

Epilepsy Society
Service, Quality & Assurance Committee Meeting
Part 1 (meeting held in public)

AGENDA

26 FEBRUARY 2021 VIA REMOTE ZOOM MEETING

1. 1.00PM WELCOME AND INTRODUCTIONS
2. 1.02PM APOLOGIES
3. 1.05PM TRUSTEES DECLARATION OF INTEREST
4. 1.10PM APPROVAL OF MINUTES OF THE MEETING HELD ON 13 NOVEMBER 2020 AND MATTERS ARISING
5. 1.20PM ACTION REGISTER (ALL)
6. 1.30PM CARE SERVICES UPDATE –
JONNY ANDERS-CANNON, DIRECTOR OF CARE SERVICES
7. 1.45PM MECHANISM FOR FAMILY ENGAGEMENT DISCUSSION –
CHAIR & NICOLA DAVIES
8. 2.00PM PRESENTATIONS:
 - 8.1 REFLECTIONS ON THE PAST YEAR –
JONNY ANDERS-CANNON & JOHN KEMBLE
 - 8.2 LOOKING FORWARD TO THE YEAR AHEAD –
REBECCA SALVATIERRA
9. 2.30PM COMPLIMENTS, COMMENTS AND COMPLAINTS - CARL CHARLESWORTH
10. 2.40PM WRITTEN UPDATE FROM MEDICAL DIRECTOR – LEY SANDER
11. 2.50PM UPDATE FROM RESEARCH COMMITTEE - ANDREW GEORGE
12. 3.00PM AOB
13. 3.05PM CLOSE PART ONE

Distribution List:

Committee members: Deborah Wheeler Chairperson
Andrew George
James Hagan
Peter Worthington
Stephen Smith
Nicola Davies Co-opted Member

Other attendees: Clare Pelham Chief Executive
Jonny Anders-Cannon Director of Care Services
Ley Sander Medical Director
Rebecca Salvatierra Head of Care
Angela Alabi Company Secretary and Governance Manager

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| Epilepsy Society Service, Quality and Assurance Committee Meeting |
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**Minutes of a meeting of the Service Quality and Assurance Committee held via Zoom at 1.00 pm on
13 November 2020**

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|-----------------------|---------------------------|--|
| Present: | Deborah Wheeler (DW) | Trustee, Committee Chair |
| | Peter Worthington (PW) | Chairman, Board of Trustees |
| | Andrew George (AG) | Trustee |
| | Jim Hagan (JH) | Trustee |
| | Christopher Blue (CB) | Trustee |
| | Stephen Smith (SS) | Trustee |
| | Nicola Davies (ND) | Co-opted Member |
| | | |
| In attendance: | Clare Pelham (CP) | Chief Executive |
| | Jonny Anders-Cannon (JAC) | Director of Care Services |
| | Rachel Perowne (RP) | Director of Medical and People Services Development |
| | Ley Sander (LS) | Medical Director |
| | Rebecca Salvatierra (RS) | Head of Care |
| | Angela Alabi (AA) | Company Secretary |

*The meeting opened at 2pm
Deborah Wheeler in the Chair*

1. WELCOME AND INTRODUCTIONS

Deborah W welcomed everyone to the meeting.

2. APOLOGIES

There were no apologies. All members were in attendance.

3. TRUSTEES DECLARATION OF INTEREST

ND declared that her daughter is a beneficiary of the Society.

DW declared that her son is a beneficiary of the Society.

SS declared that he is a Senior Adviser to the Saudi Government.

4. APPROVAL OF MINUTES OF THE MEETING HELD ON 14 FEBRUARY 2020 AND MATTERS ARISING

Following a query regarding the Business Continuity Plan, CP advised that the Land and Estates Director has been tasked with developing a plan prior to his departure.

The minutes of the meeting held on 5 June 2020 were approved as an accurate record of the meeting.

5. ACTION REGISTERS

Members discussed the action registers noting that a number of items were on hold as a result of the pandemic.

RP agreed to provide an update on the latest statistics on TDM volumes showing any fluctuations, post meeting.

It was noted that the action regarding the second co-opted person had now been logged with LS.

Members noted the report.

6. CARE SERVICES UPDATE

Members received an update on Care Services from JAC. JAC reported that two staff members had recently tested positive with coronavirus. In addition, a person whom the Society supports was found to be asymptomatic following a test.

JAC further explained that lessons learned from Wave 1 of the epidemic were being implemented in Wave 2. Furthermore, carers and those the Society supports are likely to be prioritized for receipt of the vaccine.

In response to a query regarding staffing it was noted that the Service is using less agency staff. Many of those who had moved from other sectors have stayed despite the opening up of their former industries.

RS provided a further update on agency usage. It was noted that for the previous month 79% of staff were permanent and 12% agency. This has been the lowest amount of agency usage in recent times. The Society had also reduced the number of agencies on its preferred supplier list from 10 to 5.

Members asked about staff wellbeing and whether there had been many episodes of PTSD. It was noted that morale was fairly stable however staff were feeling tired and weary.

DW asked whether staff have taken much annual leave and reiterated the importance of staff having a break from work for their wellbeing. JAC reported that staff were being encouraged to take leave.

Visiting Policy

JAC presented the Visiting Policy apologizing for the late circulation of the policy. Members discussed the policy extensively. It was noted that the handling of visits had to be done carefully to avoid the risk of regulatory sanctions. Members noted that the policy will be sent to the relevant regulators for comment following approval by the SQ&A.

Members asked about implementation, documentation and monitoring which did not appear to be included within the policy.

JAC agreed to append the risk assessment template to the policy as appendices.

ND pointed out that the booking system for visits needed to be improved and centralised and staff should be clear on expectations.

CP informed Members that the Society had received legal advice advising of one person visits. However, the Society was recommending two person visits where those individuals reside at the same address. Members agreed that it was reasonable to allow two person visits from the same household and approved the proposed approach to the implementation of the guidance.

Anonymised risk assessment to be appended to the policy

Booking system to enable visits to be checked

Policy to be sent to regulators named in guidance requiring that they respond.

Policy to be updated to include specific reference to the use of outside spaces.

Members noted the report.

7. PHARMACY CLOSURE

RP provided an update on the closure of the pharmacy. It was noted that following the Board's decision to close the onsite pharmacy it was officially closed on 30 October 2020. The move to pharmacy services and support being provided by a combination of a commercial high street pharmacy, the local Primary Care Network, the CCG and both Bucks and UCLH NHS Trusts has meant that the Society has transferred governance responsibilities for the dispensing, advice and management of pharmacy services.

It was noted that despite a few glitches the transition had been relatively smooth.

Members noted the report.

8. WRITTEN UPDATE FROM MEDICAL DIRECTOR

LS presented his report. Members noted that Covid-19 had impacted the way in which medicine is being carried out with many clinical reviews taking place remotely via telephone or video calls. In addition patients are often reluctant to attend face-to-face appointments where these are offered.

LS reported that worse outcomes had been noted in epilepsy particularly in the presence of co-morbidities. According to the Office for National Statistics the 1st Wave of the pandemic had witnessed an increase in epilepsy related deaths. Trends observed and supported by the national data indicate that service changes in epilepsy care during the pandemic were detrimental.

Members noted that Covid-19 had also had an impact on the researchers' ability to do clinical research although they have been allowed to continue to analyse previously acquired data.

Members noted that the Therapeutic Drug Monitoring Unit has provided some recent data which it is hoped will be published.

Members suggested that mini abstracts be included in the list of Covid related publications from Chalfont.

LS to include mini abstracts in the lists of publications.

Members noted the report.

9. HEALTH AND SAFETY POLICY

CP advised that the policy was before the Committee as work in progress following a decision at the March Board that the policy should go to the relevant committees.

Members pointed out that references to training lacked clarity.

Members highlighted the absence of risk assessments and further advised on the need to have an understanding of the metrics used to measure how the Society is doing against HSE standards.

It was also suggested that Officers consider Directors' responsibility around monitoring changes in the understanding of safety.

Members noted the report.

10. Comfort Break

11. COMPLIMENTS, COMMENTS AND COMPLAINTS

CC presented his report. He pointed out that the Society had received a number of complaints during lockdown, which was felt to be partly due to the fact that the Society had also decided to be bolder in its messaging. It was noted that complaints had been received around the Supporter Acquisition Programme. It was further noted that as the campaign develops fewer complaints are being received.

Members thanked CC for a comprehensive and useful report.

Members noted the report.

12. RISK REGISTER UPDATE

Members discussed the risk register presented by JAC and RP. Members queried the extent to which the documented risks truly reflected the risks that are keeping directors awake at night pointing out that they did not appear to be the issues that had been discussed over the past 6 months.

RP advised that the closure of the pharmacy had caused many risks to be downgraded.

Members noted the risk registers.

13. AOB

Members thanked Care Services and the Medical Services team for their fantastic work during the pandemic.

14. DATE OF NEXT MEETING – 1PM FRIDAY 26 FEBRUARY 2021

There was no further business.

The meeting closed at 2.46pm

AGENDA ITEM NO: 6

Services, Quality & Assurance Committee
26 February 2021



Title: Care Services Update, Director of Care Services

To be presented by:

Jonny Anders-Cannon - Director of Care Services

Contact Details:

Jonny.anders-cannon@epilepsysociety.org.uk

Executive summary:

The Care Services update papers for Services Quality Assurance Committee are used as a method for updating Members on areas of quality, compliance and plans going forward. However, as we are all too well aware the focus of everything over the course of the last 10-12 months has been COVID related. Within the agenda for the February SQ&A Committee we have reflective presentations on the last year within care and positively looking ahead to our ambitions and challenges for the coming period.

This paper seeks to update Members on the current situation in Care Services in light of wave two of the pandemic. The Committee may recall that in November we offered an update on our contingencies and approach to the anticipated wave two. Since the last SQ&A meeting, staff and people we support have faced the most significant challenges yet in the COVID crisis and this paper serves as an update for Members on this area.

Key issues for discussion:

- Review and discussion of paper.

Sub Committee(s) where previously presented and the outcome:

Not applicable

Risk and Assurance:

- **How does this item link to the Society's strategic direction?**
To sustain high quality and safe operational delivery of Care Services.
- **How does this item either mitigate or provide assurance on the control of any of the risks detailed within the Risk Register?**
Provides overview of the key risks that have been faced by people supported in care services and for staff over period of the recent pandemic.

Action required by the committee

Service Quality Assurance Committee to note the report for discussion.

1. OVERVIEW OF WAVE TWO

In the November paper Committee Members were offered a briefing of contingencies that we have in place as we entered into wave two. The paper for the November SQ&A noted, *'The overall conclusion at this point is that wave two may in many ways be harder to manage than wave one with the conditions of the winter months, high infection rates and the patterns of pandemics where wave two tends to be more impactful than the first.'* This was more than a little prophetic with Care Services experiencing the full force of the variant strains from 29 December 2020 through to the last positive case, at the time of writing, on 7 February 2021.

The story since last SQ&A was one where over December there were limited transmissions and the situation was manageable until after Christmas. However, as we are all well aware, the new variant caused a sharp uptick in cases in the South East of the country, which meant that unfortunately we were forced into robust measures prior to Christmas, including no visitors on site and complying with lock down arrangements nationally.

For Care Services, from 29 December 2020 to 7 February 2021 there were in excess of 50 positive cases involving staff or people we support. Two people living at Chalfont and three members of staff were hospitalised during this time with COVID related illness, but thankfully in each case this was for a short period of time and they have all recovered to full health. A total of eleven people living at services had positive transmissions, although most people were fortunately asymptomatic. The most significant outbreaks were at the larger services of Russell and Micholls House which placed significant operational pressures given the sheer numbers of staff either having tested positive themselves or having to self-isolate because of track & trace or family members.

2. WAVE TWO STRATEGIES APPRAISAL

• Testing & surveillance

Once again, testing at the Society proved to be the differentiator. Whilst the numbers of positive cases far outstripped our experience in wave one, in the majority of cases people were asymptomatic and in many cases surprised to find out they had tested positive. The PCR testing hit phenomenal levels, where in some weeks up to 170 PCR tests were being carried out daily. From the beginning of the January we introduced the Lateral Flow Testing across the Society before staff commenced their shift and if a positive result was returned, they were removed and then undertook a PCR test.

We followed the same strategy and learning from wave one, where the instant we became aware of a positive result the staff member was informed and removed from the service to self-isolate. For people living in the houses we would then make use of Milton House for isolation to prevent further transmissions. Upon a positive result being found, SHO's, Matthias Koepp or Simona Balestrini would carry out mass swabbing of every member of staff in the affected flat or service and all of the people living in that location. Then repeated to give confidence and this was on top of the weekly surveillance.

From interactions we have had with other social care providers and feedback from managers forums it is clear that the testing that we had in place certainly enabled us to act with pace and deal with outbreaks, whereas other care homes suffered even higher outbreaks, sadly often with the loss of life. Our learning was that people in this wave tested as 'long positive', with some individuals continuing to test positively for over six weeks.

• Isolation area

In wave one, we made good use of the option of Gowers, but in this period Milton House was the isolation area for positive cases. The service proved to be fit for purpose and at the height of the transmissions a total of eight people were isolating at the house. This was probably the most precarious time for care because we were then at capacity. Had further transmissions occurred we did not have any

easy options other than to potentially convert a flat that already had a number of positive cases into a new isolation area. Fortunately, this scenario did not occur, but it was a high risk situation for a short period of time.

The key challenge with the isolation area was staffing. Russell House and Micholls had significant staff shortages with staff who were themselves in isolation, yet we needed at times to staff an entire 'new' service with a mix of people from different houses. Logistically this was exceptionally challenging. We also learned that during this wave, there was staff resistance to working at Milton House and a genuine fear of catching COVID-19. Only through persuasive leadership and assurances about PPE were staff prepared to work at Milton House with people who had tested positive.

- **PPE**

Basic personal protective equipment did not prove to be an issue at all during wave two and there was not a period of time at all where stocks of surgical masks, gloves or aprons were low on stock. This was positive and far improved from the experience of wave one where there were occasions where the Society was down to only two days stock remaining.

The higher grade of FFP3 masks offered reassurance and safety to staff. The 'fit to face' testing with the Learning and Development team proved invaluable for staff who would be working at Milton House. There was an unlikely negative element to PPE at Milton which caused anxiety and fear for staff at the idea of working with positive people at the service. Staff who were already nervous about working at the service came across Hazmat suits, hair nets, double gloves, FFP3 masks, goggles, visors and foot covers. Routinely they would don the entire suits or refuse to work in the service. The impact was that new staff entering the house were alarmed by the sight of people wearing what appeared to be nuclear grade protection! After detailed discussions staff relented to using the appropriate, but still safe kit.

- **Infection control**

Infection control procedures were largely very well adhered to during wave two. We learned that staff, weary of wearing masks for nearly a year every shift had to be reminded to keep them over both their nose and mouth. Some poor practices had to be addressed, for example, staff would militantly self-police themselves wearing masks when supporting people, only to then let them down when they were collectively together in a small office.

Cleaning routines proved to be positive and the Estates team supported 'fogging' where there were cases of larger outbreaks.

- **Food & provisions**

Food and provisions did not prove to be an issue at all during wave two. The panic buying across the nation did not occur and teams were able to readily obtain delivery slots.

- **Care and medical integration**

The partnership working between Care Services and Medical once again was excellent. A smooth system was in place for swabbing, communication and action. Regular meet ups between care and the medics supported changes to strategy, policy or implementation of new local tactics. Care Services are very grateful to the medical teams who worked exceptional hours to support people to stay safe.

- **Workforce & leadership**

Local leadership was even more critical in wave two. The workforce had looked on as the numbers of people who died from COVID-19 breached one hundred thousand and there was understandable fear from many colleagues. Yet staff performed with great bravery and professionalism, despite being weary from so many months working under difficult conditions. The most challenging element during the

second wave was a short period of time at Russell House with staff shortages and this was even more pronounced at Micholls House.

- **Family visits**

Preparation for the Christmas period had taken weeks of work, yet as we know, just days before the festive period there was rightly a change of direction from central Government due to the new variant. This meant that families were unable to visit during that time which of course was exceptionally difficult. We have not been able to have family visits during the course of January due to the high numbers of cases across the Chalfont site and the risks this would also pose to family visitors. However, we are delighted that outdoor and screen visits recommenced on Wednesday 17 February.

3. VACCINATIONS

Staff vaccinations

Vaccinations of staff commenced in December with Pfizer and have continued during the course of January, now more frequently with Astra Zeneca. The numbers of staff that have had the first jab is approaching 70%, it has been a significant logistical task to have mass vaccinations on site in collaboration with the local CCG teams.

Of course, we would hope to increase the numbers of those vaccinated; some people have not had the 28 days clearance between being tested positive, others have medical conditions and there are of course individuals who simply do not wish to have the vaccination. We have undertaken extensive information campaigns, leaflets and Zoom Q&A with Professors to ensure that people are making the most informed choice.

People we support

All but two people we support across Chalfont and Aylesbury have had their first dose of the vaccination. We hope to have the final two people vaccinated, who are only prevented because they too had tested positive and needed the 28 days clearance.

4. SUMMARY

It is difficult to imagine a more challenging set of circumstances that most people working in Care Services will experience in their career, or to measure the impact on people we support on their quality of life over the last year or indeed the anxiety felt by families unable to see their loved ones. Yet, with the hope of the vaccination and plunging transmission numbers we are now able to look at recovery and planning for the future. In wave two, support staff and local leaders once again stepped up to ensure that people stayed safe and Epilepsy Society should rightly be proud of the huge efforts of individuals and collective teams.

Jonny Anders-Cannon

Director of Care Services

19 February 2021

AGENDA ITEM NO: 9**Services, Quality & Assurance Committee****26th February 2021**

Title: Complaints, Compliments & Comments

To be presented by:

Carl Charlesworth

Channel Marketing Manager

Contact Details:

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carl.charlesworth@epilepsysociety.org.uk

Executive summary:

This is a summary of complaints, compliments and comments received through the central register held at <https://www.epilepsysociety.org.uk/comments-compliments-and-complaints>.

It provides a year on year record of the number of complaints, compliments and comments received through this register to provide a level of benchmarking.

Detailed analysis of types of complaint are being recorded to provide Management Board and relevant Board committees with information on trends or areas of activity that may require further investigation.

The next step is to implement learning from the analysis for presentation to Trustees.

An internal marketing programme has been launched to promote the complaints, compliments and comments policy with reminders added to the weekly round up and email reminders sent around to teams on a Bi-Weekly basis.

The Director of Care Services is developing a system to capture informal and verbal compliments for service provision. This will also include ensuring compliments are cascaded to the relevant person.

Serious complaints are decided by an evaluation from the Channel Marketing Manager based in their overall judgement. Any serious complaints will be passed to the CEO. We currently have not received any serious complaints to date.

Key Statistics since reporting began:

| | 2018 | 2019 | 2020 | 2021 | Benchmark |
|-----------------|------|------|------|------|-----------|
| Care complaints | 9 | 20 | 2 | 0 | 30 |
| All complaints | 25 | 42 | 45 | 1 | 60 |
| Compliments | 91 | 113 | 264 | 14 | 130 |
| Comments | 45 | 44 | 35 | 2 | 60 |

Key Statistics since last report (for October – January 2021):

- In total 18 complaints were received, 124 compliments and 10 enquiries (comments):
- Of the complaints (detailed in section 1.2)

Key issues for discussion:

- Review and discussion of paper.

Sub Committee(s) where previously presented and the outcome:
Management Board reviews this report on a monthly basis.

Risk and Assurance:

- How does this item link to the Society's strategic direction?

This paper supports the risk register for the organisation against compliance.

- How does this item either mitigate or provide assurance on the control of any of the risks detailed within the Risk Register?

The process addresses mitigation against the risks of harm to people and reputational risk.

Legal Issues: GDPR has been considered alongside confidentiality issues.

All complaints have been copied and pasted from our online complaints, compliments and comments form, social media comments and other documents which go to form the statistics. These are transferred directly into a working password protected spreadsheet on a confidential drive, and have not been doctored in any way to protect the user in terms of representing their views fully and accurately.

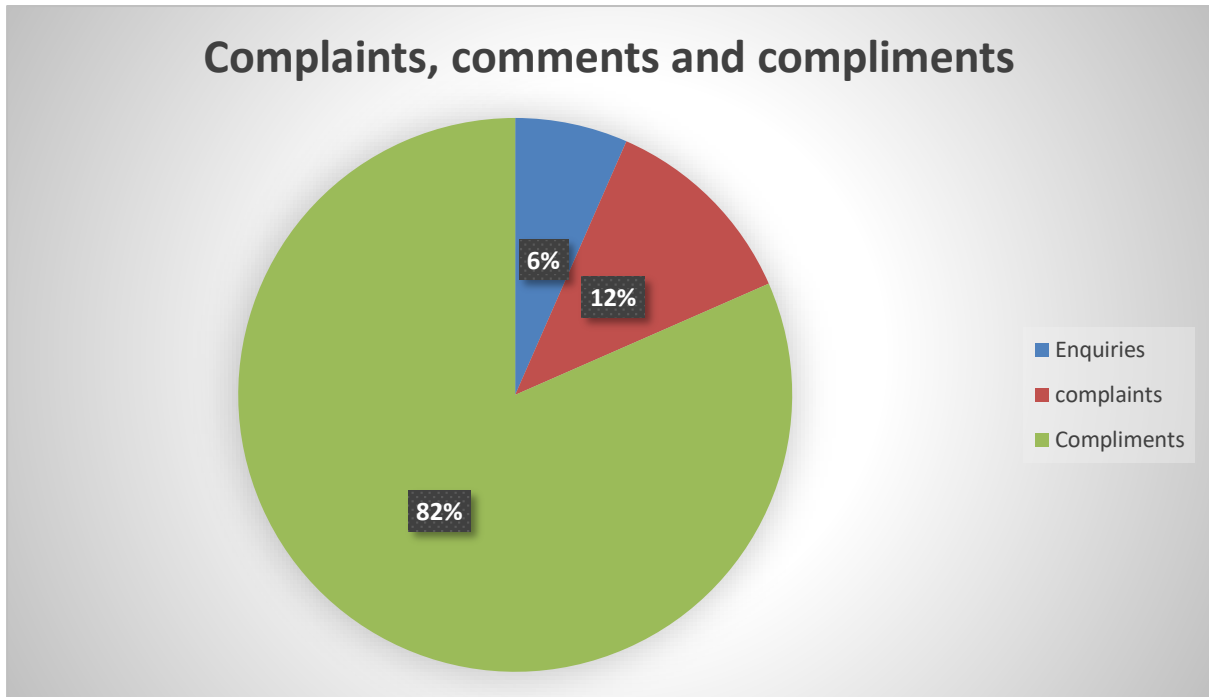
We are working with the Data Protection Officer about keeping details of individuals. Going forward closed complaints will be archived and made anonymous if necessary for GDPR (there will be no time limit on archiving).

Action required:

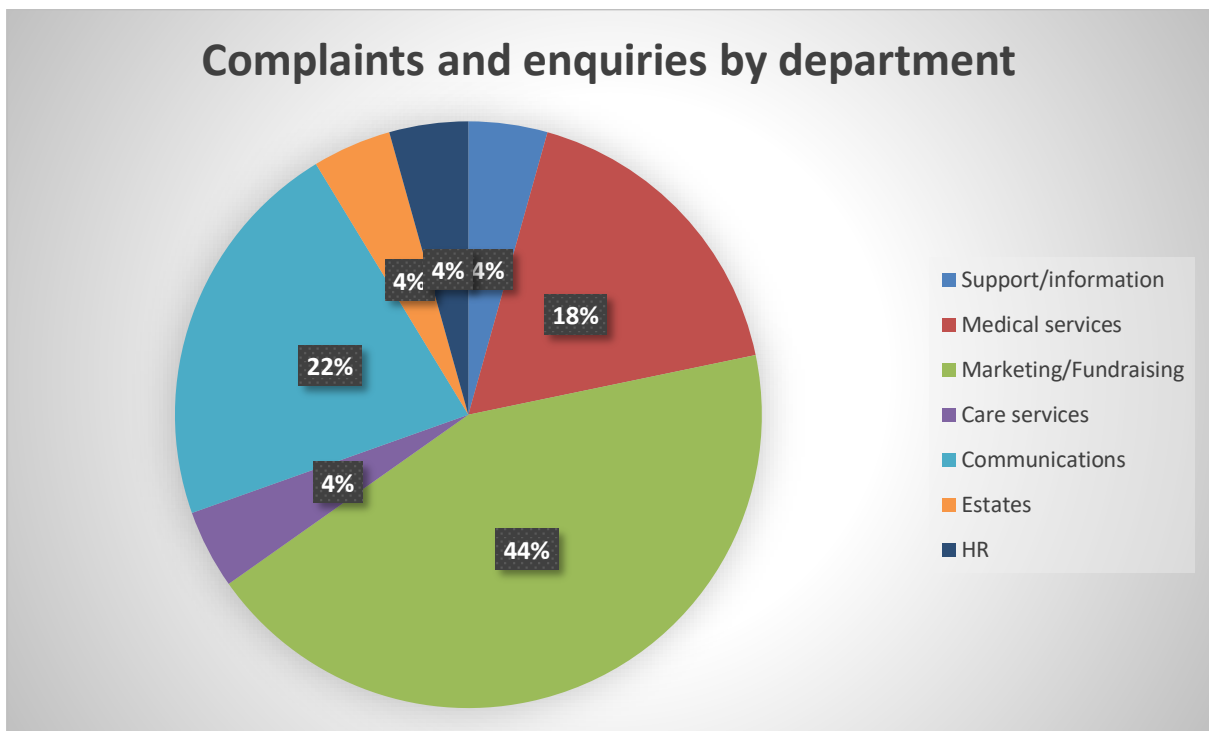
To note.

1. Key Statistics – October - January 2021

1.1 For October - January 2021 the key statistics graph shows a breakdown between complaints, compliments and comments.



Below is an analysis of the type of complaints received throughout the year (eg. in which area of our business).



For completeness all complaints which are being forwarded to UCLH will be added to the complaints, compliments and comments log, but will not be added to the dashboard analytics on this report.

1.2 Support Acquisition Programme

The Support Acquisition Programme was launched in September 2020. This programme included hard hitting and challenging videos including messaging around SUDEP (Sudden Unexpected Death in Epilepsy). This campaign has generated debate online, including complaints as well as compliments over September to present. Due to this we've seen a spike in complaints for the marketing and fundraising department.

In November 2020 we received a formal letter complaint around the campaign which is also being passed through to the Fundraising Regulator. This complaint is still ongoing.

Complaints and compliments have been included below.

1.3 Summary of complaints November – January 2021

| Date | Department/Area | Detail | Action taken | Open/Closed |
|--------------|-----------------------|---|--|-------------|
| October 2020 | Marketing/Fundraising | REF: Supporter Acquisition Programme Nine complaints added as comments on Facebook video adverts for our SAP. Complaints relate to SUDEP stats scaring people with epilepsy and causing anxiety. | Supporters directed to more information around SUDEP on our website and our helpline number. | Closed |
| October 2020 | Marketing/Fundraising | REF: Supporter Acquisition Programme Complaint in regards to one of the statistics in our Facebook videos being wrong. | Acknowledgement of mistake and the videos were edited and reuploaded with the new figures. | Closed |
| 18/10/2020 | Marketing/Fundraising | Comment on a post about a fundraising skydive left on our Facebook wall in regards to a lack of response and acknowledgement to supporters raising money for Epilepsy Society. | Hi Curtis, apologies for our delay in seeing your post. What a fantastic achievement! We are so grateful that you decided to join #TeamPurple and take on a challenge for our charity [FULL RESPONSE | Closed |

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|--------------------|-----------------------|--|--|--------|
| | | | CAN BE PROVIDED] | |
| 26/10/2020 | HR | A letter complaint in relation to having an interview for a role with Epilepsy Society and the subsequent confusion around the application form. A perceived lack of service from HR. | The Care Director has apologized for not getting back to the complainant and assured them this was an administrative error. This has now been passed to a care manager to follow up. | Closed |
| November - ongoing | Marketing/Fundraising | REF: Supporter Acquisition Programme 6 page letter complaint (with 19 pages of supporting documentation) from a supporter regarding our Supporter Acquisition Programme, with various perceived issues with the campaign. This complaint also involves the fundraising regulator. | Passed to Gordon Craig. Gordon is liaising with both the complainant and the fundraising regulator. Internal investigation being carried out by Jason Greasley. | Open |
| 21/11/2020 | Marketing/Fundraising | REF: Supporter Acquisition Programme Call from someone through the helpline who had signed up to the SAP. Her complaint was that the first thing the person on the call from the TM agency said to her was 'do you know how many people die from epilepsy each year'. She felt this | Passed to Peter Walters to discuss with the Telemarketing agency QTS. | Closed |

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| | | was a completely insensitive way to start the conversation and wanted to complain. | | |
| 21/11/2020 | Medical | Complaint from someone who was as a voluntary inpatient in 1997. This complaint has been passed to UCLH. | Rachel Perowne and UCLH | Closed |
| 14/12/2020 | Marketing/Fundraising | REF: Supporter Acquisition Programme The complainant found a call from our telemarketing team both oppressive and insensitive due to the agency ignoring the fact that they had no income and asking, without their permission, particular experiences. | Fundraising reply apologizing for any distress caused, explaining the campaign and stating that feedback will be passed to the TM agency. Fundraising have discussed with the TM agency around softening the ask and ensuring that any phone call is conducted in the right manner in line with the charity values. The complainant was also given the details of our helpline to call if they need information and support. | Closed |
| 16/12/2020 | Information team | helpline emailer asked a group of questions. Helpline replied saying that all our info was on our website and sending links. She then sent this reply – ‘No that doesn't answer my questions at all and | This was an anonymous caller, however this complaint has been noted by the information team and logged here for completeness. | Closed |

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|------------|----|---|---|--------|
| | | your medical director doesn't reassure me and I wonder what the point is of your services or your helpline or what he does at all there!! ‘ | | |
| 26/01/2021 | HR | A complaint by an ex staff member who had requested to opt out of the pension scheme when they started their employment. They unfortunately were opted into the pension scheme and asked to have the money that was taken from their salary for the pension payments to be given back to them. A lack of clarity of the process and a perceived lack of help from the charity in resolving the matter caused this person to complain. | Passed to the HR team who have touched base with the complainant and rectified the situation. | Closed |

1.4 Anxiety caused by the global pandemic

It is to be noted that we've seen an increase in complaints over the last three months which we believe has been caused by a heightened sense of anxiety caused by the global pandemic.

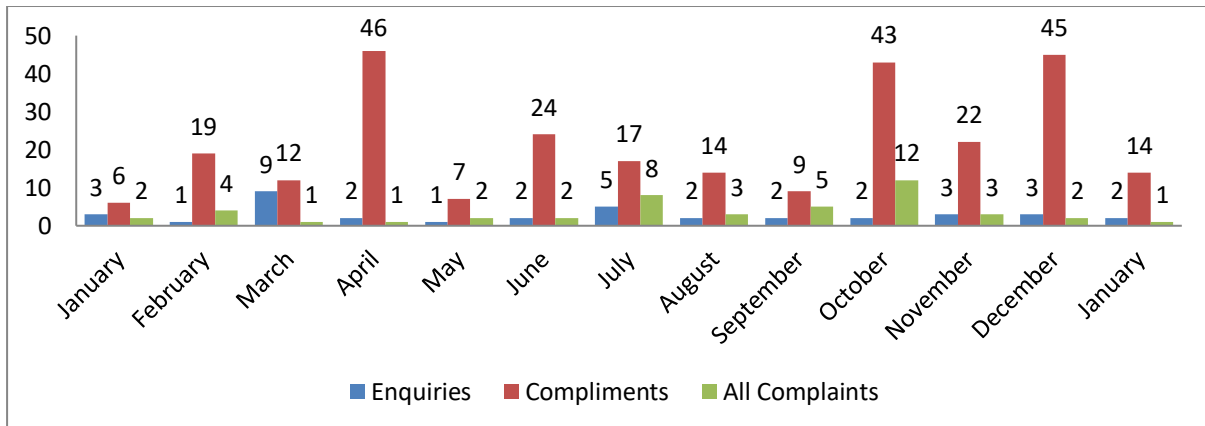
The wearing of masks has proved a very controversial issue for people with epilepsy. The wearing of masks in the public arena is now mandatory and those with epilepsy are not exempt. However, some people find that a mask can make them feel stressed, which in turn can trigger a seizure.

They can therefore carry one of the Government's exemption cards. Sadly, this has led to much judgemental criticism within the epilepsy community, with people accusing others of putting their epilepsy before Covid-19, and potentially risking other people's health.

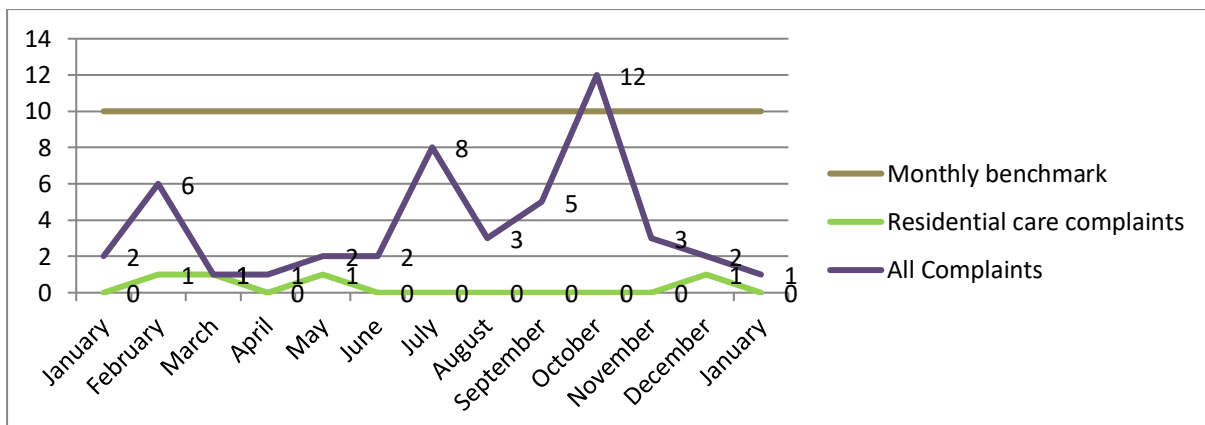
There is little concrete evidence around the benefits, or otherwise, of wearing a mask for people with epilepsy, therefore best advice is to wear one where possible, but to take regular breaks without the mask, away from the public, in a safe environment. It has been one of our most challenging communications.

2. Year-on-Year analysis

2.1 Graph to show analysis month-on-month and Year-on-Year for complaints, comments and compliments since January 2020:



2.2 Graph to show the breakdown of complaints month-on-month showing total complaints (purple line) and care complaints within this total (green line) against an assumed monthly benchmark of 10.

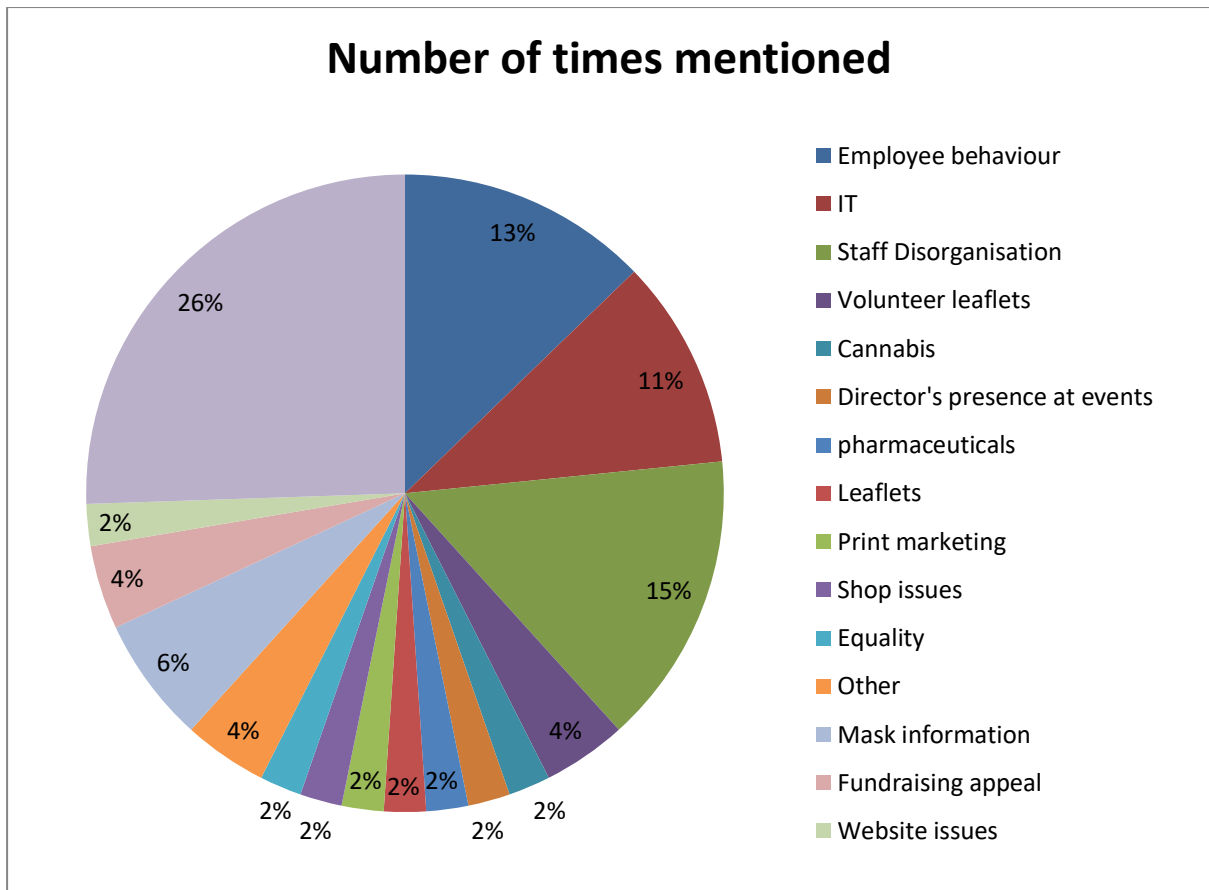


2.3 Category analysis for our complaints since reporting started.

The category analysis is based two different categories for each complaint. The complaints are broken down by:

- Department/area
- Key term/subject

The categories are chosen based on the analysis of our current complaints and patterns observed with our complaints to date.



Going forward we can breakdown the categories further. For example in the area of care services which can be used to detect patterns of behaviour by either staff or residents and can serve as potential early warning signals of issues (suggestions might be: safeguarding; medication; staffing; etc).

Annex A:

Highlighted compliments for October – January 2021:

To all staff - We were very sad to hear that [REDACTED] has died, but are happy in the knowledge that she was loved and cared for. Thank you all for that. Her parents were our lifelong friends [REDACTED] was my godmother - we met [REDACTED] at that funeral last autumn. All good wishes

[REDACTED] emailed to say that QEH families expressed their sincere gratitude and thanks to all staff in QEH for all their hard work, commitment and professionalism during the pandemic to keep our children safe and well. We all realise the sacrifice that they have and will continue to make and we are extremely grateful.

[REDACTED] from Greene House spoke [REDACTED] to pay [REDACTED] a compliment for supporting and guiding [REDACTED] the resident of Greene House back home after he seemed lost. This is such a nice gesture from [REDACTED] for being concerned about someone and taking the time to see how you could help and from [REDACTED] for taking the time to stop by my office to say thank you

Dear [REDACTED] It was good to chat today and to catch up with your future plans for Russell House and its staff and residents. It is great that there is so much positivity built in to your plans. One must remember how much the house has changed in the past two years. Thank you for bringing those changes and for bringing the wonderful new staff team who have made such a difference to the lives of our residents. Do please keep on adding your magic touch to Russell.

Sent to support worker from manager: I have just had a phone conversation with [REDACTED], she is so impressed with your attitude and communication with her. Joy said how happy she was with your appointment as Team Leader and that you were the most caring man. She also said how polite you are and how nice it is to speak with you.

Can you please pass on our thanks to the team for their wonderful work to keep our son, other residents and staff safe during this pandemic. We fully support the decisions being taken and know that it will be a long time before things can return to a degree of normality.

Just wanted to say in response to you update today - we totally support the approach. Whilst I fully understand the concerns that other families have about wanting to come and visit their relatives, its safety first for us and I am minded that the focus on what families can provide is or should be the added extra to the lives people lead at Chalfont not the main course! We are extremely heartened by the plans for the marathon and the Halloween event. [REDACTED] phoned us in great excitement wanting to invite us to it etc etc as he does (don't worry we won't come and he had not misunderstood). It was the first time for months he had something to tell us about and the lift it gave him was palpable. [REDACTED]. It does not take a lot but we are grateful to hear him energised and cheery.

I really do feel you are right to keep us back until it's safe. I also feel that the focus on attention really needs to be on the quality of life people have at ES day to day and what can be done there with staff. Its right that parents are involved and supportive and help staff where we can, but the focus is surely on their day to day lives within the centre with staff and attention here is what us makes the most difference to the quality [REDACTED] life especially now

I just wanted to send this message to thank each and everyone of you from the bottom of mine and my family's heart for the wonderful amazing job that you do, caring not only for my precious granddaughter [REDACTED] but all the other residents that are cared for at the Epilepsy society. Sadly not enough recognition is given to you all especially in these unprecedented times. I know my daughter A will be looking down and saying the very same thing. I am glad that she got to see where S now resides before she was so cruelly taken from us. I hope that it will not be too long before I am able to have her home as i miss her more than words can say. I do enjoy our WhatsApp calls.

Just to say I am right behind you and your decisions with fingers and toes crossed - most uncomfortable in the long term!

Thank you so very much for all the thought, implementation of care, and all the hard work the ES is doing to be as excellent as possible. When [REDACTED] tested positive in April she went to Gowers until tested negative. I understand how necessary it is for the resident who caught the virus in hospital to come home, better in every conceivable way.

She is so impressed with your attitude and communication with her. . [REDACTED] said how happy she was with your appointment as Team Leader and that you were the most caring man. She also said how polite you are and how nice it is to speak with you.

I received an email from one relative, [REDACTED] showing her appreciation for one particular member of staff being allocated as ID's key worker: "I am very pleased that [REDACTED] is his key worker".

Thanks all the staff at ES. The video was nice to see. It's been a long haul for everyone and yet a lot of energy went in to the Halloween event to give the residents some more change and excitement.

It was good to chat today and to catch up with your future plans for Russell House and its staff and residents. It is great that there is so much positivity built in to your plans. One must remember how much the house has changed in the past two years. Thank you for bringing those changes and for bringing the wonderful new staff team who have made such a difference to the lives of our residents. Do please keep on adding your magic touch to Russell.

Congratulations with successful working alongside GIPHY. It's an incredible website/app/service to use but I'm sure there were some things that could potentially impact those and cause them to have seizures. So glad that they've agreed to work alongside you and help stop this from happening.

Many Thanks.... Your kind Tweets do prop me up at Times /certain Times...!

I don't know if its due to campaigning but my partner (has epilepsy) and I (as his carer) have both been contacted by our doctors to have the flu vaccine :) Which has been a massive deal for us as any flu symptom effects his condition greatly, so thank you for raising this issue 🙏

Thank you so much for the reply. It really means a lot. You guys are absolutely awesome.

It has been an honour to be featured on your page, me and my sisters are so grateful that you gave us the chance we've always wanted, to share our story. And we hope the project has helped people, and that we will always be here to spread awareness.

Thank you for sending this information, I support adults with learning disabilities who are at high risk, am epileptic myself and was bit concerned if would cause any problems. I'll get my vaccination as soon as I can.

This is absolutely amazing. Well done to everyone. Wonderful stories, incredible achievements and a demonstration of true courage and fortitude. Thank you so much for sharing. - comment on Instagram on The Queen's Christmas message



Some really touching stories from people who suffer from such a difficult disability. 💜💜 - comment on LinkedIn on The Queen's Christmas message

What more can I say than a huge thank you to you personally for all your enormous care keeping everyone safe. It is a tremendous responsibility and unfortunately is not over yet but do try and put it down over Christmas and have a lovely time with your family.

Comments on post about Professor Ley Sander's ExpertScape ranking - Congratulations! It's great that you're recognised and appreciated for your hard work and commitment to improve the lives of others. 👍🙏


As Alessandra's sister I am grateful and very happy for you. Thank you very much for your wonderful work to save lives. 🙏🙏🙏🙏❤️❤️❤️ God bless you, always. Congratulations Prof. A real hero 🙏

Merry Christmas Epilepsy Society 

Thank you so much for the help and support you have given me throughout this hectic year  

Thank you for all the great advice and articles you have posted I've certainly learnt stuff and I've had epilepsy for the last 40 yrs merry Christmas to you all

The epilepsy society helpline kept me sane during lockdown

Comment on post about Calm Cushion Call messaging - This helped me so much when my partner started having seizures. My first ever encounter was pretty traumatic so I did everything possibly wrong! But once I was given info on the 3 C's I pretty much kept my cool and remember to keep calm, cushion and call for help. Such a scary thing to encounter even if you are used to it, so this simple method to remember is a god send. 

Hello,

I rang your helpline today & I wanted to leave a comment & compliment for who I spoke to. She was exceptionally helpful, compassionate, empathetic & had a complete understanding of the complexities of epilepsy & how debilitating & impactful on everyday life it is. Thank you so much!



Hello CLARE my NAME
Julie Coysn I work in
greene House and have
since February 2020
I felt I wanted to send
you this CARD to say
+ THANK you for all your
kindness and appreciation
and gifts I Am proud
to say I work at the
Epilepsy Society Looking
Forward to the years to
come working here I work
with AMAZING Team
at greene House
Best Wishes
STAY SAFE

Hello Clare my name Julie Coysn I work in Greene House and have since February 2020 I felt I wanted to send you this card to say thank you for all your kindness and appreciation and gifts. I am proud to say I work at the Epilepsy Society looking forward to the years to come working here I work with amazing team at greene house Best Wishes Stay Safe

ENDS

AGENDA ITEM NO: 10

Services, Quality & Assurance Committee

26th February 2021



Report from Professor Ley Sander, Medical Director (for information)

Since the last medical report to the SQA last November, the COVID-19 pandemic has raged on almost unchecked. During this time, the Medical Directorate has mainly supported Care Services to keep our residents safe and help all people with epilepsy who we see as outpatients predominantly remotely. We have continued with the residents and careers COVID surveillance by running twice-weekly testing runs in collaboration with UCLH and the Crick Institute.

The department, mainly through Prof Koepf and Dr Balestrini was also instrumental in organising together with the Care Services the successful deployment of the vaccine to residents and our staff.

The Gowers Assessment unit has continued to provide admissions mainly for diagnostic and the more complex drug changes, albeit in much smaller numbers. Gowers in regular times can accommodate 26 in-patients, including six EEG video telemetry beds. Currently, we are working with 8 beds, of which three are EEG-video-telemetry rooms. As Gowers has not worked to full capacity since March, including a period in which it was closed, a considerable backlog has developed. UCLH is attempting to come up with innovative ways of optimising access once the conditions allow.

The MRI unit utilisation rate has increased, but due to social distancing and the need for a sanitisation after each scan the numbers are still lower. Of note is that UCLH has now arranged for more patients to be scanned at Chalfont than previously and this should increase numbers. However not expected, we will go to full utilisation until improvements in the situation allow for the relaxation of the current rules. A similar comment could be made regarding's TDM laboratories.

The move towards more remote medicine continues unabated and seems now irreversible. Initial surveys suggest that over two-thirds of people with chronic diseases prefer telemedicine appointments for their routine follow-up appointments. This will lead to significant service reorganisation and will affect the future provision of epilepsy services.

Research has been affected, but we are still carrying on. However, a large proportion of the new clinical research funding available must be focused on COVID, so the acquisition of new external grants has been affected. We continue to acquire data from people attending the hospital for clinical needs when appropriate, and we are still allowed to analyse previously acquired data. Despite these restrictions, we have published over 50 peer-review research articles in the last six months.

At the end of January, we saw the departure of Dr Simona Balestrini after seven years in the medical and research team. She worked as a consultant and a researcher in the genomic group. She is taken up a senior leadership role in a major academic centre in Italy but will continue her link with the Society remotely to complete some research projects.

Ley Sander MD PhD FRCP FEAN - Medical Director 18/02/2021