and has had a paroxysmal event. So a funny turn. Could this be epilepsy? They've been seen in the emergency department and they're not quite sure, so they're referring onto me as an expert in the field. And my waiting lists can be a few weeks long, so I say to the the person in the emergency department 'Well if you set the family up with a vCreate account.' So we do that by the person in the emergency department emailing the secretary who then contacts the family and they set up the accounts. And then the next day Ping into my inbox comes 'there is a new video for you to review.' So I go onto the video I look at it. I can see it's an epileptic seizure. I can contact the family immediately and then I can make some plans of management. So it helps prioritise my patient load, but it also enables rapid feedback to families as well.

Story 3: Consultant Paediatric Neurologist

There was a patient...about two or three weeks ago. And the clinician who's responsible for epilepsy in [territorial health board] was on holiday and a general clinician was trying to sort it all out and they weren't sure what was going on, but they had a video so they were able to transfer the video to me. I looked at it and within 5 minutes I could tell them there was a diagnosis of epilepsy. What they needed to do and what investigations they needed to do. So, it was a very speedy process which otherwise might have required the child to have been transferred from [territorial health board] to the tertiary centre as an inpatient to have an evaluation.

Story 4: Consultant Neurologist

For the patient who has complex disability, she's got chronic pain. She's got FND, functional neurological disorder, mobility problems and she had had seizures in the past and they had recurred and she was sending me photos of herself after the seizure with lots of bruises on her face. I spoke to a witness and the witness history didn't make it that clear whether we were dealing with epilepsy or with functional seizures as part of FND. The patient was extremely keen to have a diagnosis of epilepsy, mainly because, she felt if it was epilepsy then she could just go on pills and it would all go away. So she had an EEG that actually did raise slight suspicion of epilepsy. And it was only really when we got the videos from vCreate that we could see very typical features of functional seizures. So it's incredibly helpful to have that, alongside we did get some evidence from the video telemetry as well, but it was incredibly useful to manage that patient.

Story 5: Consultant Neurologist

An example of that is a patient with, I had recently a 15 year old who was sent with the diagnosis of FND. We were able to see the video, upload it, share it. He had typical features of a very rare condition called paroxysmal kinesigenic dyskinesia, for which the treatment is carbamazepine, not epilepsy. So paroxysmal movement disorder. So the video clinched it really.

Story 6: Consultant Paediatrician

...a child and the mother was describing unusual movements that the child was making. The child was about 8 months old (8 to 9 months) and the mother's concern was that the child was having epileptic seizures, so it was referred in. And I saw the child at clinic and the mum described it, it didn't sound to me like epileptic seizures, but I did wonder if it was some sort of movement disorder. So we set her up with vCreate and she's sent us in two or three lovely video clips of the child sitting in the high chair doing these funny juddering movements. And I thought they looked non-epileptic. I thought they were probably shuddering movements, but...the consultant neurologist was doing a clinic with me? And I was able to say to him, could you have a quick look at this and immediately he said, these are definitely shuddering episodes, so that was fantastic. I was able to say to the mother not only have I looked at these episodes and think they are non-epileptic, but I had the opportunity to share them with the neurologist from [tertiary service]. So it kind of reinforced, for the mother, that we'd seen what the child was doing, and that we were happy.

Story 7: Consultant Paediatrician

So it was a boy who sees one of our colleagues in the asthma clinic. Whose mum was concerned about abnormal movements. And she had some videos which she brought to the asthma clinic. And our colleague who does that asthma clinic was uncertain about what those videos represented and that would certainly have generated a new outpatient clinic appointment and a trip up to the hospital. But the mum was able to submit videos and we were able to look, we do a clinic together at another time, so we were able to look at the videos together with me and the people who see him and actually the nurses who see him as well from an asthma point of view and they were complex stereotypies, quite happy that they are not a neurological disorder or an epileptic seizure. And it was great that we were able to sort of tie that up within a matter of days of him being seen in the clinic as opposed to waiting weeks and weeks to be seen for an outpatient appointment to get that feedback to them. And that the people who look after him, in terms of the nurses and medical staff were both able to see those videos. And be able to say yeah, right, I know that those things that he was doing, we've kind of tied that up—so that saved an outpatient appointment, a whole bunch of letters and kind of meant that everybody was a bit more on the same page. With that 'cause you know these are the kind of things that can perhaps pop up again in the future. These concerns, in that at least they know if there's something in the future that looks different to that, then then they can do the same thing but they know what those movements are.

Story 8: Consultant Paediatrician

Last week there was a girl, who had come up to the ward and seen one of my colleagues with some events that they thought sounded like they might be epileptic seizures. And had asked mum to record videos, and had taken the details 'cause they'd asked me to put it on the vCreate system. And the mum had put that up over the weekend. And you know, the information that was just the basic information that the vCreate stuff acquires about how frequently they're happening and things. And you're able to look at the events and she's having a very large number of myoclonic epileptic seizures that are obviously epileptic, on the video. She had had investigations requested by the guys 'cause that's what they felt this may have been but having that extra information, I had phoned the EEG department and she is having her EEG today and she's going to start her medicines this evening. So you know that has certainly shortened the journey to her getting her investigations and getting her treatment, and I think that that's not that unusual that it's made a difference of potentially weeks.

Story 9: Locum consultant paediatrician

I've used it in the acute admission setting for a child that was having, a baby, that was having jerking events, the family were concerned that the child had infantile spasms and they had googled infantile spasms and were incredibly worried that that's what the child had. From the history, it was, the history was not suggestive of infantile spasms, but baby didn't have any when I was in the room. But the family did have multiple videos which they'd had before, which they were able to upload to vCreate. I could see the videos which,

they were very reassuring videos, but also as a clinician with an interest in epilepsy, I was able to get support from my neurology colleagues via the vCreate app to look at those videos and that was really helpful for me and also for those parents, in reassuring them and facilitated their discharge, in a way that we might not have been able to otherwise.

Story 10: Epilepsy Nurse Specialist

I had a girl who was diagnosed with epilepsy. She was a young girl, 17 or 18, still at school. And she was having seizures that her mum was describing as generalised tonic clonic seizures but then something just doesn't sit right. They were lasting too long, so I asked to capture these and we did. Because beforehand we were uping her medication and changing her medication. She has tried about three different antiepileptic medications, nothing was working. Managed to get the video in because she was due to come in for video-telemetry but she didn't want to come in alone. And because of the COVID situation, you know carers weren't allowed to come in as well. But we managed to get videos they were non-epileptic attacks. So we put her down the psychology route. She didn't have to come in for VT and now I think it's actually doing well, they said that she's had some input from psychology.

Story 11: Epilepsy Nurse Specialist

We've got a parent, parents, are sometimes bad for labelling what they're seeing rather than describing what they're seeing...Long story short, he was labelling a particular seizure as a tonic seizure, and I eventually persuaded him to upload this video to vCreate. And what we saw was a very, very clear focal seizure. And it actually changed the direction of that child's treatment. So you know, obviously it's more complicated than that because there were generalised changes on his original EEG. But what we were seeing clinically. Uh, you know, was a very clear focal seizure. So we changed his medication, or we are going to change his medication accordingly.

Story 12: Locum consultant paediatrician

It can then be used after, you can ask patients to video later on to get a good idea of what's going on. And then for monitoring reasons as well, for example, I had a patient I've been seeing in a clinic who's having unusual head dropping episodes and It's been quite hard to tease out what they are and so that's a new thing for a family that's well established within the neurology services. So being able to video those later on has helped to sort of quantify and monitor a change.

Appendix 6: Service user's stories from interviews

Service User Story 1:

I think it was around six months that I just started noticing her doing some strange like eye movements. She kind of rolled her eyes back in her head and then she would do it sometimes for like up to a minute. And I was like, oh, this just feels a bit strange. I couldn't really record it like very well and so I ended up going to my GP and it was through the pandemic, we were in lock down and so I couldn't really go in. And she just continued to do it and it was like she was having an epileptic fit, but when she stopped doing it, she was fine. So I didn't think they were doing her any damage, it was just odd her eyes would be all the way back and then she would look like she was kind of frowning for a long time. And so I was quite worried. And yeah ended up phoning the GP. He was just like 'OK, let's just refer you to neurology.'

And I spoke to an amazing consultant...he was just amazing and he's said could you record it? Because it's just really hard to know and eventually I managed to get a few little recordings. I ended up setting up my phone at the kitchen table, when she was eating, because that was sort of when she did it and just eventually managed to capture her doing it. But then I think the consultant, as soon as he saw the video, called me back. I think it was just a few days later and that was amazing to have that quick response to someone having seen the video. And yeah, actually the conversation that we had was quite interesting because he said that he'd seen this happening to children before and he didn't think it was anything to worry about. But he was particularly interested in this, kind of expression, that she was making because it was like something that he was interested in looking at more.

So I think he actually asked if he could use the video, it's not teaching, but like maybe like have some other people look at it because it was of interest. So I think that made me feel really like, oh he's taking this seriously and he's asking for second opinions and stuff. And so it was already good. And I think she's not been discharged. I think she's being seen once a year and for her, just to monitor it. Really, it has, I think, stopped. Occasionally she'll do something a bit strange, but I think it's kind of gotten a lot better so. Yeah, I think she I think they said it wasn't epileptic.

Service User Story 2:

So my son was diagnosed with epilepsy and it's quite a rare form of epilepsy from a gene mutation.... I've got the same mutation as well and had epilepsy when I was younger, but we didn't have genetic testing back then so we didn't know about it. He was with a Doctor in [regional Hospital] but because [the] Professor was the sort of specialist in this gene, we got phone consultation meeting with him, just to get some sort of extra info and to ask some questions and also to speak to a geneticists. I think they were maybe like on the panel that looked at our genetic results and stuff like that. And when I had been discussing his seizures

with [the] Professor, he asked me if I could use the service so that he could have a look at one of the videos that I'd taken...it was more for extra confirmation, basically because [the] Professor wasn't his actual Doctor. Like his doctors was at [regional hospital], so we sort of got a diagnosis through him. But then because he was the expert and we wanted more information about potentially, if we were to have another child. That was why we were speaking to him and it was more just for confirmation. Extra information. He said that I could send the video just for him to have a look at.

Service User Story 3:

I have an 18 month old foster baby who was born at 25 weeks so he's got multiple disabilities and on one admission to hospital, he was seen to be doing these irregular movements... I had taken him up there because, I think, he had a temperature that time and then he started these movements while we were actually there being assessed, and that's when the neurologist was contacted. And was then diagnosed with infantile spasms. And that's when we started sending videos through up to [tertiary centre]. There was two different health boards...And that's when after, after the vCreate had been watched, that's when the diagnosis was made...Well, yeah, it made it a much quicker diagnosis and much quicker to treat him then. So it was invaluable, definitely.

Service User Story 4:

The reason we started using vCreate, it was my son started having kind of seizure like episodes, which you can't do on cue....when the episodes first started we went to A&E because of the panic. And they don't happen on tap. They don't happen on cue. And we were sent away and dismissed three times that it was, it was nothing. We can't find anything, so he's fine. We can't find anything, he's fine.

So they referred to neurology and neurology use that as a tool in order to see the episodes before they actually seen us, so they knew without us going what they were looking for, or looking at. So before we got an appointment I got the vCreate, set up my account and everything and I was able to use that for a good sort of 2-3 weeks before being seen, that allowed me to share specific snippets of these episodes, and allowed the neurologist team to know what avenue they were going to go down in the way of our treatment before we even stepped in the hospital. And all the COVID times even better because it reduced face-to-face appointments, it reduced poking and prodding at my son and they knew, more specifically, what was going on. And again, these episodes didn't happen when we were in the hospital

...so if we hadn't had vCreate I would have had to go and face-to-face and show them my phone. And that allowed them to have the video evidence, slow it down, look at it 'cause they showed me that. Slow it down to look specifically at what was happening with [My sons] movement and that then allowed them to know that it wasn't epilepsy. It wasn't photosensitive epilepsy etcetera, etcetera.

It also meant that I was in touch with them while we were waiting for the appointment. Things did step up a level. Things did get worse. So I was able to then continue to upload and they were able to then phone me and go 'we've looked at this. This is changing. Let's move forward.' We went in for the EEG again, continue to upload...Continue to monitor which again led to more phone calls, more touching base and and it was 10 times better.

And so the outcome was that these aren't neurological. They may in time become a behavioural issue. But my neurologist said that if he doesn't grow out of them then I could use vCreate to get that access back to him, if I felt it was necessary. So at the time of the treatment, the time of using vCreate we, we got the answers that we needed. However, moving forward, if things change based from the level that they discharged us at, then I would use vCreate to get more answers.

Service User Story 5:

My daughter has had epilepsy. I think she was diagnosed at about a year and a half, maybe age two. So [my daughter] has a diagnosis of [a rare genetic disorder]. So she has loads of different things going on. And so it wasn't purely epilepsy based questions they would have. We have to take into factor things like muscle spasms, you know? So if she is experiencing what I believe is seizure activity I would usually just called the nurse and discuss it over the phone. And then usually that meant having to go to an appointment and hope that this behaviour happened at the appointment and things like that. So and over the years it was difficult to determine what actually was going on with [daughter] in terms of could we have medication, etc.

So round about the time that I was made aware of it, [my daughter] had been doing, I called it 'funky' things, waving her hands about and making a lot of funny noises and stuff. And the nurse actually said to me, if you can catch it on video, that would be great. And then what we can do is, use the software called vCreate and we'll give your password etcetera. And you just upload it to us so we can look at it without having to bring you in to an appointment. And so yeah, that was what I did, and it was really easy. They basically just forwarded me on. I think it was a username and set a password. And I uploaded a video, well multiple videos.

That was the first, I've only used it in three times, and the first time I used it, it was when [my daughter] was displaying, kind of unusual behaviour. I added multiple recordings in order, throughout various different days, because you know sometimes it would maybe only happen for a few seconds and it was like was that? I'm not really sure. And so yeah, I just had to upload these videos and within I think a day or so the Doctor got back to me and I went from there

So, following the second and third video it required a change, not a change of medication, like an up in the dose. And we just had to keep a wee eye on the stuff she was doing. We did

eventually end up in the hospital but you know everything was kind of OK after we got the medication. So the nurse and the doctor was really good and on the ball. They saw [my daughter] and they did say there is probably going to be a seizure around the corner and they were right, the next day. After the change in medication, touch wood it's been ok.

Service User Story 6:

I would say we first used vCreate maybe about a year ago and we have used it on and off since. We have used it quite recently, when we were concerned about an episode that my son had. So immediately that is when we would take a video, and we know that we have got the vCreate service there to immediately be able to upload that. And there are quite a lot of good thorough questions, and there is space to make comments, on different things and leave additional details. And then we know that we have sent it to the doctors straight away or as soon after as we can.

Yeah we have been seeing them for quite a while now. And we still don't have a diagnosis for my son. So it's quite useful to still have access to that, so that as when these episodes occur we still have the access to upload the videos as and when it's needed it's good that that is just there. For us to be able to just log in as and when there is a need....I think the main benefit is just knowing that health professional, that really experienced health professional, that you know is going to watch this video or clip of your, concern as a parent, hopefully relatively soon and respond relatively soon and give you some sort of answer or ease those worries. So knowing that you are able to reach these professionals without jumping through a lot of different hoops and without having to go through your GP and everything else and wait months and months for appointments. Knowing that you can just get this wee clip to them, for something that has been quite concerning, knowing that for an episode that has been quite concerning, it is getting to them quite quickly is probably the best thing.