



@ncepod



### What happened in 2020...

#### REPORT PUBLICATIONS

We started the year with two report releases:

<https://www.ncepod.org.uk/2020abo.html>

<https://www.ncepod.org.uk/2020ltv.html>

#### DELAYS

Data collections for the Clinical Outcome Review Programmes were suspended through the height of the pandemic, quite rightly! We are now slowly restarting studies. The programmes are working to a 6 month delay but we hope to regain some routine next year. In the meantime we will ask you for data but will be mindful of the ongoing situation and allow extra time for it to be returned - please tell us if you are struggling!

#### VIDEOS and PATIENT INVOLVEMENT

We used the time during lockdown to develop videos on past reports, as well as interviewing a young lady called Fleur Perry about her experience on Long-term Ventilation, you can see all these [videos here](#)

We also undertook focus groups with young people and parent carers about their experiences of Transition from child to adult health services. This was a first for the team, and provided excellent insight into the themes needed for review!

#### NEW CONTRACTS

We were very pleased to be awarded new three year contracts for the Medical and Surgical Clinical Outcome Review Programme and the Child Health Clinical Outcome Review Programme, allowing us to continue the great studies we have underway and start new ones.

#### NEW ONLINE CASE REVIEWER MEETINGS

To ensure we are able to carry on with case note reviews over the coming months, and for as long as needed, we have developed a model to review anonymised case notes online. This will hopefully make things easier for healthcare professionals to continue their participation too. When we can return to holding meetings in the NCEPOD office we may well keep this as a hybrid method!

### What's planned for 2021...

#### REPORT RELEASES

The 'In Hospital Care of Out-of-Hospital Cardiac Arrests' report will be released in February and 'Dysphagia in Parkinson's Disease' will be released in the summer.

#### NEW STUDIES

We will be adding three more topics to the development pot. Two for the medical and surgical programme and one for child health. The topic selection process is almost complete, but data collection for these won't start until 2022!

**Merry Christmas and a Happy New Year to all the NCEPOD Local Reporters, Ambassadors, and Healthcare Professionals who have helped us this year and an even bigger thank you for all the care you have provided during the pandemic.**



# Study Updates



## **In Hospital Care of Out of Hospital Cardiac Arrests**

The report has been written and is due for publication on 11th February 2021.

## **Dysphagia in people with Parkinson's Disease**

Data collection for this study is now closed. The report is due for publication in the summer of 2021.

## **Physical Health in Mental Health Hospitals**

We are still accepting case identification spreadsheets but have begun case selection and dissemination of clinician questionnaires and case note requests for Mental Health Trusts (and Trusts/Health Boards with integrated mental and physical healthcare). These will continue to be sent out on a rolling basis throughout January and February 2021. We will also be sending an organisational questionnaire to participating Trusts/Health boards in early January. Further information and updates for this study can be found at: [www.ncepod.org.uk/phmh.html](http://www.ncepod.org.uk/phmh.html) or email [phmh@ncepod.org.uk](mailto:phmh@ncepod.org.uk)

## **Transition from child to adult health services**

We are in the early stages of developing this new study to explore the process of the transition of young people with complex chronic conditions from child to adult health services. Data will be collected from primary, community, secondary and tertiary care organisations. We will be in touch early in the new year with further information about the study, and data collection is due to start in the spring. More information about the study as it becomes available can be found at: [www.ncepod.org.uk/transition.html](http://www.ncepod.org.uk/transition.html) or email [transition@ncepod.org.uk](mailto:transition@ncepod.org.uk)

## **Epilepsy**

We are just finalising the protocol for this study which will look at variation in the processes of care of patients presenting to hospital following an epileptic seizure. A Study Advisory Group has been recruited and drafting the questionnaires has commenced. We will be emailing all Local Reporters from relevant hospitals in January with more information, including a recruitment advert for case reviewers. More information about the study as it becomes available can be found at: [www.ncepod.org.uk/epilepsy.html](http://www.ncepod.org.uk/epilepsy.html) or email [epilepsy@ncepod.org.uk](mailto:epilepsy@ncepod.org.uk)

## **Crohn's Disease**

We are currently forming a Study Advisory Group who will meet early in 2021 to start developing the protocol for this study. Further information will be added to our website as it becomes available.

## **Community Acquired Pneumonia**

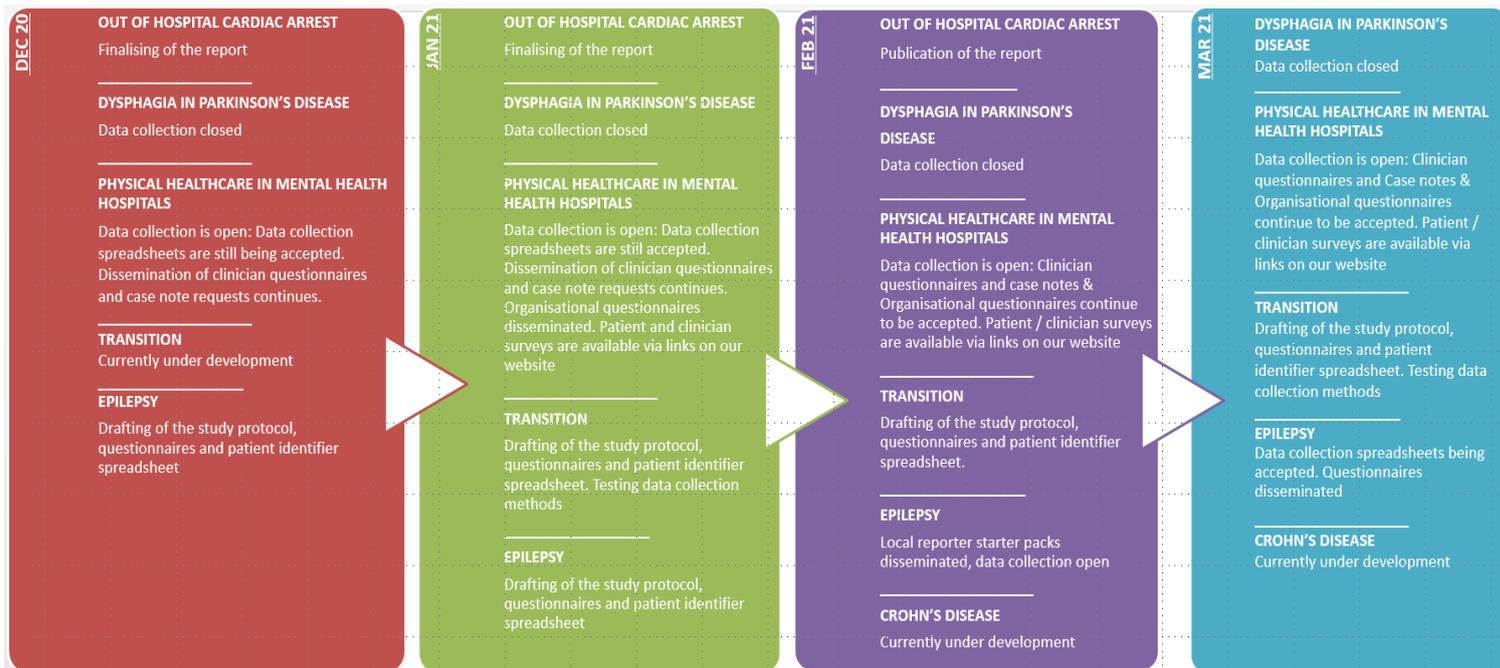
We will shortly be forming a Study Advisory Group who will meet in 2021 to start developing the protocol for this study. We have had discussions with the study proposers who are all content that that study will still be relevant, despite the timing with the pandemic. Further information will be available on our website as it becomes available.

## **Quality Accounts**

From 2021 we will no longer be providing a summary of returns for Quality Accounts as activity can be seen on the online questionnaire system.



## What's coming up...studies at a glance



### Alcohol-Related Liver Disease

In 2013 we published a report 'Measuring the Units' which looked at the care received by patients who died from alcohol-related liver disease. The report identified a number of key areas that needed improving for this group of patients. We are planning a short, mainly organisational survey, to see if some of the changes highlighted in the report have been implemented. The survey will open in mid-January and we are working with The British Society of Gastroenterology (BSG) and British Association for the Study of the Liver (BASL) to inform its members and advertise the survey. Local Reporters of relevant Trusts/Health Boards will be contacted with further information in January and the survey itself will be shared via our online questionnaire system. You can contact us about this here: [arld@ncepod.org.uk](mailto:arld@ncepod.org.uk)

### Stakeholder meetings

In the New Year we will be holding stakeholder meetings for the reports we have published on '**mental healthcare in young people**', '**pulmonary embolism**' and '**acute bowel obstruction**'. If you are aware of any local discussions, work being undertaken or changes in practice, which have been implemented following the publication of these reports, and you would like to share the details at the meeting, or generally with us, please email an outline of the work to [info@ncepod.org.uk](mailto:info@ncepod.org.uk)

### SNOMED codes

As our studies often extend into primary care, we are starting to explore the use of SNOMED codes as a means of patient identification. We would like to speak to any Local Reporters who use SNOMED codes, to help us understand how this coding works at a hospital level, and what we would need to ask in order to identify patients for inclusion in future studies. If you are able to help with this, please email us at [info@ncepod.org.uk](mailto:info@ncepod.org.uk)

### QI survey

We plan to undertake a survey of QI needs nearly next year, with aim of support local QI initiatives based on the findings of our reports. We want to see what might be useful to those undertaking QI, and how this might affect how we develop studies - details to follow in 2021!

### Realistic recommendation check

We would like to ask Local Reporters, on the receiving end of reports, to provide a 'realistic recommendation check'. If you think you would like to be involved in a small group that provides comments on how our recommendations would be enabled locally then please email us at [info@ncepod.org.uk](mailto:info@ncepod.org.uk)



## Local Reporter & Ambassador days

**Tuesday 9th March 2021**

If you are interested in attending the above virtual NCEPOD day, please send your interest to:

Anisa Warsame [awarsame@ncepod.org.uk](mailto:awarsame@ncepod.org.uk)

If you are interested in becoming an Ambassador contact us at [info@ncepod.org.uk](mailto:info@ncepod.org.uk) and we can tell you whether your hospital, or Trust/Health Board has someone already.

## Contacting us

We are still not fully back in the NCEPOD office and the office will be closed 21st Dec to 4th Jan. Please use email to contact us, either directly to a team member or via [info@ncepod.org.uk](mailto:info@ncepod.org.uk)

If you call the office there are emergency numbers on the answerphone, or if not urgent leave us a message and we will pick it up - we are in the office at least once a week.

## Returning case notes to NCEPOD

### By email - our preferred method of delivery

- ◆ Scan the notes as a PDF or save PDFs from your electronic patient record
- ◆ Always password-protect the files (do not use easy-to-guess passwords, such as the hospital or study name, and don't put the password in the email with the attached files)
- ◆ Email them to us (in a logical order) at [ncepod@nhs.net](mailto:ncepod@nhs.net), not one of the study or personal email addresses
- ◆ Phone us to inform us when they have been sent and to let us know the password—you can speak to any staff member who answers the phone.

### By post

If you are unable to email the notes to us they should be packaged securely and sent via our freepost address. Plastic envelopes can be obtained from us.

The freepost licence number is **RTBS - XCXG - RGLA**. Use this licence number, along with our full address below to send any correspondence to us. We recommend that all case notes are sent via recorded delivery. To use Royal Mail recorded delivery, you need to add £1.10 onto the freepost envelope.

On receipt of case notes you should receive an email notifying you that they have been logged on our database. Clinicians completing questionnaires who provide an email will also receive a similar email when they submit a questionnaire so that they can record the activity for their CPD.

## Information Governance

NCEPOD is registered with the Information Commissioner's Office for the purpose of data protection: number **Z5442652**  
In March 2020 we completed and submitted our Data Security and Protection Toolkit to NHS Digital. Information about our data security and protection arrangements is on our website. We have approval to collect patient data under Section 251 of the NHS Act (2006) for all our work programmes.

**For all our approvals, data security and confidentiality information please click [here](#) or contact the office.**

**For information on how patients can opt out of their data being used by us then please click [here](#)**



We are pleased to confirm that we have also just had our Cyber Essentials certification renewed for 2020/2021

NCEPOD now has access to a MESH mailbox to allow us to check files before sharing NHS numbers to match data across different Trusts/Health Boards. Information on the national data opt-out process can be found here:

<https://digital.nhs.uk/services/national-data-opt-out>