

**From the Permanent Secretary
and HSC Chief Executive**



Cllr Sean McPeake
Chair,
Mid Ulster District Council
Cookstown Office
Burn Road
BT80 8DT

info@midulstercouncil.org

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Email: richard.pengelly@health-ni.gov.uk

Our ref: RP2803
SCORR-0658-2018

Date: 14th August 2018

Dear Cllr McPeake

Thank you for your letter of 25 July 2018 on behalf of Mid Ulster District Council regarding access to lumacaftor and ivacaftor (Orkambi) for the treatment of cystic fibrosis.

Firstly, allow me to say that I fully appreciate that patients should wish to avail of the best treatment that the health service can provide, and in a timely manner.

The Department has a formal link with the National Institute for Health and Care Excellence (NICE) under which, NICE Technology Appraisals (which make recommendations on the use of new and existing medicines and treatments within the NHS) are reviewed locally for their applicability in Northern Ireland. Where found to be applicable they are endorsed by the Department for implementation within Health and Social Care (HSC). NICE can only recommend that treatments be routinely funded within the NHS when there is clear evidence that the treatments are both clinically effective and represent good value for money.

NICE does not recommend the use of lumacaftor and ivacaftor for treating cystic fibrosis and has published guidance to this effect (TA398). Currently lumacaftor and ivacaftor for treating cystic fibrosis is not routinely commissioned in any of the UK jurisdictions.

In August 2016 the Department endorsed TA398 as applicable in Northern Ireland, therefore Orkambi is not offered as a routinely commissioned treatment for cystic fibrosis

NICE has confirmed that the position has not changed from the following statement provided in July 2017:

“Our appraisal of lumacaftor–ivacaftor (Orkambi) for treating cystic fibrosis will next be considered for review in July 2019. However, if new evidence becomes available that is likely to affect the current recommendations before then, or if

the company puts forward a proposal that demonstrates their drug is cost-effective, we can consider whether it is appropriate to bring forward the review.

At this stage, we have not been informed of any evidence that could lead to a proposal to review the guidance, including any new proposals from the company.

We do understand how important a new treatment option would be for people with cystic fibrosis; but for the benefits it offers, the cost of Orkambi is currently too high. We can only recommend treatments be routinely funded on the NHS when we are certain they are both clinically effective and represent good value for money. If the company is able to put forward a proposal that provides Orkambi at a cost-effective price, we would welcome it".

Lumacaftor and ivacaftor for treating cystic fibrosis will next be considered for review by NICE in July 2019. However, as the NICE statement above indicates, NICE will consider whether it is appropriate to bring forward the review and we will revert to that guidance. Companies are free to engage with NICE regarding the price and cost effectiveness of their drugs at any time.

Yours sincerely



RICHARD PENGELLY

FROM THE PERMANENT SECRETARY
Noel Lavery



Netherleigh
Massey Avenue
Belfast BT4 2JP
Tel: 028 90529441
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Councillor Sean McPeake
Mid Ulster District Council

Our Ref: SCOR-320-2018

chair@midulstercouncil.org

6 September 2018

Dear Councillor McPeake

Thank you for your letter of 30 August 2018 regarding concerns in relation to the outcome of inspections on the non-domestic RHI scheme and the lack of correspondence with participants.

I can confirm that on completion of each site inspection in the Mid Ulster District Council area, the Department for the Economy has written to individual participants advising them of any issues that have been identified during their site inspection and that require further consideration. The participants have also been written to by Ofgem, who administer the Scheme on our behalf, and advised of the areas of non-compliance and the action they need to take to address them. In the correspondence from Ofgem, they are also advised how they may instigate a formal review of any decisions made.

Ofgem have also confirmed that to date no participant in the Mid-Ulster Council area has requested a copy of their inspection report. If a participant would like a copy of their report they can request this by writing directly to Ofgem at rhi.compliance@ofgem.gov.uk.

I trust that the processes we are following assures you that we are actively engaging with the participants throughout the inspection and compliance process.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'Noel Lavery', written over a light blue rectangular background.

NOEL LAVERY
Permanent Secretary



Planning Department
Mid Ulster District Council
Magherafelt Office
Ballyronan Road
Magherafelt
BT45 6EN

30th August 2018

TIME SENSITIVE DOCUMENT – REPLY REQUIRED

Our reference: - JB-02879632450

Dear Sir or Madam,

REMOVAL OF PUBLIC PAYPHONE:

I am writing to advise you that BT are proposing to permanently remove the kiosk at Megargy Road near Junction Dunarnon Road, Magherafelt. BT45 5HP. After an assessment of the area and the need for a payphone at this location we discovered that the payphone has received no use during the past twelve months. We are proposing to permanently cease service at this site.

Our obligation to provide a Universal Service will be maintained, as there are other kiosks within the vicinity.

Before we can remove a kiosk we have an obligation to consult with relevant public bodies on the proposed removal. As part of the consultation process it is a requirement that the Council reply in writing to BT after 42 days and within 90-days giving their comments or any objections received from the local community. Further information on the consultation process can be found at: http://stakeholders.ofcom.org.uk/binaries/consultations/uso/statement/removing_callboxes.pdf

If you do not reply, it will be taken that the council and interested parties have no objection to the permanent removal of this payphone.

A notice of our proposal is being displayed in the kiosk and a copy is enclosed with this letter for your information.

If you require any further information or have any queries please do not hesitate to contact me via email at btpcfo@bt.com

Yours faithfully

Jim Blanch

BT Payphones - Commercial Field Officer



Planning Department
Mid Ulster District Council
Magherafelt Office
Ballyronan Road
Magherafelt
BT45 6EN

30th August 2018

TIME SENSITIVE DOCUMENT – REPLY REQUIRED

Our reference: - JB-02879642264

Dear Sir or Madam,

REMOVAL OF PUBLIC PAYPHONE:

I am writing to advise you that BT are proposing to permanently remove the kiosk Slaghtneill Road at Old Post Office, off Tirkane road Maghera. BT46 5NJ. After an assessment of the area and the need for a payphone at this location we discovered that the payphone has received no use during the past twelve months. We are proposing to permanently cease service at this site.

Our obligation to provide a Universal Service will be maintained, as there are other kiosks within the vicinity.

Before we can remove a kiosk we have an obligation to consult with relevant public bodies on the proposed removal. As part of the consultation process it is a requirement that the Council reply in writing to BT after 42 days and within 90-days giving their comments or any objections received from the local community. Further information on the consultation process can be found at: http://stakeholders.ofcom.org.uk/binaries/consultations/uso/statement/removing_callboxes.pdf

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Yours faithfully

Jim Blanch

BT Payphones - Commercial Field Officer



Planning Department
Mid Ulster District Council
Cookstown Office
Burn Road
Cookstown
BT80 8DT

30th August 2018

TIME SENSITIVE DOCUMENT – REPLY REQUIRED

Our reference: - JB-02886763781

Dear Sir or Madam,

REMOVAL OF PUBLIC PAYPHONE:

I am writing to advise you that BT are proposing to permanently remove the kiosk outside 120 Lough Fea Road near Ballypriest Orange Hall, Cookstown. BT80 9QL. After an assessment of the area and the need for a payphone at this location we discovered that the payphone has received no use during the past twelve months. We are proposing to permanently cease service at this site.

Our obligation to provide a Universal Service will be maintained, as there are other kiosks within the vicinity.

Before we can remove a kiosk we have an obligation to consult with relevant public bodies on the proposed removal. As part of the consultation process it is a requirement that the Council reply in writing to BT after 42 days and within 90-days giving their comments or any objections received from the local community. Further information on the consultation process can be found at: http://stakeholders.ofcom.org.uk/binaries/consultations/uso/statement/removing_callboxes.pdf

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