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In response to an enquiry from the developers of vCreate Neuro

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# vCreate Neuro for the diagnosis and treatment of adults and children with epilepsy and other neurological disorders (Phase 1 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 due to COVID-19 had a profound effect on access to health and care, and necessitated the exploration of both synchronous and asynchronous remote consultations (see *Glossary*) across Scotland. vCreate Neuro is an asynchronous service that was developed by clinicians within the Royal Hospital for Children, Glasgow (RHCG). 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. The objective assessment of data collected during this extension period will inform a decision on the potential nationwide procurement of vCreate Neuro.

## 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 the quantitative and qualitative data from the survey 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 phase 1 report will be presented to the vCreate Neuro clinical team and the neurology clinical specialty across Scotland.

A phase 2 and final report, based on additional follow-up data, will be published in 2022.

## Key findings

vCreate Neuro may add value to the delivery of care for people (adults and children) suffering from 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

- No direct evidence was identified that discusses the advantages and disadvantages of using an asynchronous video-recording service such as vCreate Neuro.
- 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 evidence 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

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

- Patients and cares who used vCreate Neuro within paediatric 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. Being 'connected' was defined by the project team as 'having easy access to the team and a positive relationship.' 'Access' was not defined. Use of 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.
- More than half of the responses from paediatric service clinicians indicated that using vCreate Neuro led to a shorter time to diagnosis and treatment selection and none indicated the opposite. Similar findings were observed across adult

service clinicians, apart from one instance where a clinician felt that use of vCreate Neuro led to a longer time to diagnosis.

### Qualitative analysis

A qualitative analysis of the free text comments from the clinician and service user surveys was undertaken to understand the user experience of vCreate Neuro and to identify suggestions for improvements to the app.

- The clinicians, patients and carers valued vCreate Neuro and found it useful. Users felt that vCreate Neuro saved time and resources for the NHS, patients, and carers, and has a positive impact on the clinician-patient/carer relationship. One carer shared their concern about vCreate Neuro replacing face-to-face appointments rather than being used as an adjunct diagnostic tool.
- Clinicians found vCreate Neuro particularly useful for diagnoses and identifying cases for which urgent treatment or investigation is required. By identifying non-epileptic events, clinicians suggest that it can prevent unnecessary investigations, treatment and travel; and provide rapid reassurance for patients and carers, especially in the case of those who live remotely or in rural settings.
- Patients and carers from vulnerable groups (such as people with neurological conditions who live alone) and people without access to high-speed internet may require assistance with accessing vCreate Neuro.
- A number of improvements were suggested by users including the facility to upload multiple videos, receiving a consistent form of feedback, the facility to leave longer free text responses, a 'not applicable' response option, the ability to edit submissions and a clearer method of uploading videos
- Sentiment analysis revealed that 59% of clinician's comments were positive in tone, 18% were neutral and 23% were negative. Carers and patients tone was more balanced between positive (44%) and negative (53%) and just 3% of their comments were neutral. Most negative comments by carers and patients were about the experience of technical issues while trying to log onto vCreate Neuro or upload their videos.

### Economic analysis

- Economic analyses based on the survey and 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.
- The findings were sensitive to the cost and number of inpatient admissions and the cost of consultant time estimated to review the uploaded videos. Any change in these parameters simultaneously creates substantial uncertainty in the conclusions.

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## Abbreviations

CT	computed tomography
HVR	home-video recording
EEG	electroencephalogram
ES	epileptic seizures
GP	general practitioner
INAHTA	International Network of Agencies for Health Technology Assessment
MRI	magnetic resonance imaging
NHS A&A	National Health Service Ayrshire and Arran
NHS GGC	National Health Service Greater Glasgow and Clyde
NICU	neonatal intensive care unit
NPHWs	non-physician health workers
NPV	negative predictive value
PNES	psychogenic non-epileptic seizures
PPV	positive predictive value
PWE	person with epilepsy
PhysNEE	physiologic non-epileptic events
SHTG	Scottish Health Technologies Group
TEC	Technology Enabled Care
VEEG	video electroencephalogram

## Glossary

**Asynchronous** means 'out of sync'. In this report it is used in reference to asynchronous communication which means communication that doesn't 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.

**Median:** A value in a series arranged from smallest to largest below and above which there are an equal number of values or which is the average of the two middle values if there is no one middle value. The median of the set 1, 3, 7, 12, 19 is 7.

**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.

**Epileptologists:** An adult or paediatric neurologist who specialises in the treatment of patients with epilepsy

**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.

**Gold standard:** In medicine and statistics, a gold standard test is usually the diagnostic test or benchmark that is the best available under reasonable conditions. Other times, a gold standard is the most accurate test possible without restrictions.

**Video-EEG (VEEG)** monitoring is a procedure done during an inpatient hospital stay using continuous recording of electroencephalogram (EEG) and video. The goal is to record your usual events and determine if they are epileptic seizures or some other condition.

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

**Tukey post hoc test** is a post-hoc test used after a one-way analysis of variance test to determine between which groups a difference may lie.

**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.

**Statistical significance:** In research, statistical significance is a measure of the probability of the null hypothesis being true compared to the acceptable level of uncertainty regarding the true answer.

**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 artifacts. The data are generally nonnumerical.

**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.

**Interquartile:** In descriptive statistics, the interquartile range, also called the midspread, middle 50%, or H-spread, is a measure of statistical dispersion, being equal to the difference between 75th and 25th percentiles, or between upper and lower quartiles.

**Seizures:** A seizure is a burst of uncontrolled electrical activity between brain cells (also called neurons or nerve cells) that causes temporary abnormalities in muscle tone or movements (stiffness, twitching or limpness), behaviours, sensations or states of awareness.

**Paroxysmal seizure:** Epileptic seizures are paroxysmal, abnormal behaviours caused by excessive, hypersynchronous firing of neurons in the brain.

**Semiology** is defined as a study of signs and symbols. In medical terms, it comprises the study of symptoms, somatic signs and laboratory signs, history taking and physical examination.



## Introduction

Digital technologies have the potential to reshape and improve health and care services, support person-centred care, and improve outcomes for people in Scotland.<sup>1</sup> In 2014, the Scottish Government (SG) established the Technology Enabled Care (TEC) programme, which included a series of five interrelated workstreams to drive the widespread adoption of technology to support self-management, access to care and remote management within health and social care.<sup>2</sup> In 2021, the TEC programme - part of the Digital Health and Care Directorate, 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.<sup>3</sup> Remote health pathways are 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 patients with a disease or illness. This can be done in real-time (synchronous communication) via video conference, phone call or chat application (app), or through asynchronous platforms that involve communication between clinician and patient at times convenient to them. Asynchronous platforms may apply to various formats such as text, photo or a video, where a patient uploads data which is then assessed by a clinician at a later date. The clinician then advises the patient on a treatment plan or recommends further investigation 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.<sup>4,5</sup>

Societal restrictions due to COVID-19 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 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.<sup>6,7</sup> vCreate Neuro is one example of an asynchronous service that was developed by clinicians within the Royal Hospital for Children Glasgow (RHCG). vCreate Neuro enables patients or carers to share smartphone-recorded videos and associated data with their clinical team for remote clinical interpretation and management advice. Guidelines by the Scottish Intercollegiate Guidelines Network (SIGN) highlight the value of and need for videos in epilepsy diagnosis. The SIGN guideline notes that a secure video transfer service could have a significant impact on diagnosis and management of epilepsy.<sup>8</sup>

In April 2020, the Digital Health and Care Directorate, 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. The data collected during this period are being analysed by SHTG as part of a technology assessment to inform a decision on the nationwide procurement of the technology.

## 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 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 and other neurological disorders.
- Collect and analyse survey data from clinicians, patients and carers after they had 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 transfer of short recorded (asynchronous) 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 (NICU) to families of babies admitted in NICU. The response to this technology was positive and vCreate secure video technology can be found in over 80% of UK neonatal units.<sup>9</sup>

Building on this 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) who have had their first seizure or are already diagnosed with epileptic seizures (ES) are asked to register for this service, download the smartphone app, 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 earlier 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.<sup>10</sup> At present, vCreate Neuro is not CE or UKCA marked, however it was approved by NHS England as an ‘NHS trusted app’ after undergoing assessment as part of the NHS Digital Tools Library. vCreate Neuro is expected to receive Digital Technology Assessment Criteria (DTAC) approval by early 2022.<sup>9,11</sup>

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 United Kingdom. vCreate Neuro meets the General Data Protection Regulation (GDPR) requirements – which incorporates Data Protection Impact Assessment (DPIA) - by complying with the GDPR checklist for data controllers.<sup>9,12</sup>

vCreate Neuro is 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.<sup>9</sup>

## 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 for further investigation. The standard referral route to secondary care is via general practitioners (GPs) or following attendance at accident and emergency (A&E).<sup>13,14,15</sup> 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 (indicated by route ‘a’ in *Figure 1*). 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.<sup>16</sup> 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.

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 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 (indicated by route 'b' in *Figure 1*). 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. vCreate Neuro is suitable for integration with TrakCare, yet due to COVID-19 pressures, its integration has been delayed as part of the National Digital Platform (NDP). *Figure 1* provides an overview of the current care pathway with the new vCreate Neuro pathway.



## Literature review

A rapid review of literature was undertaken 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.

### Search process

The literature search was carried out between 5 August 2021 and 12 August 2021 using the following databases: Medline and Embase (OVID platform).

The epilepsy search filter used within SIGN guideline 159 was applied, along with a secondary search filter based on search terms provided by the requester. The SIGN economics search filter on the OVID databases was also applied. No restrictions were set for age group, study design, setting or geography. Only publications from 2011 until July 2021 were included. See *Appendix 1* for details on search terms and search strategy used.

### Findings

Four hundred and twenty seven records were identified. A single reviewer screened the titles and abstracts and excluded 409 records. The remaining 18 records were considered for full text screening, of which only two records were found suitable to be included. Due to the lack of relevant literature, an additional search was conducted using Google scholar and the vCreate Neuro clinical team was also contacted, as experts in the field. An additional seven records were identified which met the inclusion criteria.

All studies were cross-sectional in nature with six out of the nine classified as cohort studies while two were case-control studies.<sup>17</sup> The remaining study was a field evaluation trial conducted at an epilepsy camp. The main difference between cohort and case-control test accuracy studies was the manner in which they selected their participants. In cohort test accuracy studies, the participants were recruited on suspicion determined by presence of risk factors or results from previous tests; all participants received the index test and the reference test (gold standard test or method) to determine their current status. In case-control test accuracy studies, the participants were selected based on their health status or outcome, and the results of the index test of participants with a positive reference test result or event (cases) are compared with the results of the index test of participants with a negative reference test result or no event (controls). Eight studies used videos as a key component of the index test, and one study only used textual information via a smartphone app to assess its utility compared to standard of care. *Table 1* provides an overview of the included records.

Table 1: Included studies (n=9)

Record author	Study design	Brief description of the study	Study participants	Author conclusions
Amin et al. 2021 <sup>18</sup>	Prospective cohort study	This study investigated the value of smartphone videos as an adjunct tool for diagnosis by comparing the diagnosis based on smartphone videos to the final diagnosis based on standard video-electroencephalography (VEEG) monitoring.	54 patients (32 females), mean age: 34.7 with standard deviation (SD) of 17 years.  Five epileptologists reviewed the videos. Four were blinded to each other's interpretation.	Smartphone videos provide a powerful extension and validation of the history and proved to agree with the eventual diagnosis based on standard VEEG.
Karakas et al. 2021 <sup>19</sup>	Prospective case-control study	This study assessed the predictive diagnostic value of expert evaluation of home videos in predicting epileptic seizures (ES) versus psychogenic non-epileptic seizures (PNES) in US veterans.	50 videos from 50 patients (30 males), mean age: 47.7 years.  Four epileptologists reviewed the videos. All were blinded to patients' history including VEEG diagnosis.	Home videos are useful tools in helping epileptologists predict ES versus PNES reliably in US veterans referred for the evaluation of seizures.
Patterson et al. 2020 <sup>20</sup>	Field evaluation	This study conducted a field evaluation of an epilepsy management app to demonstrate its utility for non-physician health workers (NPHWs) in diagnosing and managing patients with suspected epilepsy in resource-limited settings.	23 patients (11 females), mean age: 14 (2–47) years.  Five personnel involved: Four epilepsy-inexperienced doctors and one NPHW.	The app is a worthwhile tool to help inexperienced doctors or non-physician health workers to manage suspected epilepsy with input from remote epilepsy specialist.

Tatum et al. 2020 <sup>21</sup>	Prospective cohort study	This study assessed the diagnostic accuracy of smartphone videos reviewed to correctly identify VEEG diagnoses of epileptic seizures. A secondary aim was also to determine the diagnostic accuracy of smartphone videos to correctly identify VEM diagnoses of psychogenic non-epileptic attacks and the association of experts vs trainees with video interpretation.	44 patients (31 females), mean age: 45.1 (20–82) years.  44 smartphone videos interpreted by 19 personnel: 10 epilepsy experts and nine neurology residents, all blinded.	Outpatient smartphone video review by experts has predictive and additive value for diagnosing epileptic seizures. Smartphone videos were also found to be reliable in diagnosing psychogenic non-epileptic attacks, especially when motor signs were present.
Ramanujam et al. 2018 <sup>22</sup>	Prospective cohort study	This study assessed the contribution home videos made on mobile phones can make to the diagnosis of PNES.	269 patients (47% females); age range 10–50 years.  Two personnel involved: One epilepsy fellow reviewed home-video recordings (HVRs) (blinded to clinical history), one epileptologist reviewed VEEG (blinded to HVR diagnosis)	Home videos of good quality can complement VEEG in diagnosing PNES in a cost-effective way and help initiate appropriate management.
Wasserman et al. 2017 <sup>23</sup>	Retrospective case-control study	This study investigated the ability to correctly diagnose ES from PNES in different groups and seniorities of medical professionals based on video semiology alone.	10 VEEG recordings, five of PNES and five of ES shown to 46 personnel: 26 non-neurological professionals and 20 neurological professionals.	The likelihood of making a correct PNES vs ES diagnosis using video semiology alone is strongly correlated with medical staff specialty but not to seniority. This suggests the need for taking videos of



				episodes and have an education plan for first responders.
Dash et al. 2016 <sup>24</sup>	Prospective cohort study	This study evaluated the diagnostic yield of different semiological signs inferred from the medical history provided by the caregivers of person with epilepsy (PWE) and compared them to those obtained from home videos to correctly classify the type of epilepsy.	624 videos from 312 patients, mean age $26.76 \pm 7.5$ years.  Three personnel involved: One epileptologist and one epilepsy fellow reviewed HVRs and VEEG recordings and one epilepsy resident took the medical history. No blinding.	Home videos are more reliable in picking up semiological signs and classifying epilepsy type than medical history provided by caregivers of PWEs. They can surely serve as a complementary tool, especially in developing countries.
Erba et al. 2016 <sup>25</sup>	Prospective cohort study	This study investigated if, when, and to what extent visual information contained in a video-recorded event allows experienced epileptologists to predict the diagnosis of PNES without the aid of EEG.	23 videos from 21 patients. All patients >18 years.  Five neurologists reviewed the videos. Four were blinded to the EEG findings, patient history and final diagnosis	A confident diagnosis of PNES or ES can be established on clinical grounds based on video data alone in a third of total cases and this is particularly beneficial for those with no access to VEEG monitoring units.
Beniczky et al. 2012 <sup>26</sup>	Retrospective cohort study	This study assessed and compared the diagnostic accuracy of the interpretation of semiological data inferred from seizure descriptions and by reviewing video recordings.	41 seizure video recordings from 30 patients (19 females), mean age: 23 (2–62) years.  Five epileptologists reviewed the videos. All were blinded to history and other clinical data	Video recordings increased the accuracy of seizure interpretation.

The majority of studies included patients over the age of 17 or 18 years. The number of patients and video reviews varied between the studies; three studies had an equal number of patients and videos and four studies included more videos than patients in the study. For the remaining two studies, one did not use videos while the other used 10 video recordings from a database with no information on patient numbers. The number of medical personnel varied across studies, with seven studies having five or fewer medical personnel who performed the diagnosis. One study involved 19 medical personnel as part of the diagnosis, and one study involved 46 medical personnel.

One study by Tatum et al. (2020) was conducted at multiple locations. The study assessed the diagnostic accuracy of smartphone recorded paroxysmal neurological events in eight tertiary care epilepsy centers and also compared diagnostic performance between neurology residents (registrar) and epilepsy experts. History and physical examination (HP) and video-encephalography (VEEG) results were used as a reference standard to assess the index test (smartphone video-based diagnosis). The authors found that for all events (n=42), a correct diagnosis was more likely when HP and smartphone video results were combined compared with HP results on their own (95.2% compared to 79.0%). The diagnostic level of confidence amongst clinicians was also found to be higher after viewing smartphone video when compared to diagnosis obtained from HP alone. When all reviewers were considered, the diagnostic accuracy of smartphone videos interpretation against VEEG diagnoses for epileptic seizures was 82.7% (95% CI 78.7 to 86.2) and for psychogenic epileptic seizures (PNES) was 81% (95% CI 76.8 to 84.7). When only epilepsy experts were considered, the diagnostic accuracy increased to 89.1% (95% CI 84.2 to 92.9) for epileptic seizures and 85.9% (95% CI 80.6 to 90.2) for PNES. Overall, the study illustrated the diagnostic value of smartphone videos in adult outpatients with epilepsy, especially in cases where PNES diagnosis exclusively relies on HP.<sup>21</sup>

Similar conclusions were reached following a recent single-center study conducted by Amin et al. (2021). Smartphone videos were deemed to be a powerful extension and validation of the medical history, and were in line with the eventual diagnosis made using the standard VEEG. In this study the authors found that when smartphone video conclusion was graded as definite epileptic or definite non-epileptic alongside a conclusive VEEG diagnosis, it was 100% in accordance with VEEG (13/13 for non-epileptic and 5/5 for epileptic). This indicated a 100% sensitivity and specificity of smartphone video for definite epileptic and non-epileptic episodes. When the smartphone video interpretation specified PNES within the non-epileptic group, video interpretation matched 93% of final VEEG cases (13/14).<sup>18</sup>

Karakas et al. (2021) conducted a study that included US armed forces veterans. Using VEEG diagnosis as the gold standard, the authors assessed the predictive diagnostic value of expert evaluation of home videos of habitual events with or without additional limited demographic data. They found that diagnostic accuracy of home videos against VEEG diagnosis for ES was 88% (95% CI 82.7 to 92.2), with a positive predictive value (PPV) of 75.8% (95% CI 65.7 to 83.7) and negative predictive value (NPV) of 93.5% (95% CI 88.7 to 96.3). Using the sensitivity (83.9%) and specificity (89.6%), they estimated that there was an eight times greater likelihood that a patient was correctly diagnosed as having ES compared to non-epileptic events (such as PNES and physiologic non-epileptic events (PhysNEE)) based on video reviews. Although the study was conducted in a homogeneous sample population,

findings were found to be largely consistent with other studies that included civilian samples.<sup>19</sup>

One study (Patterson et al. 2020) conducted a field evaluation of an epilepsy management app to demonstrate its utility for non-physician health workers (NPHWs) in diagnosing and managing patients with suspected epilepsy in resource-limited settings. The study tested a smartphone app that can be used by NPHWs or epilepsy-inexperienced local doctors to record answers to pre-specified questions and generate a summary that can be sent remotely to an epilepsy specialist to diagnose and manage epilepsy. The results from the app (in terms of accuracy of data entry, diagnosis of epileptic events, diagnosis of provoked or symptomatic seizures, diagnosis of epilepsy type and appropriate treatment if untreated) were matched against the results from a traditional face-to-face consultation with an epilepsy specialist. A high level of agreement between the app management and the gold standard of face-to-face examination was found with an app misdiagnosis rate of 4%. Although the study did not assess the use of a video, it was included in this review due to the asynchronous nature of the app used in diagnosing epilepsy in comparison to a standard face-to-face consultation.<sup>20</sup>

A study conducted by Wasserman et al. (2017) used a video-based survey to investigate the diagnostic accuracy of home-video recordings (HVRs) among different groups and seniorities of medical professionals based on video semiology alone. The authors showed 10 video recordings of paroxysmal seizure like episodes (five PNES, five ES) to 46 participants (20 neurological and 26 non-neurological personnel) and found that only medical staff specialty was highly correlated to the chance of making a correct PNES or ES diagnosis. For instance, epileptologist, general neurologist and neurology nurses correctly diagnosed 87.5%, 72.8% and 69.8% of cases respectively compared to 58% by ER nurses, 54% by internal medicine physicians and 44% by emergency department physicians.<sup>23</sup>

Three studies (Ramanujam et al. 2018; Benzicky et al. 2012; Erba et al. 2016) explored the clinical value of HVRs in differentiating non-epileptic seizures from epileptic seizures.<sup>22,25,26</sup> Benzicky et al. compared the accuracy of interpreting seizure semiology from witnessed description compared with video recordings and found that a consensus conclusion (at least three identical diagnoses between five epileptologists) was reached in more cases based on the interpretation of video recordings (88%) than on the descriptions (66%) along with overall accuracy being higher for the video recordings (85%) than for the descriptions (54%).<sup>26</sup> Erba et al. reported that a confident diagnosis of PNES or ES can be established based on video data alone in one third of total cases (7 out of 23, 30.4%).<sup>25</sup> Ramanujam et al. specifically assessed the contribution home videos using mobile phones can make to the diagnosis of PNES and found that HVRs help diagnose PNES with a sensitivity of 95.4% (95% CI 87.3 to 99), a specificity of 97.5% (95% CI 94.3 to 99.2), and PPV and NPV of 92.7% (95% CI 84.1 to 96.8) and 98.5% (95%CI 95.6 to 99.5) respectively.<sup>22</sup>

A study by Dash et al. (2016) assessed the diagnostic yield of different semiological signs inferred from the medical history (provided by the caregivers) of a person with epilepsy (PWEs) compared with those obtained from home videos to correctly classify the type of epilepsy. The authors found that the mean number of semiology features recorded after analysis of home videos (3.3) gave a higher yield when compared with the mean number of semiology features obtained from medical history (2.1). The findings indicated that HVRs

were more reliable in picking up semiological signs and can serve as a significant aid in diagnostic classification of paroxysmal seizure like episodes, especially in developing or resource-limited countries.<sup>24</sup>

A study by Tatum et al. (2020) indicated that no adverse events were encountered during use of a smartphone video or VEEG in any patient.<sup>21</sup> Practical issues with using HVRs, such as privacy regulations, legal compliance and ethical issues were briefly referenced in three studies (Karakas et al. 2021; Tatum et al. 2019; Wasserman et al. 2017).<sup>19,21,23</sup> Most of the issues identified were found to be generic to using telemedicine or telehealth which can potentially be resolved if clear guidelines are issued by respective health authorities.

*Following completion of the systematic search and literature review, another systematic review was published by Ricci et al.<sup>27</sup> Ricci et al. reviewed the existing literature on the use of HVRs to support physicians in the differential diagnosis of paroxysmal seizure-like episodes (PSLE). The conclusions by Ricci et al. reflect the findings of our review.*

## Summary

Summary points from the rapid review of published literature include:

- At present, due to 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 EEG or triage them based on urgency and need.

## Survey data analysis

In order to evaluate the use of vCreate Neuro within NHSScotland, we were asked to undertake analyses of quantitative and qualitative 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
  - Adult patients or carers of adult patients using the adult neurology service
- 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 a seizure episode on the system. A seizure episode can comprise one incident video or multiple incident videos related to the same episode, which means that the number of responses in the survey samples may not be equal to the number of individuals completing the surveys. Due to this it was not possible to determine how many times each respondent (service user or clinician) completed the survey.

Data for all user groups were collected using surveys from May 2020, comprising open questions with free text response and closed questions with answers that were a mix of categorical and continuous variables. Due to 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 2*). The updated survey was implemented in May 2021. The open questions, allowing for a free text response, and resource use questions remained unchanged between the surveys.

To maximise the use of data gathered in the old and new versions of the surveys without compromising on data quality, the following were agreed for this report.

- Quantitative analysis will be carried out on the data collected from the new service user and clinician surveys only. A data cut-off point from 5 May 2021 to 14 August 2021 was selected (analysis of data began on 15 August 2021).
- Qualitative analysis will be carried out on the free text responses collected from surveys with a data cut-off point from 1 October 2020 to 4 May 2021.
- Economic analysis will be carried out using the data collected from the clinician surveys with a data cut-off point from 1 October 2020 to 4 May 2021.

## 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.

## 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 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 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 was 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 13 sites and to adult service users and clinicians at three sites (*Table 2*). In total there were 312 survey responses from paediatric service users (from 418 uploaded videos), 14 survey responses from adult service users (from 161 uploaded videos), 204 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 2*.

*Table 2: 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	81	0 <sup>+</sup>	103	9
NHS Lothian	49	*	27	*
NHS Grampian	29	14	11	16
NHS Tayside	7	0	15	1
NHS Ayrshire & Arran	12	- <sup>^</sup>	3	-
NHS Dumfries & Galloway	5	-	2	-
NHS Fife	1	-	0	-
NHS Forth Valley	9	-	1	-
NHS Highland	4	-	0	-
NHS Lanarkshire	13	-	22	-

Site	Responses from paediatric service users	Responses from adult service users	Responses from paediatric service clinicians	Responses from adult service clinicians
NHS Sheffield	19	-	15	-
Evelina London Children's Hospital	65	-	3	-
Great Ormond Street Hospital	18	-	2	-
<b>Total</b>	<b>312</b>	<b>14</b>	<b>204</b>	<b>26</b>

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

^ '-' indicates that responses for vCreate Neuro are not applicable for these boards since almost all adult neurologists in Scotland are based in the four tertiary centers (GGC, Lothian, Grampian and Tayside) and will link their outreach patients to their tertiary service.

\*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. Abbreviations: GGC: Greater Glasgow and Clyde

### Paediatric service user survey results

Response rate to the survey was 75% (312 responses to 418 videos uploaded). Eighty-eight percent of responses to the paediatric service user survey were from females, 95% were from parents of the patient, with a mean age of 37.4 years (SD 8.7). Sixty 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 3 Table A*.

Key findings from the paediatric service user survey (n=312).

- 87% of responses (n=205) indicated that vCreate Neuro app was either 'very easy' or 'easy' to use for the first time. This increased slightly to 93% (n=70) based on repeated use of the app.
- The majority of responses (65%, n=119) from paediatric service users indicated that vCreate Neuro made them feel more connected to the clinical team.
- The majority of responses (60%, n=112) from paediatric service users indicated that vCreate Neuro increased the quality of care provided.
- The majority of responses (66%, n=207) from paediatric service users indicated that vCreate Neuro allowed for easier communication with the clinical team.
- Use of vCreate Neuro avoided what would otherwise have been a work or school absence approximately 20% of the time the app was used.
- The most common modes of transport avoided from using the app were car (n=241) and train (n=30).



- The median mileage of travel avoided from using the app was 20 miles (interquartile range 9 to 40 miles).
- 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=0.42).

Detailed results are presented in *Table 3* and *Tables B and C in Appendix 3*.

*Table 3: 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 use for first time (n=235)	46% (109)	41% (96)	9% (20)	3% (8)	<1% (2)
Ease of use after the first time (n=76)	57% (43)	36% (27)	7% (5)	0 (0)	1% (1)
-	No or n/a	Yes	Half day	Full day	-
Avoidance of school absence (n=312)	80% (249)	20% (63)	41% (26)	59% (37)	-
Avoidance of work absence (n=312)	82% (257)	18% (55)	49% (27)	51% (28)	-
Mileage of travel avoided (n=310)	Median = 20, IQR 9 to 40 (KS test p<0.001)			-	-
-	More connected	Neither more nor less	Less connected	Don't know/ not sure	-
Feeling more or less connected (n=182)*	65% (119)	23% (41)	5% (9)	7% (13)	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/ not sure	-
Quality of care (n=188)*	60% (112)	18% (33)	2% (4)	21% (39)	-
-	Yes	No	Don't know/ not sure	-	-
Help easily communicate with clinical team (n=312)	66% (207)	4% (14)	29% (91)	-	-

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

## Adult service user survey results

Response rate to the adult service user survey was 9% (14 responses from 161 videos uploaded). This is a substantially lower response rate compared with the paediatric survey and came from a single centre. Three of the centres which offered the vCreate Neuro service to their adult patients did not receive any responses (NHS GGC, NHS Tayside and NHS Lothian). NHS Grampian was the only centre with responses from adult service users (n=14).

*Note: The project team reported that prior to the survey change in May 2021 there was engagement from the adult service users but this was not evident after the changes were made to the survey.*

Of the 14 responses to the survey in NHS Grampian, eight were from females and six from males. The mean age was 41.9 (SD 15.1) years. Twelve responses were from patients, one a carer and one from a patient's wife. Twelve of the responses were from service users already known to the neurology service before vCreate Neuro was available. Due to the small numbers, percentage results were not generated from the survey.

Key findings from the adult service user survey (n=14).

- The majority of responses (n=9) 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.
- The majority of responses (n=7 out of 12) were from adult service users who thought that vCreate Neuro improved the quality of care provided.
- Half of responses were (n=7) were from adult service users who thought that vCreate Neuro allowed for easier communication with the clinical team. Two responses were from services users who felt it hindered communication and five were not sure.
- Use of vCreate Neuro avoided absence from work in two instances.
- Modes of transport that were avoided were bus (n=6), ferry (n=1) and car (n=7).
- Mean mileage of travel avoided was 62.5 (SD=86.1) (due to the small numbers, the distance travelled was not compared according to how connected a service user felt).

Detailed results are presented in *Table 4*.

Table 4: 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=12)	5	4	1	1	1
Ease of use after the first time (n=2)	1	1	0	0	0
-	No or n/a	Yes	Half day	Full day	-
Avoidance of work absence (n=14)	12	2	1	1	-
Mileage of travel avoided (n=14)	Mean = 62.5, SD = 86.1, KS test $p < 0.3305$			-	-
-	More connected	Neither more nor less	Less connected	Don't know/ not sure	-
Feeling more or less connected (n=11*)^	3	2	3	3	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/ not sure	-
Quality of care (n=12)^	7	2	1	2	-
-	Yes	No	Don't know/ not sure	-	-
Help easily communicate with clinical team (n=14)	7	2	5	-	-

\*one responder selected that this question was irrelevant to them because they had not used neurology services previously, this is despite them stating that they were known to the neurology service in another question.

^ only patients already known to service

### Paediatric service clinician results

There were a total of 204 responses from clinicians of paediatric services. One hundred and thirty responses were from clinicians in NHS GGC and NHS Lothian. Two of the vCreate Neuro project team worked within these boards and completed the clinician survey. To allow for comparison the results from these two boards are displayed separately from the rest of the participating boards in *Table 5*. The clinicians in the vCreate neuro project team have now stopped completing the clinician survey in advance of the phase two evaluation.

Responses were from clinicians reviewing data for return patients (57%, n=116) and new patients (43%, n=86). There was missing data for n=1 and one clinician responded 'review with general colleague'.

The results were positive. Responses from the clinicians in NHS GGC and NHS Lothian were more positive compared to the other sites combined. The following summary of results is from sites not including NHS GGC and NHS Lothian although NHS GGC and NHS Lothian data are presented in parenthesis for comparison.

Key findings from the paediatric service clinician survey (n= 204):

- The majority of responses (87%, n=63) were from paediatric service clinicians who thought that vCreate Neuro was either 'very easy' or 'easy' to use. (NHS GGC and NHS Lothian: 100%, n=130)
- Almost all responses (98%, n=71) from paediatric service clinicians indicated that vCreate Neuro was either 'very useful' or 'useful' in the overall management of the patient. (NHS GGC and NHS Lothian: 99%, n=125)
- Almost all responses (98%, n=72) from paediatric service clinicians indicated that the video quality was either 'high quality' or of 'adequate quality'. (NHS GGC and NHS Lothian: 100%, n=130)
- The majority of responses (89%, n=65) from paediatric service clinicians indicated that vCreate Neuro made them feel more connected to the patient. (NHS GGC and NHS Lothian: 98%, n=125)
- The majority of responses (89%, n=66) from paediatric service clinicians indicated that vCreate Neuro improved the quality of care provided. (NHS GGC and NHS Lothian: 100%, n=129)
- The majority of responses were paediatric service clinicians indicated that vCreate Neuro was either 'very useful' or 'useful' in making a diagnosis (89%, n=63) or selecting a treatment (73%, n=49). (NHS GGC and NHS Lothian: 97%, n=123 and 94%, n=112 respectively)
- Over half of responses (58%, n=36) from paediatric service clinicians indicated that vCreate Neuro allowed for a shorter time to diagnosis. (NHS GGC and NHS Lothian: 90%, n=103)
- Over half of responses (53%, n=28) from paediatric service clinicians indicated that vCreate Neuro allowed for a shorter time to treatment. (NHS GGC and NHS Lothian: 84%, n=97)
- From the responses (n=66), a median time of 10 min (interquartile range 5 to 75, range 1 to 90) was spent by clinicians reviewing the videos and responding to the patient. (NHS GGC and NHS Lothian: n= 86, median 5 min, interquartile range 5 to 5, range 1 to 20).

Detailed results are presented in *Table 5*.

Table 5: 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=73)	66% (48)	21% (15)	11% (8)	3% (2)	0
<i>GGC &amp; Lothian</i> (n=130)	98% (127)	2% (2)	0	0	0
-	High (easy to interpret)	Moderate (interpret with effort)	Poor (unable to interpret)	-	-
Video quality (n=73)	82% (60)	16% (12)	1% (1)	-	-
<i>GGC &amp; Lothian</i> (n=130)	95% (123)	5% (6)	<1% (1)	-	-
-	More connected	Neither more nor less	Less connected	Don't know/ not sure	-
Feeling more connected to patient (n=73)	89% (65)	10% (7)	0	1% (1)	-
<i>GGC &amp; Lothian</i> (n=127)	98% (124)	<1% (1)	0	2% (2)	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/ not sure	-
Quality of care (n=74)	89% (66)	11% (8)	0% (0)	0% (0)	-
<i>GGC &amp; Lothian</i> (n=129)	100% (129)	0	0	0	-
-	Very useful	Useful	Not useful or made no difference	Made more difficult	-
Useful for making a diagnosis (n=71)	48% (34)	41% (29)	12% (8)	0	-
<i>GGC &amp; Lothian</i> (n=127)	85% (108)	12% (15)	3% (4)	0	-
Useful for choosing a treatment (n=67)	27% (18)	46% (31)	27% (18)	(0)	-
<i>GGC &amp; Lothian</i> (n=120)	87% (104)	7% (8)	7% (8)	0	-

Research question (n of responses)	Response categories				
	Results % (n)				
-	Shorter than usual	Same time	Longer than usual	-	-
Time to diagnosis NP n=23, RP n=41	NP 61%(14) RP 54%(22)	NP 39%(9) RP 41%(17)	NP (0) RP (0)	-	-
<i>GGC &amp; Lothian</i> <i>NP n=55, RP n=60</i>	<i>NP</i> <i>87%(48)</i> <i>RP</i> <i>92%(55)</i>	<i>NP 13% (7)</i> <i>RP 8% (5)</i>	<i>NP (0)</i> <i>RP (0)</i>	-	-
Time to treatment NP n=18, RP n=35	NP 56%(10) RP 51%(18)	NP 44%(8) RP 49%(17)	NP (0) RP (0)	-	-
<i>GGC &amp; Lothian</i> <i>NP n=53, RP n=63</i>	<i>NP</i> <i>79%(42)</i> <i>RP</i> <i>87%(55)</i>	<i>NP 21%(11)</i> <i>RP 13%(8)</i>	<i>NP (0)</i> <i>RP (0)</i>	-	-
-	Very useful	Useful	Not useful	Hindered a bit	Hindered greatly
Useful for overall patient management (n=73)	57% (41)	41% (30)	3% (2)	(0)	(0)
<i>GGC &amp; Lothian</i> <i>(n=126)</i>	<i>90% (114)</i>	<i>9% (11)</i>	<i>&lt;1% (1)</i>	<i>0</i>	<i>0</i>

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

Sites without GGC & Lothian in first row for each question. NHS GGC & NHS Lothian results in are in rows in italics

## Adult service clinician results

There was a total of 26 responses from adult service clinicians across three NHS sites, 13 were reviewing new patients and 13 were reviewing return patients. Due to the small numbers, percentage results were not generated from the survey.

Key findings from the adult service clinician survey (n=26).

- The majority of responses (n=21) were from adult service clinicians who thought that vCreate Neuro was either 'very easy' or 'easy' to use.
- Almost all responses (n=21 out of 22) 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=15) or of adequate quality (n=10).
- The majority of responses (n=16) were from adult service clinicians who thought that vCreate Neuro made them feel more connected to the patient.
- The majority of responses (n=16) 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=21 out of 22) or selecting a treatment (n=20 out of 22).
- The majority of responses were from adult service clinicians who thought that vCreate Neuro lead to shorter time to diagnosis (n=12 out of 16) and a shorter time to treatment (n=9 out of 14).
- From the responses (n=17), a median time of 10 min (interquartile range 5 to 20, range 0 to 30) was spent by clinicians reviewing the videos and responding to the patient.

More detailed results can be seen in *Table 6*.

*Table 6: 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=26)	13	8	3	1	1
-	High (easy to interpret)	Moderate (interpret with effort)	Poor (unable to interpret)	-	-

Research question (n of responses)	Response categories				
	Results (n)				
Video quality (n=26)	15	10	1	-	-
-	More connected	Neither more nor less	Less connected	Don't know/ not sure	-
Feeling connected to patient (n=26)	16	7	0	3	-
-	Improves quality of care	No effect	Reduces quality of care	Don't know/ not sure	-
Quality of care (n=26)	17	9	0	0	-
-	Very useful	Useful	Not useful or made no difference	Made more difficult	-
Useful for making a diagnosis (n=22)	9	12	1	0	-
Useful for choosing a treatment (n=22)	7	13	2	0	-
	Shorter than usual	Same time	Longer than usual	-	-
Time to diagnosis NP n=9, RP n=7	NP (7) RP (5)	NP (2) RP (1)	NP (0) RP (1)	-	-
Time to treatment NP n=8, RP n=6	NP (5) RP (4)	NP (3) RP (1)	NP (0) RP (0)	-	-
	Very useful	Useful	Not useful	Hindered a bit	Hindered greatly
Useful for overall patient management (n=22)	13	8	1	0	0

## Summary

Summary points from the quantitative analyses are as follows:

- Users of paediatric services were predominantly positive in their opinion 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. The use of vCreate Neuro avoided absence from school or work approximately 20%



of the time it was used, and the median mileage of travel avoided was 20 miles per vCreate Neuro service use.

- Paediatric and adult service clinicians were predominantly positive in their opinion of 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.
- More than half of the responses from paediatric and adult service clinicians indicated that using vCreate Neuro led to a shorter time to diagnosis and selecting treatment.

## Qualitative Analysis

A qualitative analysis of the free text comments from the clinical and service user surveys was undertaken to understand the user experience of vCreate Neuro in greater depth and to identify suggestions for improvements to the app.

### Methodology

Thematic and sentiment analyses were used to analyse the qualitative comments received in the free text response box of both the service user and service clinician surveys<sup>\*\*</sup>.<sup>28,29</sup> The analyses were carried out in NVivo® 11. Sentiment analysis is an auto-coding function in NVivo, all of the results of the auto-coding were checked and corrected manually. Sentiment analysis has limitations in qualitative research, which is why it was intended as a supplement to the more extensive thematic analysis and to provide an overview of the emotional tone of the comments.

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. A single submitted comment with multiple elements was coded as both positive and negative when appropriate. All qualitative comments were coded and then an iterative process of theme development and refinement took place. Only one researcher was involved in the analysis process.

### Findings

Qualitative free text comments were received from service clinician surveys across seven health boards and from service user (patient/carer) surveys across eight health boards. In total, 131 service user surveys (107 from paediatric and 24 from adult service users) and 43 service clinician surveys (40 from paediatric and three from adult neurologists) containing qualitative data were included in the analyses. A breakdown of the number of qualitative responses by user type and NHS site can be seen in *Table 7*.

*Table 7: Qualitative responses by user type and NHS site*

NHS site	Qualitative comments from service user surveys <sup>a</sup>		Qualitative comments from service clinician surveys <sup>b</sup>	
	Parent/carers of paediatric patients	Adult patients/carers	Paediatric neurologists	Adult neurologists
NHS GGC	42	9	11	-
NHS Lothian	26	8	11	1
NHS Grampian	16	7	3	2

<sup>\*\*</sup> Free text responses analysed for this were collected as part of the patient/carer and service clinician surveys. A data cut-off point beginning from October 2020 until 4<sup>th</sup> May 2021 was selected for this analyses.

NHS Tayside	8	-	7	-
NHS Ayrshire & Arran	2	-	3	-
NHS Forth Valley	3	-	2	-
NHS Highland	6	-	-	-
NHS Lanarkshire	4	-	3	-
<b>Total</b>	<b>107</b>	<b>24</b>	<b>40</b>	<b>3</b>
<b>Grand total</b>	<b>131</b>		<b>43</b>	

<sup>a</sup> The qualitative comments were received in only around third of the total service user survey responses (n=421; 359 paediatric and 62 adult service users)

<sup>b</sup> The qualitative comments were received in only around fifth of the total service clinician survey responses (n=233; 219 paediatric and 14 adult neurologists)

## Thematic analysis

Clinicians', patients' and carers' experiences were grouped under two overarching themes: benefits and challenges. Under each overarching theme, a set of sub-themes are described.

### Benefits

#### A useful tool

*“Excellent system. saves time, money for NHS and stress. Ditto for families.” (clinician 24)*

The clinicians were highly positive about vCreate Neuro and the value of the tool was a strong theme in clinicians' comments. Clinicians found it efficient and easy to use and considered it beneficial for services, patients and carers. Being able to view patient/carer responses to a fixed set of questions alongside the video was valued by clinicians because it aided their interpretation of the video. Clinicians indicated that it is difficult for carers to describe symptoms over the phone or in a clinic appointment and carers found the ability to submit a video a relief given how challenging it can be for them to describe a seizure like event. vCreate Neuro provides a tool that the carers described as a quick and direct way to get a video to a clinician for review.

Views on the ease of using vCreate Neuro were more variable amongst patients and carers than clinicians, with some finding the tool “very easy to use” (Patient/carer 7) and others struggling with technical issues (described in detail under the ‘challenges’ theme).

#### Rapid remote review and diagnosis

*“I viewed 4 videos of this young infant in a district hospital taken at home and at the hospital. The videos showed a variety of seizure types. This allowed me to discuss a plan of investigation and treatment with the local paediatrician. The videos allowed me to say that this is a very serious condition. (Clinician 2)”*

Clinicians described a key benefit of receiving videos via vCreate Neuro as the facilitation of rapid clinical review, particularly of new referrals with unknown diagnoses. vCreate Neuro

enabled the provision of remote expert review of cases, and the facilitation of telemedical review for clinicians in remote and rural settings, which was considered extremely valuable. The facilitation of remote review enables the rapid identification of urgent cases and subsequent investigation and treatment.

For patients and carers, vCreate Neuro made remote review (especially while waiting to be seen for a clinic appointment) more beneficial. Patients and carers thought that submitting videos via vCreate Neuro led to a speedier review of their case by clinicians and provided a standardised way to get videos reviewed quickly outside of fixed appointments:

*“When you have something to show your child's consultants that is very important that can't be sent through normal email and your child needs to be seen, but can't due to COVID-19 or no appointments available. Having using this service for first time today I think it is vital that we can continue to use this service for all family's.” (Patient/carer 3)*

#### Time and resources

*“Offered second opinion on videos of events occurring from sleep in a child with epilepsy. The events were non-epileptic parasomnias. The video therefore saved a clinic review, prevented an ambulatory EEG and helped ensure the child did not have anti seizure medication increased.” (Clinician 7)*

Clinicians' comments stated that, a key benefit of video sharing via vCreate Neuro was saving time and resources for the NHS by identifying non-epileptic cases or events. They described the avoidance of unnecessary:

- visits and clinical contacts,
- investigations, such as EEG,
- treatment, in particular increases in medication,
- multi-disciplinary reviews.

#### Unnecessary travel and stress

*“What a excellent tool. In the past I have struggled to explain my daughters symptoms over the phone. Being able to upload a video so her neurologist can see it first hand is a huge benefit. Saved us both time, an extra appointment and it gave me peace of mind the same day I uploaded the video!” (Patient/carer 4)*

Clinicians, patients, and carers highlighted that the review of videos sent via vCreate Neuro provided reassurance for patients and carers quickly, especially in instances of non-epileptic events. Some carers described travel for appointments as stressful and they believed that of the use of vCreate Neuro reduced the need for travel. For some carers this was especially important because of long-distance travel to specialist clinics. One reason for this described reduction was that vCreate Neuro improved the identification of cases where clinical input from neurological services was unnecessary, or non-urgent. Reduction in travel was valued

by the carers of children with a disability, and people with mobility problems, particularly in the context of the COVID-19 pandemic.

## Challenges

Patients and carers faced challenges using vCreate Neuro which are described under a series of sub-headings below. Clinicians described very few challenges, noting the upload of unhelpful material, such as photographs and post-event videos, and slow video buffering.

### Technical issues

A strong theme for patients and carers was the experience of technical issues and difficulty accessing vCreate Neuro, although some patients and carers did describe vCreate Neuro as “quick and easy” to use (Patient/carer 1). The main technical issues experienced are listed in *Table 11* below. Patients and carers noted, issues related to accessing the tool, slow uploads leading to being timed out, difficulties uploading files or doing so from certain devices, and difficulties transferring files from one device to another for upload.

*Table 8: Technical issues experienced by patients and carers and illustrative quotes*

Technical issue	Illustrative quote
Setting up vCreate Neuro	<i>We spent 2 1/2 hours trying to work out how to use the software. We were unable to download the vcreate app onto android or upload the videos from phones to an ipad. We found it very frustrating and that we were unable to do this. (Patient/carer 62)</i>
Slow upload leading to timing out	<i>I have a terrible time with this as the system kept timing me out while I was uploading the video, which was around 500mb. I ended up cropping it and did eventually get it to go. This is not much use for people with poor internet connections i.e. where you can't get fibre. (Patient/carer 113)</i>
Difficult to upload multiple videos	<i>Yes, i am uploading new videos one after the other just now but when I upload the next video the previous video is being uploaded I now have more than one of the same video which is frustrating and also the last video I tried to upload said it was successful but when I went to my dashboard it has not uploaded. (Patient/carer 41)</i>
Transfer across hardware	<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. (Patient/carer 63)</i>
Logging in	<i>Doesn't always let me log in but easy to use once logged in. (Patient/carer 40)</i>

Cannot upload a file	<i>This is the first time our son has had two seizures in one day. we are very unsettled by this. We managed two different video recordings. second one cannot be uploaded the message "Sorry, this file type is not allowed." results when trying to upload. (Patient/carer 117)</i>
Inconsistent or temperamental	<i>I don't understand how sometimes I upload and get no acknowledgement and then other times I do. (Patient/carer 76)</i>

## Accessibility

*"How could you do this video if you do not have an email address.. and no body to take the video .. if you live on your own" (Patient/carer 93)*

vCreate Neuro can be difficult for patients and carers to access. For people without high-speed internet connections, uploading videos was time-consuming and frustrating often requiring multiple attempts before success. On occasions, users were left uncertain as to whether the video had uploaded successfully.

For patients and carers that are less familiar with the use of computers and smart devices, or do not have easy access to an email address or internet, the tool was challenging to use. One patient highlighted that people who live alone may be unable to capture video of a suspected epileptic event. 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.

## Format of questions

*Some of the questions didn't really apply or didn't have the answer I wanted to put down. (Patient/carer 130)*

Patients and carers found the format of the questions and answers to be restrictive, and difficult to answer on some occasions. Not all the questions were applicable in their case. The fixed choice answers did not always offer the response that they wanted to give. For each video uploaded, a patient or carer must answer the same set of questions. When a patient or carer wanted to submit multiple videos at one time, they needed to answer the same set of questions on each occasion. This was frustrating for the users.

## Communication and relationship

*"Allowed me to reassure mother that the episode was of normal sleep behaviour in a child with epilepsy. Mother was anxious that the episode was a seizure. I was able to communicate with mother through vCreate messaging." (Clinician 9)*

Clinicians, patients, and carers described the positive impact of vCreate Neuro on communication and relationship building. vCreate Neuro provides a useful medium to communicate through video and written text quickly outside of clinic appointments, and this was often reassuring for all people involved. The COVID-19 pandemic has increased

restrictions on face-to-face meetings and clinicians, patients and carers mentioned the importance of the tool in the current climate:

*“This was fantastic for us. We would not have been able to meet in person due to covid restrictions but we really needed this appointment. Was far better than a standard phone call or emailing. So glad we were able to do this.” (Patient/carer 111)*

The submission of videos via vCreate Neuro can also feel “impersonal” (Patient/carer 48) and one carer expressed a concern that the review of videos would not give a clear idea to clinicians about what was happening to her child and that “My daughter needs [to be] seen” (Patient/carer 39). This suggests that some patients and carers may be concerned that vCreate Neuro may replace some face-to-face appointments, rather than be used as an adjunct to them.

### Improvement suggestions

Patients and carers suggested multiple improvements to the tool, which are presented alongside illustrative quotes in *Table 12* below. Suggested improvements included the facility to upload multiple videos at one time and the ability to answer one set of questions for a similar set of videos. Patients and carers would value a facility to answer individual questions with a free text response, including the option of ‘not applicable’ responses; the current format lacked flexibility. Users would also appreciate the ability to write a longer free text explanation, to capture all context and background. The ability to review and edit submissions before upload was also requested.

The current system leaves some patients and carers uncertain about when and how their videos will be reviewed and how they are going to receive feedback from clinicians. Patients and carers suggested that a consistent approach to feedback and a standardised message with information about what they can expect would be helpful.

*Table 9: Suggestions for improvements to vCreate Neuro*

Suggestions for improvements – Patients and carers	
Upload multiple videos at one time	<i>Love this facility. However, it would be good to upload multiple video clips for the one form, rather than complete the same form for each video clip especially when related to the one/similar episodes of activity/behaviour. (Patient/carer 8)</i>
Offer a consistent form of feedback	<i>We are also a little unsure if the medical team actually received our uploads and what they do with it. Last week we uploaded lots of videos but we haven't heard back. Not sure how it works and leaves you as a customer little in the unknown of what is happening next. (Patient/carer 131)</i>
Add a free text comment box with large word limit	<i>I wish there was more space to write comments. I have a chronology I would like to share with my clinician but unsure if it would</i>

	<i>format OK if I copy and paste into the comment box or if there is a word limit. (Patient/carer 127)</i>
Provide a not applicable option for questions/free text box	<i>Some questions are not applicable so would be good to have that option to select. (Patient/carer 124)</i>
Enable editing of submissions	<i>It would be better to be able to scroll/review and edit additional comments section. No way to edit without deleting it all (Patient/carer 125)</i>
Make upload “button” clearer	<i>...the upload page could be a bit clearer. Step one should advise to 'click here to choose your file' or something like. (Patient/carer 102)</i>

Clinicians made very few suggestions for improvements to the service. They did note that patients and carers should be able to upload multiple videos at one time and that it seemed burdensome to have to answer the same set of questions for each video in a set. A clinician described a carer struggling to set up an account on vCreate Neuro:

*Only difficulty arose with parent losing the original email contact. I then couldn't re-invite them as email was already in use. They had to set up a new email account so that I could resend an invitation - which was all a bit of a rigmarole. (Clinician 19)*

One clinician requested the facility to directly download videos, without the assistance of an administrator. One clinician requested adding the patient's name and date to the note field.

### Sentiment analysis

Sentiment analysis revealed that 59% of clinician’s comments were positive in tone, 18% were neutral and 23% were negative. Service users’ tone was more balanced between positive (44%) and negative (53%) and just 3% of their comments were neutral. The full results of the sentiment analysis can be seen in *Table 8* and *Table 9*. As shown in the thematic analysis, both groups were positive about the current and potential usefulness of vCreate Neuro as a tool for diagnosis. Compared with clinicians, patients and carers described many more technical issues and challenges and made more suggestions for improvements. These experiences were reflected in the sentiment analysis with just 23% of clinicians’ comments displaying a negative tone and 53% of patients and carers’ comments expressing a negative tone.

*Table 10: Results of clinical sentiment analysis*

Clinicians' views	
Sentiment	Percentage of comments
Positive	59%
Neutral	18%
Negative	23%



Table 11: Results of patient and carer sentiment analysis

Patient and carer views	
Sentiment	Percentage of comments
Positive	44%
Neutral	3%
Negative	53%

A group of clinicians in the NHS GGC and NHS Lothian sites were involved in the expansion of vCreate Neuro across Scotland. A separate sentiment analysis was conducted that included only those comments made by clinicians within NHS GGC and NHS Lothian (23 comments), and found a higher proportion of positive comments and a lower proportion of negative and neutral comments (see Table 10). 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 appears to be the reason for a higher proportion of negative comments from those boards.

Table 12: Clinicians' views in NHS GGC and NHS Lothian Health Boards

Sentiment	Percentage of comments
Positive	87%
Neutral	4%
Negative	9%

## Summary

The key points from the qualitative analyses were as follows:

- vCreate Neuro is a valued and useful service for clinicians, patients, and carers. Users think that it saves time and resources for the NHS, patients, and carers along with having a positive impact on the relationship between clinicians, carers and patients. One carer shared their concern around vCreate Neuro replacing face-to face appointments rather than be used as an adjunct to them.
- Clinicians found vCreate Neuro particularly useful for diagnoses and identifying cases for which urgent treatment or investigation is required. By identifying non-epileptic events, clinicians suggest that it can prevent unnecessary investigations, treatment and travel; and provide rapid reassurance for patients and carers, especially in the case of those who live in a remote or rural setting.

- Patients and carers 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. People with lower levels of IT literacy may need assistance to use vCreate Neuro.
- Patients and carers submitted more negative free text comments than clinicians (44% and 23% respectively). A number of improvements were suggested by vCreate Neuro service users including the facility to upload multiple videos, receiving a consistent form of feedback, the facility to leave longer free text responses, a 'not applicable' response option, the ability to edit submissions and a clearer method of uploading videos.

## Economic analysis

An economic analysis was undertaken to quantify the estimated resource utilisation associated with delivering care to patients with epilepsy and other neurological disorders. The purpose of the analysis is to illustrate whether using vCreate Neuro as an option within the existing pathway may provide good value for money for NHSScotland; particularly in terms of resource utilisation and opportunity cost. 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.

### Assessment methods

The costing analyses only include data obtained from the clinician surveys in Scottish paediatric centres, specifically clinicians' responses to three resource-specific questions from the initial service clinician survey. They were as follows:

- 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 episode (videos and data uploaded on this occasion) and respond to the patient/carer?
- (See questions 9, 10 and 11 in service clinician questionnaire in *Appendix 4* for further details).

### Avoided resource use

Based on the responses to the initial service clinician survey, it is expected that asynchronous platforms such as vCreate Neuro will lead to fewer in-person appointments (visits) and a reduction in the requirement for diagnostic tests.

A clinician is 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 assumed that if a patient uploaded multiple videos in close succession (presumably relating to the same event), the clinician only completed one survey.

A summary of avoided resource use as indicated by 219 completed service clinician surveys are shown in *Table 13* below.

Table 13: Avoided resource use indicated in paediatric service clinician surveys by health board (n=219)

NHS Health board	Prevented visits			Prevented diagnostics			
	Clinic or outpatient	Elective admission	Emergency admission	EEG	Inpatient EEG	MRI scan	CT scan
A&A	3	0	0	2	1	0	0
Forth Valley	1	0	0	1	0	0	0
GGC	34	3	3	22	2	2	0
Grampian	13	1	19	17	5	3	1
Highlands	0	0	0	0	0	0	0
Lanarkshire	13	0	1	4	1	0	0
Lothian	27	0	1	8	1	0	0
Tayside	1	0	0	3	0	0	0
<b>NHSScotland</b>	<b>92</b>	<b>4</b>	<b>24</b>	<b>57</b>	<b>10</b>	<b>5</b>	<b>1</b>

**Abbreviations:** A&A, Ayrshire and Aaron, GGC, Greater Glasgow and Clyde; EEG, electroencephalogram; MRI, magnetic resonance imaging; CT, computed tomography;

## Costs

Clinical time will be required to review and respond to the uploaded video(s). The average time in minutes spent by clinicians to review an uploaded episode and respond to the patient/carer was estimated based on responses to question 11 in the initial service clinician survey (see *Appendix 4*).

Costs included in the analysis were obtained from various sources, predominantly the ISD cost book for Scotland where available.<sup>31</sup> The cost of vCreate Neuro is marked as confidential. For this phase one analysis, only the cost of vCreate Neuro equivalent to the duration of data collection (8 months) has been considered. Additionally, the costs of the two adult centres (Lothian and 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 █%. These are shown in *Table 14*

Table 14: Costs

Unit	Cost	Source
Electroencephalography (EEG)	£259	ISD cost book, Scotland 2021, R046
Inpatient video EEG (VEEG)	£2,315	NHS England reference costs, 2020, AA81Z
Magnetic resonance imaging (MRI)	£191	ISD cost book, Scotland 2021, R120X
Computed tomography (CT) scan	£83	ISD cost book, Scotland 2021, R120X
In-hospital admission (average estimate based on 3–5 days of stay)	£3,107	NHS England reference costs, 2020, PR02 B-C
In-hospital admission (low estimate based on overnight stay)	£809	NHS England reference costs, 2020, PR02 B-C
Outpatient clinic appointment (Neurology)	£236	ISD cost book, Scotland 2021, R044X
vCreate costs (12 months)	██████	vCreateNeuro team
vCreate costs (12 months)(excluding adult centres)	██████	vCreateNeuro team (estimated)
vCreate costs (8 months) (excluding adult centres)	██████	Estimated (interim report)
Consultant (per hour)	£119	PSSRU, 2020 <sup>30</sup>
Consultant (per minute)	£2	PSSRU, 2020
Consultant (per episode)	£16	Calculated*

\* Cost of consultant time was calculated using the average duration of reviewing and responding to the paediatric patient-uploaded video(s) as indicated by the clinicians and the cost per minute of consultant time. The average duration of time was 8 minutes per episode with a standard deviation of 6 minutes

## Results

Results were estimated at a national level based on the survey sample and scaled up using the number of paediatric patients who have used vCreate Neuro. It should be noted that since all health boards with paediatric neurology services in Scotland were taking part during this period, patient numbers are likely to be representative of those in routine practice in the same time period.

In the 8 months of phase one data collection, 1,171 paediatric patients were invited to register for vCreate Neuro and 1,033 (88%) uploaded data (3,541 videos, an average of three videos per patient). It was assumed that all videos uploaded per patient related to the

same event. Estimated numbers of avoided resource use in those who uploaded videos are presented in *Table 15* below.

*Table 15: Estimated number of resources avoided*

Resources avoided	Number (n=219)	%	Estimated number of resources avoided (n=1033)
Outpatient clinic appointments	92	42.01%	434
Inpatient admission	28	12.79%	132
Electroencephalography (EEG)	57	26.03%	269
Inpatient video EEG (VEEG)	10	4.57%	47
Magnetic resonance imaging (MRI)	5	2.28%	24
Computed tomography (CT) scan	1	0.46%	5

Gross resource savings associated with avoided resource use due to using vCreate Neuro are presented in *Table 16* below.

Base-case results show that use of vCreate Neuro generated gross resource savings in excess of £145,000 when using available survey data, which if scaled up to include potential users nationally equates to £696,339. Net savings were estimated by subtracting the estimated cost of consultant time and vCreate Neuro software.

*Table 16: Estimated cost savings*

Resources avoided (clinicians' survey paediatrics)	Cost (n=219)	Estimated cost savings (n=1033)
Outpatient clinic appointments	£21,689	£102,307
Inpatient admission	£87,010	£410,415
Electroencephalography (EEG)	£14,739	£69,521
Inpatient video EEG (VEEG)	£23,149	£109,189
Magnetic resonance imaging (MRI)	£957	£4,516
Computed tomography (CT) scan	£83	£391
<b>Total savings (gross)</b>	<b>£147,627</b>	<b>£696,339</b>
Less cost of consultant time	£3,509	£8,346
Less cost of vCreate software (8 months)	████████	████████
<b>Net savings</b>	████████	████████

## Deterministic sensitivity analysis

Five scenario analyses were carried out to explore the sensitivity around the cost savings (Table 17). The results shows that the cost of in-patient admission is a key driver of cost savings, as is the exclusion of NHS Grampian clinicians' responses - where vCreate Neuro in NHS Grampian help avoid 20 of the 28 in-patient admissions reported to have been avoided in total (see Table 13 above). The cost of consultant time estimated to review the uploaded videos was also a driver of cost savings.

Table 17: Scenario analyses

No.	Scenario	Base case	Total savings (gross) (n=219)	Net savings (n=219)	Difference in net savings
0	Base case	-	£147,627	£ [REDACTED]	-
1	Cost of in-patient stay avoided for 1 night	Cost of in-patient stay avoided for 3 to 5 days (average duration)	£83,278	£ [REDACTED]	-£64,348
2	Cost of consultant time based on number videos: 8 minute per video	Cost of consultant time based on number of patients who uploaded videos: 8 minutes per patient	£147,627	£ [REDACTED]	-£53,234
3	Scenario 1 + 2	As above	£83,278	-£ [REDACTED]	-£117,582
4	Excluding GGC and Lothian clinicians' responses	All clinicians' responses included	£96,408	£ [REDACTED]	-£36,149
5	Excluding Grampian clinicians' responses	All clinicians' responses included	£65,785	£ [REDACTED]	-£74,346

## Summary

Summary points from the economic analyses are as follows:

- Base case results demonstrated that using vCreate Neuro as an option 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 gross savings in excess of £145,000 which if scaled up nationally to include all service users equates to around £696,000. Substantial net resource savings remain after subtracting the cost of consultant time and cost of vCreate software.

- Scenario analyses show that the base case result is sensitive to the finding that the use of vCreate Neuro reduces inpatient admissions and the use of diagnostic tests. Costs of in-patient admissions and the cost of consultant time estimated to review the uploaded videos are also important drivers. If scenarios were to combine and occur simultaneously, then the results of the analyses should be considered less robust.



## 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 in the existing literature, and the analyses (quantitative, qualitative and economic) undertaken to inform this phase one report. They are as follows:

- Quality assessment of studies included in the literature review was not undertaken. The findings presented here may be biased in favour of HVRs in diagnosing PSLE.
- 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.
- The results from the adult service user surveys and adult clinician surveys should be interpreted with caution due to the small number of responses.
- 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 multi-faceted term with different applications in a care pathway.
- Individuals could upload multiple videos and respond to the surveys 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.
- Survey data was generated by patients who used vCreate Neuro. No information was collected from people who did not use the technology and this creates a risk of non-responder bias in favour of vCreate Neuro.
- Qualitative analysis was based on one free text response box that may restrict responders to convey the richness and depth of their experience of vCreate Neuro. Recruitment is underway to hold focus groups and interviews with patients/carers and clinical staff, the findings of which will be included in the final vCreate Neuro report.
- 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.<sup>32</sup> 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). There were no data from NHS Highland, and NHS Ayrshire and Arran and NHS Forth Valley constitute only a small proportion of the available data (2.7% and 1.4% respectively).

- 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 – 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. Moreover, we have not been able to assess the impact of using this technology on health inequalities as it is likely that social deprivation coupled with other issues such as low digital literacy or poor access to internet or smartphone technology could increase health inequalities.

## Conclusion

Qualitative and quantitative analyses found that vCreate Neuro offers some value for delivering care to people (adults and children) with epilepsy and other neurological disorders. Economic analyses indicated that the use of vCreate Neuro can lead to hospital resource savings through the avoidance of unnecessary clinical visits and investigations.

No direct published evidence was identified specifically relating to the use of an asynchronous video-recording service like vCreate Neuro to diagnose and treat epilepsy patients. Available literature indicates that HVRs of seizures can be of diagnostic value in epilepsy diagnosis and management as they are low cost, time-saving and relatively effective when compared to witness description. HVRs may have particularly high clinical value if used by epileptologists in distinguishing epileptic and non-epileptic seizures, and this is a function vCreate Neuro facilitates.

Further work is underway to address some of the limitations identified in this report. For example, SHTG is conducting focus groups and interviews to gather in-depth qualitative data and explore using routinely collected administrative data to strengthen the quantitative and economic analysis. The final report for vCreate Neuro is due to be published in Spring 2022.

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- Dr. Neil Patel, Consultant Neonatologist - NHS Greater Glasgow & Clyde, Clinical Innovation Lead - West of Scotland Innovation Hub
- Mr. Craig Ramsay, Director, Health Services Research Unit, University of Aberdeen
- Dr. Jay Shetty, Consultant Paediatric Neurologist, NHS Lothian
- Dr Elma M Stephen, Consultant Paediatric Neurologist, NHS Grampian
- Dr. Ian Thompson, Primary Care Clinical Lead in Digital Health and Care Directorate, Scottish Government
- Dr Killian Welch, Consultant Neuropsychiatrist, NHS Lothian
- Dr Joseph Wherton, Senior Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford

### **Healthcare Improvement Scotland (HIS) development team**

- Neil Anand, Senior Health Economist
- Evan Campbell, Lead Health Services Researcher
- Naomi Fearn, Health Services Researcher
- Maria Dimitrova, Senior Health Economist
- James Stewart, Public Involvement Advisor
- Juliet Brown, Health Information Specialist
- Jess Kandulu, Programme Manager
- Ed Clifton, Scottish Health Technologies Group- Unit Head

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## Appendices

### Appendix 1: Search terms and search strategy

#### Search terms suggested by requester:

Epilepsy/Seizures/Neurology, Smartphone/Cell phone/Mobile, Video, Asynchronous, Remote, Digital, Virtual, Diagnosis/Misdiagnosis, Treatment, Telemedicine (tele-medicine)/Telecare, Evaluation/Assessment, Benefits, Healthcare resource savings, Quality of life, Access, Patient experience/attitudes, Staff experience/attitudes

#### Medline

Database: Ovid MEDLINE(R) ALL <1946 to August 06, 2021> (Similar strategies used for EmBase)

Search Strategy:

- 
- 1 \*Epilepsy, Frontal Lobe/ or \*Myoclonic Epilepsy, Juvenile/ or \*Epilepsy, Generalized/ or \*Epilepsy, Post-Traumatic/ or \*Epilepsy, Rolandic/ or \*Epilepsy, Absence/ or \*Epilepsy, Partial, Motor/ or \*Epilepsy, Partial, Sensory/ or \*Epilepsy, Reflex/ or exp \*Epilepsy/ or \*Epilepsy, Temporal Lobe/ or \*Drug Resistant Epilepsy/ or epilepsy.mp. or \*Epilepsy, Tonic-Clonic/ or \*Epilepsy, Complex Partial/ (153305)
  - 2 epilep\$.kw. (25625)
  - 3 (asynchronous adj video adj recording).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (0)
  - 4 asynchronous video recording.mp. (0)
  - 5 EEG.mp. or \*Electroencephalography/ (108855)
  - 6 \*Brain Mapping/ (31309)
  - 7 1 or 2 (153735)
  - 8 3 or 4 or 5 or 6 (136178)
  - 9 7 and 8 (26197)
  - 10 limit 9 to (english language and yr="2011 -Current") (9727)
  - 11 ECONOMICS/ (27356)
  - 12 "Costs and Cost Analysis"/ (49836)
  - 13 Cost Allocation/ (2008)
  - 14 Cost-Benefit Analysis/ (85733)
  - 15 Cost Control/ (21598)
  - 16 Cost Savings/ (12295)
  - 17 Cost of Illness/ (29246)
  - 18 Cost Sharing/ (2618)
  - 19 "Deductibles and Coinsurance"/ (1788)
  - 20 Medical Savings Accounts/ (543)
  - 21 Health Care Costs/ (41789)



- 22 Direct Service Costs/ (1204)
- 23 Drug Costs/ (16727)
- 24 Employer Health Costs/ (1094)
- 25 Hospital Costs/ (11560)
- 26 Health Expenditures/ (21754)
- 27 Capital Expenditures/ (1997)
- 28 Value of Life/ (5756)
- 29 exp Economics, Hospital/ (25244)
- 30 exp Economics, Medical/ (14275)
- 31 Economics, Nursing/ (4005)
- 32 Economics, Pharmaceutical/ (3009)
- 33 exp "Fees and Charges"/ (30828)
- 34 exp BUDGETS/ (13869)
- 35 (low adj cost).mp. (67636)
- 36 (high adj cost).mp. (16337)
- 37 (health?care adj cost\$).mp. (13430)
- 38 (fiscal or funding or financial or finance).tw. (163674)
- 39 (cost adj estimate\$).mp. (2456)
- 40 (cost adj variable).mp. (47)
- 41 (unit adj cost\$).mp. (2745)
- 42 (economic\$ or pharmaco-economic\$ or price\$ or pricing).tw. (337438)
- 43 or/11-42 (799951)
- 44 10 and 43 (126)

\*\*\*\*\*

## Cochrane

Search Name:

Date Run: 09/08/2021 16:16:24

Comment:

ID	Search	Hits
#1	MeSH descriptor: [Epilepsy] explode all trees	2454
#2	MeSH descriptor: [Epileptic Syndromes] explode all trees	417
#3	MeSH descriptor: [Epilepsy, Temporal Lobe] explode all trees	176
#4	epilepsy	8573
#5	epileptic	2176
#6	#1 or #2 or #3 or #4 or #5	9191
#7	asynchronous recording	20
#8	MeSH descriptor: [Video Recording] explode all trees	2674
#9	#7 or #8	2690
#10	#6 and #9	28

## Appendix 2: Survey questions used for quantitative analysis

### 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 i.e. 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 i.e. 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 3: Quantitative analysis

Table A Demographics from responses to the paediatric parent or carer survey

Variable	Result
Age, n=310 (missing data n=1, reported aged of parent as 3 years old, n=1)	Mean 37.4 SD 8.7
Gender, n=312	Female n=275, male n=36, prefer not to say n=1
Relationship to patient, n=307 (missing data n=5)	Parent n=296, 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=1, grandparent n=2, great aunt n=1, patient n=43 (reported ages of responders was 3, 14, 15, 43 years), sibling n=1, 'speciality doctor of ward where she's admitted' n=1, teacher n=1)

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

Mode of transport that was avoided	Count*
<b>Public transport</b>	
Bus	25
Train	30
Ferry	2
Air travel	2
<b>Private forms of transport</b>	
Car	241
Taxi	10
Walk	5
Patient transportation provided by hospital	3

\*total is greater than number of responses (312) due to some responders stating that they would have used more than one type of transport.

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

N=182*	More connected	Neither more nor less	Less connected	Don't know/ not sure
n	117 (missing distance data n=2)	41	9	13
Distance travelled (miles)	Med: 20 IQR: 10, 36 Mean: 36.0 SD: 76.3	Med: 20 IQR: 10, 42 Mean: 34.9 SD: 39.6	Med: 50 IQR: 18, 60 Mean 41.8 SD 27.8	Med: 18, IQR: 3, 40 Mean 27.8 SD 33.3
Kolmogorov-Smirnov test <sup>^</sup>	p<0.001	p=0.020	p=0.9137	p=0.5607
Kruskal-Wallis test	p=0.42			

\*n=6 stated they has not used neurology services before despite saying that they were already known to the system, these were removed.

<sup>^</sup>p<0.05 indicates that data were not normally distributed.

## Appendix 4: Old survey questions used for qualitative and economic analysis

### Service clinician questionnaire

1. **Did this video upload relate to a new patient referral OR an existing patient in the service?**  
New referral  
Existing patient in service  
Re-referral of patient previously discharged from service  
Other (free text)
2. **What was your experience of using the vCreateNeuro service?**  
1-10 scale (1 very difficult, 10 very easy)
3. **How would you rate the quality of the uploaded video**  
1-10 scale (1 poor quality – could not be interpreted, 10 high quality – easy to interpret)
4. **Does using the service affect your connection with the patient and their carers?**  
1-10 scale (1 much LESS connected, 10 much MORE connected)
5. **How does the service affect the quality of care provided?**  
1-10 scale (1 REDUCES quality of care, 10 IMPROVES quality of care)
6. **Was the uploaded information (video and associated data) useful for making a DIAGNOSIS?**  
1-10 scale (1 not useful at all, 10 very useful)
7. **Was the uploaded information (video and associated data) useful for choosing a THERAPY (or no therapy)?**  
1-10 scale (1 not useful at all, 10 very useful)
8. **How did using the service affect the time to reach a diagnosis and treat this patient?**  
1-10 scale (1 longer time than usual, 10 shorter time than usual)
9. **Did the uploaded data prevent the need for any of these additional investigations?**  
CT scan  
MRI scan  
EEG  
Inpatient video EEG  
No  
Other (free text)
10. **Did using the video service on this occasion prevent an in-person review?**  
Prevented clinic or outpatient review  
Prevented elective admission  
Prevented emergency admission  
Prevented inter-hospital transfer  
No  
Other (free text)
11. **How many minutes did you take to review the uploaded episode (videos and data uploaded on this occasion) and respond to the patient/carer?**  
Free text
12. **How would you rate your overall experience of this video upload service?**  
1-10 scale (1 not useful at all, 10 very useful)
13. **Do you have any other comments about the service**  
Free text

### Parent/Carer questionnaire

15. **What was your experience of using the vCreateNeuro service?**  
Scale 1-10 (1 very difficult to use, 10 very easy to use)
2. **By using this service today, how connected do you feel to the clinical team compared to the past?**  
Scale 1-10 (1 less connected, 10 more connected)
3. **How does vCreateNeuro service affect your quality of care?**  
Scale 1-10 (1 reduces quality of care, 10 improves quality of care)

4. **How does the vCreateNeuro service affect your access to the clinical team?**  
Scale 1-10 (1 reduces access, 10 improves access)
5. **Did using the video service on this occasion prevent a trip in person to the hospital or to the outpatient clinic?**  
Yes, we didn't have to go to the hospital or clinic  
No, we still had to go to the hospital or clinic  
Not sure
6. **What was your overall experience of the vCreateNeuro video upload service?**  
1-10 scale (1 not useful at all, 10 very useful)
7. **Do you have any other comments on the vCreateNeuro video service?**  
Free text