



## Survey of Current ECG Status & CQC Intervention in Care Settings in England (November 2021)

### 1. Background

In March 2020, in line with national restrictions, care settings across the UK went into lockdown, with visits from relatives and friends not permitted in all but a very few cases (e.g. end of life). Despite subsequent easing of restrictions in the community over the course of 2020, care home visiting guidance remained highly restrictive and the majority of care providers continued to enforce outright bans on face-to-face contact between residents and their loved ones throughout 2020 and well into 2021. On 8<sup>th</sup> March 2021, new Government guidance for care home visiting in England was released. This guidance recognised the vital role that loved ones play in the health and well-being of residents in care settings. As well as allowing all residents to have one ‘designated indoor visitor’, the guidance stipulated those residents deemed as having a ‘high’ level of need could also nominate an ‘Essential Care Giver’ (ECG) who would have enhanced access to the resident in order to provide additional support for their physical or emotional needs.

On 17<sup>th</sup> June 2021, official Government guidance was further updated to state that every resident in England would now be entitled to nominate an ECG. Crucially in July 2021 the wording of the guidance was updated to recognise the importance of ‘companionship’, stating that “The essential care giver role is intended as a way of supporting residents to benefit from companionship and additional care and support being provided by someone with a unique personal relationship with the resident” ([Guidance on care home visiting - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/care-home-visiting)). The guidance also clearly stated that ECGs should be enabled to visit in all circumstances, including periods of isolation or if the care home is in an outbreak. Despite this, over the last 5 months, reports from members of the Rights for Residents campaign group have indicated that many providers are still not following this aspect of the guidance, with residents still being refused an ECG.

When questioned on this issue, the regulator for care settings in England, the Care Quality Commission (CQC), refer to figures published by the Department of Health and Social Care (DHSC) which state that “in the week ending 24 August 2021, 92.1% of care homes in England were able to accommodate residents receiving visitors within care homes in all circumstances” ([Adult social care monthly statistics, England: September 2021 - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/statistics/adult-social-care-monthly-statistics-england-september-2021)). However, these figures are based on care provider’s own self-reported responses to the DHSC ‘Capacity Tracker’ and unless reporting on visiting is made a requirement then it cannot be seen as giving a full picture of the situation across England. Furthermore, the term ‘supporting visiting’ could encompass any types of visits and does not give an indication of the proportion of providers actually providing high quality, meaningful, face to face contact between residents and loved ones, nor does it indicate the number supporting and implementing the ECG role.

Attempts to determine the number of residents who have actually been granted an ECG from the DHSC or CQC have proved futile, with Freedom of Information Requests revealing that neither the CQC nor the DHSC have monitored or collected data on the number of residents

who have an ECG ([17-11-21Daily-Express-FIO-article.pdf \(rightsforresidents.co.uk\)](#)) despite this having been a key aspect of current care home visiting guidance for the last 5 months.

## 2. Aim of survey

The aim of this survey was to obtain data on the current scale of the issue of residents being denied ECG and the effectiveness of the CQC in supporting residents who have been refused an ECG.

Specifically, the survey was designed to inform the campaign of:

- The current proportion of care home residents in England who do not have an ECG
- The proportion of care home residents who have applied but been refused ECG by their care provider
- The effectiveness of the CQC in supporting families to obtain ECG when this is refused by the care provider

## 3. Survey Design & Implementation

The survey was designed using GoogleForms. A link to the survey was posted three times on both the Rights for Residents Facebook Page and the Rights for Residents Twitter account between 01/11/21 – 12/11/21, with an accompanying message encouraging group members/followers to complete the survey. The only pre-requisite to completing the survey was that the care home resident must live in a care setting in England (as the ECG role only applies in England).

The survey consisted of two main questions, each with checkbox options (questions are detailed in the analysis section for each question below). Both questions required a response, with responders only able to select one of the options listed for each question. Those responding 'other, please specify' in Q2 were directed to a 3<sup>rd</sup> question where they were asked to give further details in a free-text field.

The survey opened on 01/11/21 and was closed to responses on 17/11/21. 436 responses were received over this 17-day period.

## 4. The Proportion of Residents in Care Settings Currently Without an ECG

Question 1 was designed to obtain a 'snapshot' picture of the current situation with regard to the number of residents with and without an ECG (and for those without, the reason why):

**Q1: Does your loved one in a care setting have at least one relative/friend with ECG status?**

- YES
- NO - resident/family have never requested ECG
- NO - resident/family currently in process of requesting ECG or have applied and waiting to hear back from care provider
- NO - resident/family have requested ECG but this has been refused by care provider

A summary of the 436 responses obtained from Q1 is shown in **Appendix 1**.

## Scope / Limitations of Q1

The scope of this question is limited to examining whether ECG is currently in place. This question did NOT look at whether the cases *with* ECG had been refused *at some stage* by the care provider (i.e. only awarded after repeated requests/complaints). In other words, for those who answered 'Yes' (have ECG) in Q1, the survey does not determine how difficult it was for them to gain this ECG status.

The scope of this question is also limited to issues around applying for / being granted ECG status and does not assess the 'quality' of the ECG status given (i.e. if the ECG is actually given an enhanced level of contact and whether they are allowed to visit during an outbreak, as per the Government guidance).

A further limitation of this survey is that the responders may not be fully representative of the wider care home resident population in England with regards to ECG status. This is because the survey was completed by members of our campaign group who as a result of following the group are, on the whole, very well informed about current government guidance, the ECG role, and their loved ones' rights, compared to the wider general population of care home residents/and families. Furthermore, members of our group are provided with resources and support in applying for ECG status and are also signposted by the campaign to other groups for additional support where required.

## Analysis of Data - Q1

### a) What Proportion of Residents Do Not Have an ECG?

Responses to Q1 show that, in the population surveyed, 33% of residents in care settings (1 in 3) do NOT currently have an ECG (Fig. 1).

It is important to note that **the true proportion of care home residents in England without ECG is likely to be considerably higher than 33%** because, as discussed above, members of our campaign group are likely to be much better informed about the ECG role (so are more likely to have applied) and are provided with resources and support in applying for ECG status (so are more likely to be successful when applying).

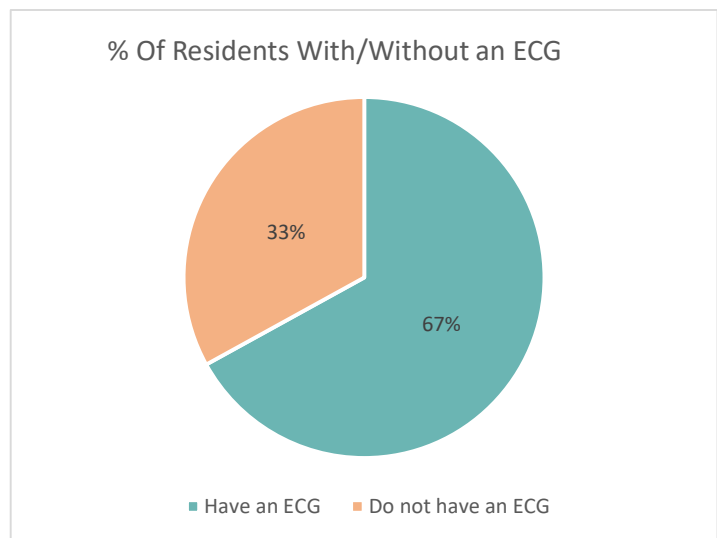


Fig. 1

## b) Why do 1/3 of residents not have an ECG?

Responses to Q1 show that for the 33% of residents not having ECG (Fig. 2) the reasons are: residents/families not having requested ECG (14%), families currently being in the process of applying for ECG (8%) or ECG having been refused by the Care Provider (11%).

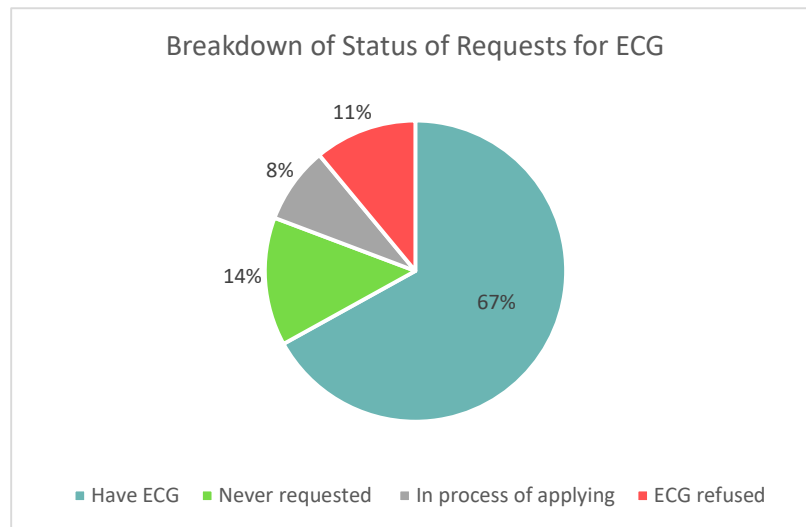


Fig. 2

The fact that even within our campaign group 14% (almost 1 in 7) of residents/families have never requested ECG suggests a significant proportion of families, even if knowing of the existence of ECG, may remain unaware of the importance of having ECG status in order to protect their loved one's access to family support, should further lockdowns or outbreaks occur.

Outside of the survey response group, the proportion of families not requesting ECG is likely to be even higher than 1 in 7. A huge amount of anecdotal evidence received by Rights for Residents (e.g. emails, comments on campaign Facebook page etc.) has suggested that in the general population of care home residents/relatives there is a huge lack of awareness of the official Government guidance for care home visiting and in particular of the ECG role, and that many providers are not informing residents families of this role. Q2 of the survey allowed some responders to leave additional comments (see Q2 analysis below), some of which illustrate this point:

*"....the care home has still not communicated anything about the availability of ECG to families so I am not sure how many of the 70+ residents have one". (Appendix 4.2, Response 1)*

*"Other relatives not aware of ECG and not informed of it by care home" (Appendix 4.2, Response 6)*

*"Care home hasn't told other relatives about ECG. As far as I know I'm only ECG in 60 bedded home". (Appendix 4.2, Response 8)*

The fact that many providers are not pro-actively informing their residents and families of the existence of the ECG role is deeply concerning, especially considering that official government

guidance stipulating all care home residents can nominate an ECG has been in place for 5 months by the time of this survey.

### c) What Proportion of Those Requesting ECG Are Successful?

96 of the responders in Q1 indicated that they had either never requested ECG or were currently in the process of doing so. Excluding these 96 leaves a sample group of 340 who had requested ECG and received a response. Looking at this population gives an indication of the proportion of requests for ECG that are being granted or refused.

Out of those 340 who had requested ECG, our data show that 14% (almost 1 in 7) were ultimately refused (Fig. 3).

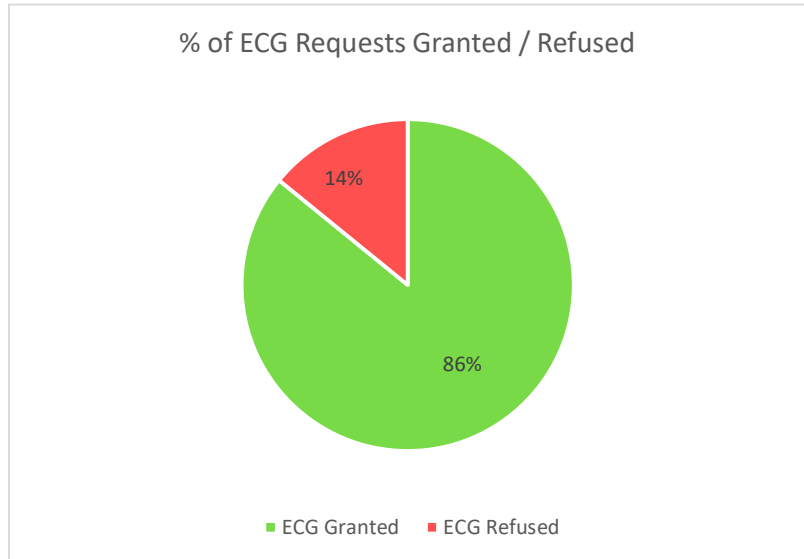


Fig. 3

As discussed under 'scope and limitations of Q1' (above), the scope of this question does NOT examine what proportion of the 86% who do have ECG status were also initially refused by the provider. A large amount of anecdotal evidence received by Rights for Residents (e.g. emails, comments on campaign Facebook page) indicates that many relatives have to make repeated requests and often have to escalate the issue to other parties (e.g. Local Authority, CQC) before finally being granted ECG status. Some of the comments received as part of this survey also illustrate this issue, for example some responders who do have ECG status commented in Q2:

*"My initial application for ECG was refused as they implied my mum wouldn't get anything from it! A week later my mum refused visits, and demanded to be left in her room to die then the management changed their minds" (Appendix 4.2, Response 2)*

*"I emailed the DOLs team at Lancashire County Council (and copied in my MP, County Councillor, Alzheimer's Society and John's Campaign). DOLs rang the nursing home daily until I was granted full essential carer status. (Appendix 4.2, Response 4)*

*"We reported been denied to LA safeguarding team, who got LA contract team involved with SW and Dols advocate who challenged the care home to then agree to ECG" (Appendix 4.2, Response 6)*

*"Contacted LA safeguarding team, who involved LA quality care assurance team for care homes, who also got SW involved, then care home finally agreed to ECG". (Appendix 4.2, Response 8)*

*“Initially ECG was refused but showing the home manager the guidelines and threatening to inform cqc was enough to make them change their mind”. (Appendix 4.2, Response 17)*

Therefore, the proportion being refused ECG by the provider at the time of first request is likely to be significantly higher than 14% (1 in 7), and it is only because of significant perseverance that some families eventually get ECG status. Again, this is of huge concern given that Government guidance states that all care home residents are entitled to an ECG.

#### **d) Effectiveness of the ECG Role**

As discussed under ‘scope and limitations of Q1’, this survey was limited to looking at issues around gaining ECG status. The ‘quality’ of ECG status when given (i.e. whether those with ECG actually get enhanced access and are allowed to visit during outbreaks, as stipulated in the government guidance) is outside of the remit of this survey.

However, it is worth mentioning that anecdotal evidence received by the campaign (e.g. emails, comments on campaign Facebook page) suggest that in many cases, ECG status does not actually result in the access and level of contact it should do according to the guidance. Some of the comments received in Q2 of this survey also illustrate this issue, for example:

*“I now have to share ecg with sister, on a 2 week basis with a 2 week break in between our visits....”. (Appendix 4.2, Response 2)*

*“...care home not allowing ECG in again due to covid again 4 weeks against gov ECG guidance”. (Appendix 4.2, Response 6)*

*“My sister and myself were given ECG status by manager of mum's nursing home but we are only allowed 2 X 1 hourly visits per week. I have requested to be allowed to visit more often but keep getting stonewalled ie your mum's mental health has not deteriorated” (Appendix 4.2, Response 9)*

*Got ECG after further pressure from ourselves on the home but with restrictions on visit frequency (Appendix 4.2, Response 10)*

*“ECG refused initially by care home. Informed Care Home I would contact CQC and they relented and grudgingly allowed ECG with limited visiting” (Appendix 4.2, Response 19)*

*“I've got ECG got refused visit in outbreak....” (Appendix 4.2, Response 20)*

*“My husband is down as ECG for his mum , but only allowed to visit via behind screen at moment due to covid outbreak” (Appendix 4.2, Response 22)*

*“I have ECG but got refused entry when home had outbreak which is the propose of a ECG” (Appendix 4.2, Response 28)*

So, while our data show that 86% of requests for ECG within our survey group were ultimately successful, the proportion of those who actually gain true ‘ECG status’ (with all the enhanced access that is supposed to bring) is likely to be lower than 86% in practice.

## 5. Effectiveness of the CQC in Supporting Residents Who Are Refused ECG

Question 2 was designed to assess what proportion of those who had been refused ECG (at any point) escalated this to the CQC, and for those who did escalate to CQC, how effective the regulator were in supporting them to ultimately get ECG status.

**Q2: If your loved one in a care setting has EVER had ECG refused by the care provider at ANY TIME (whether or not they now have ECG), did you or your family raise a complaint about this with the Care Quality Commission (CQC)? (please read all options carefully and select the most appropriate)**

- N/A - we have never applied for ECG
- N/A - my loved one was granted ECG without the need for CQC intervention
- N/A - we are currently in process of applying for ECG (or have applied and are waiting to hear back from provider)
- NO - ECG has been refused by the care provider but we have not contacted CQC
- YES - we contacted the CQC and ECG has now been awarded following CQC intervention with care provider
- YES - we contacted CQC and care provider awarded ECG when they discovered we had done this (but as far as I am aware this was not due to CQC intervention)
- YES - we contacted CQC and they have intervened, but care provider has still not agreed to ECG
- YES - we contacted CQC and they have responded, but they have not yet contacted the care provider / I do not know if they have contacted the provider
- YES - we have contacted CQC but have had no response from CQC to date
- OTHER (please specify in next question)\*

\* Responders selecting 'other' were directed to Q3 where they were asked to provide further details (free text response box).

A summary of the 436 responses obtained from Q2 is shown in **Appendix 2**.

### Scope / Limitations of Q2

The scope of this question was limited to examining whether for those who refused ECG at any point, they had escalated this to the CQC. Data on other parties/groups involved in supporting families to obtain ECG, and data on other issues around refusal, were outside the scope of this question.

However, because the 'other' option was included in Q2 (necessary because it was impossible to design a range of options covering every scenario in this complex situation), respondents were able to opt to provide additional information (often relating to other, non-CQC related, issues). 53 people responded 'other' to Q2 and were therefore directed to provide further details in Q3. This in itself was useful and provided some qualitative evidence to support the results of this survey (e.g. see statements included in analysis of Q1 above). However, on analysis of this 'additional info.' many of the responses could clearly be re-allocated under one of the alternative options originally provided in Q2. Because the scope of this question was limited specifically to looking at CQC involvement, (and because removing the large number of 'other' responses would have diluted/skewed the data), responses of 'other' were, where appropriate, re-allocated to one of the alternative Q2 responses provided.



The 53 individual responses to 'other - please specify' in Q3 are listed in **Appendix 4**, along with details of the alternative response they were re-allocated to (if applicable). The adjusted data summarising responses to Q2, after responses to 'other' had been re-allocated, are shown in **Appendix 3**.

*All Q2 data analysis detailed below is based on the data after re-allocation (Appendix 3).*

### **Analysis of Data – Q2**

In Q2, a total of 95 responders in Q2 said they had never applied for ECG or were currently in the process of applying. Because the scope of this question was only looking at those who had applied and had received a response, this group of 95 was excluded from further analysis. Excluding the 95 left a sample group of 341 who had requested ECG and had received a response from the provider. These 341 responses were analysed further, as detailed below.

#### **a) What proportion of CQC requests were granted without CQC intervention?**

Of the 341 in Q2 who had applied for ECG and had a response, 242 (71%) stated they had had ECG agreed without the need for CQC intervention. As discussed in Q1, it is worth noting that within this group, a significant proportion may have been refused by the provider on first request and so, while 71% received ECG without involving the CQC, some of these will have required repeated requests to the provider and/or support & intervention of other parties in order to finally obtain ECG.

#### **b) What proportion of those refused ECG escalated this to the CQC?**

Excluding the 242 who had been awarded ECG without the need for CQC intervention left a sub-group of 99 other responders who had ECG refused and could potentially have involved the CQC. Of these, 32 (32%) contacted CQC, 56 (57%) did not contact CQC, and 11 (11%) were categorised as 'other'.

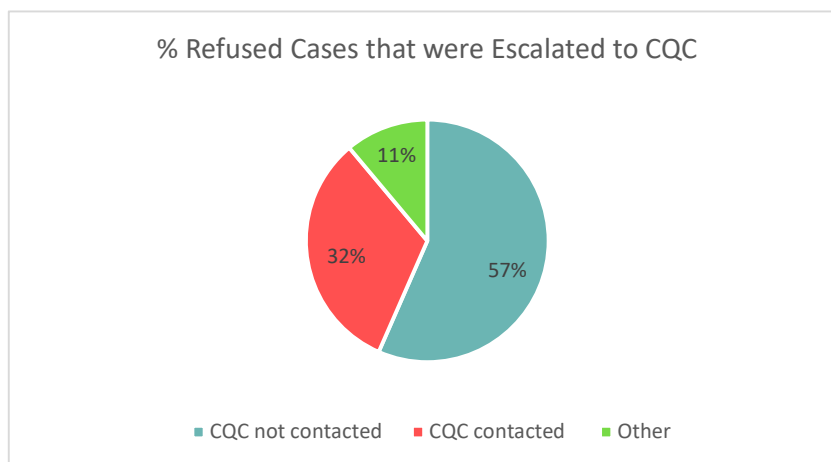


Fig. 4

The fact that only around 1 in 3 of those who could have done so actually contacted CQC may be a result of several different factors. Two possible explanations could be residents/relatives being unaware that they can escalate the issue to CQC and/or being unwilling to complain to the regulators because of concerns around having to name the home and resident when



making complaints and the fear of repercussions. This is highlighted by the following comments received in the survey:

*"...ECG was initially refused by the care provider but I did not contacted CQC because at the time I didn't know it was possible". (Appendix 4.2, Response 32)*

*"I contacted CQC but didn't want to name the care home, due to causing bad feeling between provider and relatives, my loved one with mental capacity doesn't want an going disagreement between family and the home he lives in...". (Appendix 4.7, Response 3)*

### c) How effective are the CQC in supporting residents to obtain ECG status?

In total, 32 respondents contacted CQC after bring refused ECG. While this a relatively small sample, this group can still provide information on the role/effectiveness of the CQC in supporting residents who have had ECG refused. The outcome of complaints to CQC is shown in Fig. 5.

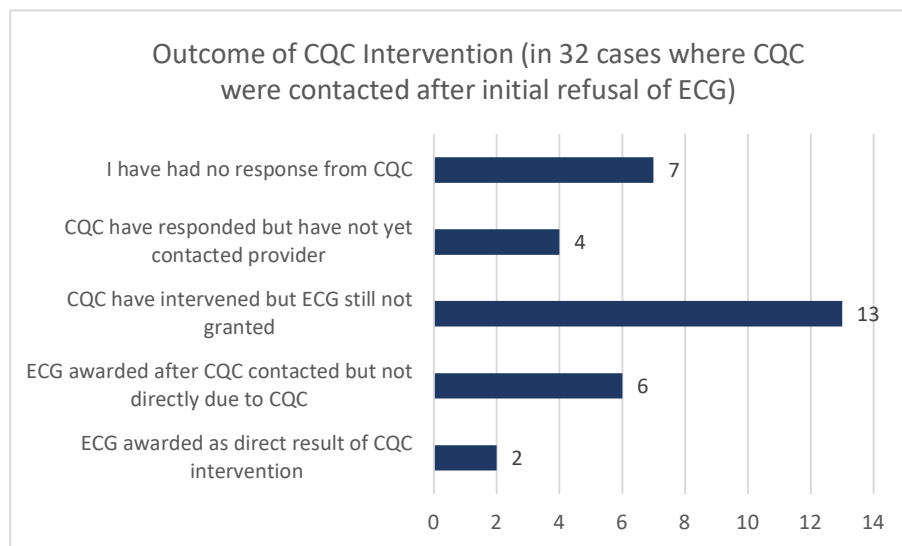


Fig. 5

Of the 32 cases escalated to CQC only 2 (6%) responded that ECG status was then awarded as a direct result of CQC intervention. In contrast, 13 (40%) reported that even after CQC intervention ECG still had not been granted.

Of the remainder, 7 (22%) had received no response from CQC, 4 (13%) reported that CQC had not yet contacted the provider/they did not know if they had contacted provider, and 6 (19%) indicated that ECG had been granted after they had complained to the CQC, but they did not feel this was a direct result of CQC intervention. Reasons for this may include a provider 'backing down' and awarding ECG once they hear that CQC have been contacted, or the intervention of another 3<sup>rd</sup> party persuading the provider to grant ECG before CQC intervenes, as demonstrated by the comment below:

*"I was initially refused ECG, I contacted CQC who responded but the care home manager granted me ECG before they could intervene after I put pressure on her by repeatedly quoting the government guidance and telling her I had contacted PHE and social services who both supported my request" (Appendix 4.5, Report 1)*

Additionally, of the 11 responders categorised as 'other' (who are not included in the 'made complaint to CQC' group of 32), a further 4 of these also mentioned that they considered the involvement of CQC in their case (in whatever capacity) had made no difference to the outcome (see below). Note: These 4 responses remained categorised as 'other' for the analysis (See Appendix 4.7) because either a) it was unclear whether refusal of ECG was the main focus of the complaint to CQC or b) the complaint was dropped by the family:

*"I reported the care homes to the CQC for the unjustified eviction and refusal for ECG. Their reply just said the inspector had contacted the care home and they were following government guidance which wasn't true". (Appendix 4.7, Response 2)*

*"I contacted CQC but didn't want to name the care home ,due to causing bad feeling between provider and relatives, my loved one with mental capacity doesn't want an going disagreement between family and the home he lives in , I was hoping CQC wiuid just send a email to all care homes promoting ECG". (Appendix 4.7, Response 3)*

*"CQC did nothing. I had to report issues of concern to safeguarding. A sec 42 enquiry was held. Neglect was found and only then was I awarded ECS". (Appendix 4.7, Response 6)*

*"ECG was granted once mum was admitted to hospital with dehydration. Neglect. CQC did nothing". (Appendix 4.7, Response 9)*

Overall, the fact that only 6% of those who raised a complaint to the regulator specifically about ECG being refused said that CQC intervention resulted in them being granted ECG status is concerning, and will do little to give residents and families confidence in the ability of the regulator to protect and uphold their right to meaningful contact with loved ones.

## **6. Conclusions**

The results of this survey indicate that a high proportion of residents in care settings in England (1 in 3) still do not have an ECG. Due to the nature of the sample group (who are well-informed and well supported in requesting ECG) the true proportion without an ECG in the wider care home community is likely to be significantly higher than 1 in 3. The reasons why such a large proportion do not have an ECG are likely to include lack of awareness amongst residents/families of the existence of the ECG role, lack of understanding of the importance of having an ECG, failure of many care providers to promote the ECG role and refusal of some care providers to grant ECG when requested.

The data from this survey indicate that of those applying for ECG, 14% (almost 1 in 7) are ultimately unsuccessful. Furthermore, both the survey data and anecdotal evidence suggest that of those 86% who are successful, a significant proportion of these are initially refused, often only getting ECG status after a huge amount of persistence and in some cases escalation of complaints to other bodies such as the Local Authority, Social Services or the CQC. Furthermore, being granted ECG in many cases does not in practice translate to the relative actually getting the level of access that ECG status should bring. The difficulties faced by families in applying for and being granted ECG, and how far the terms of ECG access are being adhered to, will be examined in more detail in future surveys.

Of those refused ECG by their provider at some point, our data suggest that only around 1 in 3 escalated this to the official regulator (CQC). This may be a result of several different factors including lack of awareness amongst families of the regulator's role or unwillingness to raise complaints for fear of repercussions. Of those who did escalate to the regulator, only 6% felt that the involvement of the CQC directly resulted in them subsequently obtaining ECG status.

In summary, the results of this survey indicate that a high proportion of care home residents in England are still being denied an ECG despite government guidance entitling them to this being in place for 5 months. Without a nominated ECG, thousands of care home residents will not be getting the enhanced access to loved ones that they are entitled to and are likely to face total (and often prolonged) isolation from loved ones in the case of outbreaks in the home, or future surges in cases or lockdowns.

The failure of the government and regulator to enforce or even monitor the ECG aspect of the government guidance has allowed this unacceptable situation, of residents being denied their basic human right to contact with loved ones, to persist. The harm that isolation causes to the health and well-being of care home residents has been well documented. Without action, this harm will continue with devastating and long-lasting effects on both residents and their loved ones.

## **APPENDIX**

### **Appendix 1: Table showing responses to Q1**

Q1: Does your loved one have at least one relative/friend with ECG status?

| <b>Response</b>   | <b>No. of Responses</b> |
|---|-------------------------|
| Yes   | 292                     |
| NO - resident/family have never requested ECG   | 60                      |
| NO - resident/family currently in process of requesting ECG or have applied and waiting to hear back from care provider | 36                      |
| NO - resident/family have requested ECG but this has been refused by care provider                                      | 48                      |
| <b>TOTAL:</b>   | <b>436</b>              |

### **Appendix 2: Table showing responses to Q2 (before re-allocation)**

Q2: If your loved one in a care setting has EVER had ECG refused, did you or your family raise a complaint about this with the Care Quality Commission (CQC)?

| <b>Response</b>  | <b>No. of Responses</b> |
|--|-------------------------|
| N/A - we have never applied for ECG  | 62                      |
| N/A - my loved one was granted ECG without the need for CQC intervention   | 209                     |
| N/A - we are currently in process of applying for ECG (or have applied and are waiting to hear back from provider)   | 30                      |
| NO - ECG has been refused by the care provider but we have not contacted CQC   | 54                      |
| YES - we contacted the CQC and ECG has now been awarded following CQC intervention with care provider  | 2                       |
| YES - we contacted CQC and care provider awarded ECG when they discovered we had done this (but as far as I am aware this was not due to CQC intervention) | 5                       |
| YES - we contacted CQC and they have intervened, but care provider has still not agreed to ECG   | 10                      |
| YES – we contacted CQC and they have responded, but they have not yet contacted the care provider / I do not know if they have contacted the provider      | 4                       |
| YES - we have contacted CQC but have had no response from CQC to date  | 7                       |
| OTHER (please specify in next question)  | 53                      |
| <b>TOTAL:</b>  | <b>436</b>              |

**Appendix 3: Table showing responses to Q2 (before & after re-allocation)**

Table showing responses to Q2 before and then after re-allocation of the responses to 'other' based on additional info. given in Q3 (see Appendix 4 below for details of individual responses to Q3 and re-allocations)

| <b>Response</b>  | <b>No. of Responses in original question</b> | <b>No. of responses re-allocated to this category</b> | <b>Adjusted No. of responses</b> |
|--|--|---|----------------------------------|
| N/A - we have never applied for ECG  | 62   | 1   | 63                               |
| N/A - my loved one was granted ECG without the need for CQC intervention   | 209  | 33  | 242                              |
| N/A - we are currently in process of applying for ECG (or have applied and are waiting to hear back from provider)   | 30   | 2   | 32                               |
| NO - ECG has been refused by the care provider but we have not contacted CQC   | 54   | 2   | 56                               |
| YES - we contacted the CQC and ECG has now been awarded following CQC intervention with care provider  | 2  | 0   | 2                                |
| YES - we contacted CQC and care provider awarded ECG when they discovered we had done this (but as far as I am aware this was not due to CQC intervention) | 5  | 1   | 6                                |
| YES - we contacted CQC and they have intervened, but care provider has still not agreed to ECG   | 10   | 3   | 13                               |
| YES – we contacted CQC and they have responded, but they have not yet contacted the care provider / I do not know if they have contacted the provider      | 4  | 0   | 4                                |
| YES - we have contacted CQC but have had no response from CQC to date  | 7  | 0   | 7                                |
| OTHER (please specify in next question)  | 53   | (- 42)  | 11                               |
| <b>TOTAL:</b>  | <b>436</b>                                   |   | <b>436</b>                       |

#### Appendix 4:

Tables 4.1 - 4.7 show the individual free-text responses to Q3 and indicate which Q2 response they were re-allocated to or whether they remained as true 'other' responses after analysis.

#### Appendix 4.1: Re-allocation to “N/A – we have never applied for ECG”

|    | Response  | Notes: |
|----|---|--------|
| 1. | “The care manager has been reasonable with access so far (we argued my mum was end of life - in January...). The manager told my sister she would get ECG status if ever needed. I actually thought she had it until recently. Makes me nervous... I am unclear if more than one person can apply”. |        |

Total no. of responses re-allocated to this category: 1

#### Appendix 4.2: Re-allocation to “N/A – my loved one was granted ECG without the need for CQC intervention”

Notes: Several responses below indicate that initial request for ECG was refused but residents were granted ECG after trying various routes that did *not* involve direct appeal for help to CQC (e.g. relative repeated request to care home after initial refusal, or appealed to Local Authority, social services or other groups for help). These have been re-allocated to this category because the scope of this survey is limited to examining how many residents are able to get ECG without CQC involvement. We recognise that within this group, several of the cases will have involved initial or repeated refusals of ECG by the care provider and/or required intervention by other parties before ECG was awarded, but this is outside the scope of this survey. Similarly, several of the responses indicate that ECG has been awarded but the terms of ECG not properly respected (e.g. visits being limited or visits refused in outbreak). The scope of this survey is limited to numbers of residents being awarded ECG (a previous RfR survey has examined the level of adherence of providers to the actual terms of ECG).

|    | Response  | Notes  |
|----|---|--|
| 1. | “Both me and my sister contacted the C q c late last year when it was clear my fathers care home were not following visiting guidance . They spoke to the manager and even did an inspection ( probably remotely) which concluded that the manager was following guidance as best she could . We were very angry. Our request for E C G was allowed only when the guidance changed to all resident being able to nominated one. However the care home has still not communicated anything about the availability of ECG to families so I am not sure how many of the 70+ residents have one”. | <i>Note: (responder indicates CQC was contacted but this was last year i.e. prior to ECG being</i> |

|    | <b>Response</b>   | <b>Notes</b>                                  |
|----|---|---|
|    |   | <i>in guidance so N/A in relation to ECG)</i> |
| 2. | “My initial application for ECG was refused as they implied my mum wouldn’t get anything from it! A week later my mum refused visits, and demanded to be left in her room to die then the management changed their minds! This happened 2 weeks after her care plan was finalised stating she was happy and content ( even though I told them the opposite) I now have to share ecg with sister,on a 2 week basis with a 2 week break in between our visits, still having to book and wear full ppe”. |   |
| 3. | “I asked for ecg status in the summer and was told ok. As I was taking my mum out every week the ecg status wasn’t an issue. However when I wanted to visit mum in her room to sort her clothes out I was told it wasn’t possible. I then used part of your template letter to request I was listed as ecg on mums carehome plan. The home went into lockdown with D&V and it was put on hold for another two weeks and finally today, after another letter, they have granted it”.                   |   |
| 4. | “I emailed the DOLs team at Lancashire County Council (and copied in my MP, County Councillor, Alzheimer's Society and John's Campaign). DOLs rang the nursing home daily until I was granted full essential carer status. I still have to make appointments to visit Mum, but it is usually 4 times per week for 3 hours per day. Rights for Residents and John's Campaign are absolutely amazing- thank you so much”.   |   |
| 5. | “We wrote to the head of our home corporation giving reasons why ECG status should be allowed (using R4R templates), primarily mental well-being, but they wrote back and said ECG was not possible as the home was providing all necessary care. Only when the government said every resident could nominate one person did they then allow it”.   |   |
| 6. | “We reported been denied to LA safeguarding team, who got LA contract team involved with SW and Dols advocate who challenged the care home to then agree to ECG. However care home not allowing ECG in again due to covid again 4 weeks against gov ECG guidance. Other relatives not aware of ECG and not informed of it by care home”.  |   |
| 7. | “Refused in first instance but because I followed the steps on RfR, complained about them on this site that one of their regional managers contacted us via this site but at the same time home manager backed down and granted ecg. The regional manager never replied to our email after contacting us!”  |   |
| 8. | “Contacted LA safeguarding team, who involved LA quality care assurance team for care homes, who also got SW involved, then care home finally agreed to ECG. Care home hasn't told other relatives about ECG. As far as I know I'm only ECG in 60 bedded home. XXXX care homes”   |   |



|     | <b>Response</b>  | <b>Notes</b> |
|-----|--|--------------|
| 9.  | "My sister and myself were given ECG status by manager of mum's nursing home but we are only allowed 2 X 1 hourly visits per week. I have requested to be allowed to visit more often but keep getting stonewalled ie your mum's mental health has not deteriorated" |              |
| 10. | "Got ECG after further pressure from ourselves on the home but with restrictions on visit frequency It allows me to visit her in her room once a week which is all I can manage anyway so haven't pushed it. Not yet tested if would be allowed during an outbreak"  |              |
| 11. | "I applied for ECG three times when my Mother was put on end of life and was refused three times saying my Mother wouldn't benefit emotionally physically or mentally and that the carers give my Mother all she needs, I have got it now but with stipulations".    |              |
| 12. | "I was told that I am the only resident to have asked about ecg out of 29. It's taken a while for it to be actioned but tomorrow I am to visit mum in her room after nearly two years! Very strict instructions/restrictions but at least I will be with her".       |              |
| 13. | "We were refused multiple times so I sent a copy of letter to adult social care Peterborough and that worked and care home then agreed mum and I could be both ECG and we were finally allowed into dads room to see him".   |              |
| 14. | "ECG was initially refused twice on the basis resident was eating and drinking well. They even provided her weight chart to support their decision! After challenging decision the care home relented and granted ECG"   |              |
| 15. | "Have applied for ECG and have a 'Yes' in principle as I am able to visit (still have to make appointments), BUT nothing in writing and no official line on ECG on any of the care provider's website".  |              |
| 16. | "Got refused ECG many times, Mums home had lots of different manager changes, but eventually it was granted to me by a temporary new manager, so never had to get CQC involved".   |              |
| 17. | "Initially ECG was refused but showing the home manager the guidelines and threatening to inform cqc was enough to make them change their mind"  |              |
| 18. | "Ecg revoked at covid outbreak. After 4 days and several conversations with manager who contacted head office mha was allowed in after 3 days".  |              |
| 19. | "ECG refused initially by care home. Informed Care Home I would contact CQC and they relented and grudgingly allowed ECG with limited visiting"  |              |

|     | <b>Response</b>   | <b>Notes</b>   |
|-----|---|--|
| 20. | "I've got ECG got refused visit in outbreak contacted cqc I had to explain government guidelines lady on phone didn't know them".   |  |
| 21. | "I became essential caregiver due to the fact I found him who runs the Nursing Home and I put my request in to them"  |  |
| 22. | "My husband is down as ECG for his mum , but only allowed to visit via behind screen at moment due to covid outbreak"   |  |
| 23. | "I was initially refused ECG status but contacted local public health and social care. After some arguments ECG given"  |  |
| 24. | "Declined it first off then agreed to it was going to CQC but didn't have to in the end thankfully".  |  |
| 25. | "Was refused at first but reapplied a few weeks later and it was granted did not complain to CQC".  |  |
| 26. | "I appalled the decision with an informative email and got ECG status within 3 days of my email"  |  |
| 27. | "Originally refused, but agreed to when another lockdown was underway so visits were allowed".  |  |
| 28. | "I have ECG but got refused entry when home had outbreak which is the purpose of a ECG"   |  |
| 29. | "ECG was refused initially but contact with local CCG meant that it was accepted"   | CCG = local clinical commissioning group   |
| 30. | "I was given ECG for my husband without asking."  |  |
| 31. | "Was given it when asked after a short wait"  |  |
| 32. | "NO - ECG was initially refused by the care provider but I did not contact CQC because at the time I didn't know it was possible. I only got ECG status thanks to XXXX intervention with the XXXX head office. Many thanks again!"  |  |
| 33. | "Only one ECG allowed. I am Mum's carer and can't go in with her and also she is elderly and doesn't want to have to change her clothes to comply with ECG requirements to visit her husband. We are therefore continuing to suffer booked and timed 30-minute slots in the pod, wearing full PPE. I just don't understand why, if Dad was well enough to be taken out of the home, we could go anywhere and bring him back into the home without any restrictions. We just want our family to be able to visit him comfortably in his own room but this is still not possible. My Dad is now running out of time..." | Account suggests that responder's Mum has been awarded ECG but is not able to meet provider's individual |

|  | Response | Notes                  |
|--|----------|------------------------|
|  |          | requirements for this. |

Total no. of responses re-allocated to this category: 33

#### Appendix 4.3: Re-allocation to “N/A - we are currently in process of applying for ECG (or have applied and are waiting to hear back from provider)”

|    | Response  | Notes |
|----|---|-------|
| 1. | “I was told by the Manager that she needed to raise this with the CEO of the Care Home, which I sure do not understand as to why? I am still to date waiting to hear back, I have been requesting this since August, and no further forward with this, as it’s deemed ‘Government Guideline’ and not ‘Law or Mandatory’ which is what we need to change for all Care Homes, for it to be made ‘Law’”. |       |
| 2. | “I keep been promised it by The Manager for over a month now, but still nothing resolved, and she keeps telling me she needs or ask her Manager which is so annoying and frustrating as I don’t know why she needs it ask her Manager when the Government Guideline say I am entitled to it”.   |       |

Total no. of responses re-allocated to this category: 2

#### Appendix 4.4: Re-allocation to “NO - ECG has been refused by the care provider but we have not contacted CQC”

|    | Response   | Notes |
|----|--|-------|
| 1. | “I applied for ECG back in March when Government first stated that residents in care homes could have an ECG but I was refused on the grounds that the care home could meet my mums needs and she didnt meet the strict criteria. I didnt know at that time I could contact the CQC” |       |
| 2. | “We requested it but were reassured it wasn't necessary and so far have had what we consider to be reasonable (although restricted time, booked appointments, limited to one visit per day per person, PPE and LFT) access”.   |       |

Total no. of responses re-allocated to this category: 2

**Appendix 4.5: Re-allocation to “YES - we contacted CQC and care provider awarded ECG when they discovered we had done this (but as far as I am aware this was not due to CQC intervention)”**

|    | <b>Response</b>  | <b>Notes</b> |
|----|--|--------------|
| 1. | “I was initially refused ECG, I contacted CQC who responded but the care home manager granted me ECG before they could intervene after I put pressure on her by repeatedly quoting the government guidance and telling her I had contacted PHE and social services who both supported my request”. |              |

*Total no. of responses re-allocated to this category: 1*

**Appendix 4.6: Re-allocation to “YES - we contacted CQC and they have intervened, but care provider has still not agreed to ECG”**

|    | <b>Response</b>  | <b>Notes</b>   |
|----|--|--|
| 1. | “We asked cqc many things and query about egc was included. They contacted care home but nothing changed, as they didn’t covered everything I had asked. I put in a complainly against cqc and they treated it as a complaint against the home, which it wasn’t. At this point I gave up contacting CQC” |  |
| 2. | “We contacted CQC They contacted home and there was no change. When adult social care then contacted home ECG was awarded”.  | Although ECG was eventually awarded, the response indicates that CQC intervention had no effect on this. |
| 3. | “We contacted a solicitor in order to get ECG status as all other avenues including MPs and CQC do d not come to anything”   | Although ECG was eventually awarded, the response indicates that CQC intervention had no effect on this. |

*Total no. of responses re-allocated to this category: 3*

#### Appendix 4.7: Responses remaining as true 'other' category

|    | Response   | Notes  |
|----|--|--|
| 1. | “ECG status originally refused by Care Home - quote "carers were ECG". Had a meeting with Area Manager and Home Manager in May and was told I could be ECG, however after trying three times to go in (was just told to just turn up), I went back to Area Manager who said I should have been told about PCR testing and relevant paperwork. This was eventually put in place. Had first visit but this has been my only visit inside. PCR test results were a) not received by myself b) communicated to me via Care Home. I was told if I hadn't received results, I was not allowed in. Hence not allowed in. Have stuck with pod visits. Then I've been unable to visit for personal reasons. The Area Manager has said he will let me know if my works PCR can be used but it's quite frankly been a shambles. As of 1st November I've heard nothing, nor had messages replied to (from September)”. | Unclear from account whether ECG status remained in place or was revoked because of issue of PCR tests.                    |
| 2. | “I asked for ECG in April, the request was refused and mum was served an eviction notice. I reported the care homes to the CQC for the unjustified eviction and refusal for ECG. Their reply just said the inspector had contacted the care home and they were following government guidance which wasn't true”.   | Response suggests resident was evicted as result of ECG request so true 'other' category.                                  |
| 3. | “I contacted CQC but didn't want to name the care home ,due to causing bad feeling between provider and relatives, my loved one with mental capacity doesn't want an going disagreement between family and the home he lives in , I was hoping CQC wiuid just send a email to all care homes promoting ECG” .  | CQC were contacted but relative could not see through this complaint because of resident's concerns about naming provider. |
| 4. | “I enquired about ECQ status in Dads new care home to be told they follow all government guidelines but have never heard of ECG! I reported to Healthwatch as few homes I've spoken to offer freely”.  | Unclear if relative has actually applied for ECG and/or been accepted  |
| 5. | “Complicated! We contacted the CQC with regard to the neglect. We achieved ECG status for one family member after huge battle with company that run the care home”   | Unclear if CQC intervened on ECG status or only on neglect issue.  |

|     | <b>Response</b>  | <b>Notes</b>  |
|-----|--|---|
| 6.  | "CQC did nothing. I had to report issues of concern to safeguarding. A sec 42 enquiry was held. Neglect was found and only then was I awarded ECS".                            | Unclear if family reported ECG issue to CQC as well as neglect.   |
| 7.  | "Mum has ECG now, because we moved her to another home that complies with the ECG government guidance the previous home would not allow any ECGs"                              | ECG only awarded after move to new home                           |
| 8.  | "I requested verbally but the Home has never confirmed it . There's not been a lockdown for a couple of months , and I visit in Mum's own room without any time restrictions " | Unclear if ECG awarded verbally even if not confirmed in writing. |
| 9.  | "ECG was granted once mum was admitted to hospital with dehydration. Neglect. CQC did nothing".  |   |
| 10. | "ECG was refused by the home until the family threatened legal action"   | Unclear if CQC were involved                                      |
| 11. | "Told the care home to read the government recommendations"  | Unclear if ECG actually awarded or waiting to hear                |

*Total no. of responses remaining as 'other': 11*