A nighttime photograph of the Liverpool city skyline, featuring the illuminated Liverpool City Hall and other buildings, with their lights reflecting in the water in the foreground. The sky is dark, and a crescent moon is visible in the upper left.

**Mind the gap**  
Effect of COVID-19 on UK botulinum toxin  
(BtX) services

**Dr Peter Moore**

*The Walton Centre NHS Foundation Trust*

*Liverpool, UK*

# Disclosures

Research funding, travel grants, consultancy and speaker payments from Allergan, Ipsen, Merz

# Current state

- Many BtX clinics have closed to
  - Reduce risk of virus transmission
  - Free up resources to treat COVID-19
- A few still running
  - Depend on local hospital policies
  - Negotiated with individual clinician Leads
  - Mostly limited and / or selected throughput
  - Various conditions imposed around safety and availability of facilities

# Consequences

- Large and increasing gap in treatment cycles
  - Big impact on
    - patients with short effective cycles
    - patients with critical benefits – pain, function, ADLs, carers, work, safety
  - Reverting to alternative treatments
    - Less effective, AEs
  - Anxiety about re-starting BtX clinics
    - Timing and priorities uncertain

# BNN Guidelines

- Aim to develop discussion rather than dictate policy
- Identify issues for each service to consider
- Recognise each service has unique constraints and options
- Sent to members rather than published on website

# Practical issues

- Full or phased return of clinics
- Staff and resource availability
- Strategy for call-up and prioritisation
- Buy-in from patients

# Clinic Appointment Strategies

- Restart regular 3 month cycle in booked sequence / from longest interval
- Prioritise patients by severity, risk and disability
- Additional clinics to clear the backlog?
  - but avoid an ongoing ‘bulge’?
- How many can you process?

# Efficiency and safety

- Avoid attendance if
  - potentially infected, or shielding
- Preparing patients for first visit back
  - Timing of transport to minimise queues
  - Waiting area and treatment room set-up
  - Information to bring
  - Restrictions during clinical interactions



# Clinic Room Considerations

- Social distancing in clinic and waiting room
- PPE (refer to local guidelines)
  - Patient and injector
  - Depends on procedure
- Palpation / injection from behind the patient where possible for CD
- Avoid speaking during procedure

# BtX and COVID-19 interactions

- No known effect of BtX on COVID-19
- ?COVID-19 affects BtX Rx
  - Myalgia (CK), neuropathy, post-viral immune
  - Trauma to local tissues (eg tracheostomy)
  - Drug interactions
  - Susceptibility to anti-toxin antibodies

# Unique natural experiment

- Nature and effect of restart strategies
  - Optimum 2<sup>nd</sup> lockdown/unlock policies
- Effect of gap in treatment
  - Patients quality of life
    - Could support improved service provision
    - More susceptible sub-groups
  - Quality of BtX response

# BtX and underlying disease

- Is effect of BtX different after a gap?
  - ?irretrievable reduction in benefit
  - ?usual response 1<sup>st</sup> restart cycle, or need several
- Progression of the underlying disease
  - ? Differential effect in eg dystonia / migraine
  - Does severity or apparent pattern dystonia change?

# Service Evaluation / Audit / Research?

- Unlock timescale and pace uncertain
  - Longer gap more informative
  - Complex prospective studies slow to initiate
  - Red tape
- Restarting clinics very busy
  - Can we use routinely collected information?
  - Minimise in-clinic burden
- Single-centre vs multicentre
  - Numbers, controls

# Mind the Gap

- Service Evaluation
- Livechart to collect process and outcome data
  - In use in some centres already
  - PROM – single sheet / cycle, completed by patient
  - Scan and email to collection point
- Collect for 4 cycles
  - Pre-Lockdown prospective / retrospective

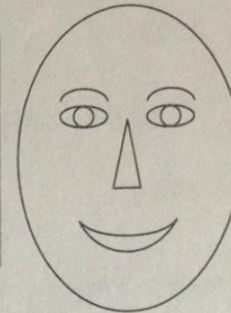


# Classic response

## LIVECHART The LIVERpool botulinum toxin effects CHART

Ms WO [redacted]  
29 [redacted]  
[redacted] e Road  
Chester  
CH1 [redacted] 5NN  
PAT [redacted]

Botox®	Dysport®	Neurobloc®	Xeomin®
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	Right	Left
SM	125	
SC	75	
LS	100	50
T	50	
Total	400	[redacted]

Section 2. How well are your symptoms controlled?

WEEK	BAD	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100			
1	10/2/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
2	18/2/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
3	26/2/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
4	5/3/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
5	14/3/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
6	21/3/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
7	29/3/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
8	7/4/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
9	16/4/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
10	24/4/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
11	1/5/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
12	9/5/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
13	17/5/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
14	24/5/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
15	3/6/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
16	11/6/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
17	20/6/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
18	29/6/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100
19	5/7/12	0	5	10	15	20	25	30	35	40	45	50	55	60	65	70	75	80	85	90	95	100

Hair Loss GOOD

- Section 3.
- a low soon did you feel some effect? 2 days/weeks
  - b low long before it was working reasonably well? 2 days/weeks
  - c low long did this response last? 14-15 days/weeks → ?
  - d low long ago did it start to wear off? approx 3 days/weeks
  - e or how long has it not been working well enough? 3 days/weeks
  - f ow long since it wore off completely? 2 days/weeks

Continuation grid overleaf

Section 4. Did you experience any side effects? Please describe these side effects in the boxes below.

Side effects	Start - days/weeks	End - days/weeks	How long did it last?	Severity - Mild/Moderate/Severe
Sore Throat	Start Mid Feb	lasted approx 2 weeks		Moderate
Dry Eyes	Started beginning March	Continued on + off for 2 months		Moderate
Hair loss	During March + April		When combing hair, more hair than usual coming out in comb	Mild to Moderate

Section 5. While it was working what was the effect of your injection?

Major deterioration	Moderate deterioration	Minor deterioration	No effect	Minor benefit	<b>Moderate benefit</b>	Major benefit
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# Not used Livechart?

- For any condition treated with BtX
  - Simplifies clinic, avoids disease-specific scales
  - Same chart for multiple conditions
- Clear record treatment and effect on one page
- Takes 3-4 minutes to explain first time
  - Training video and instructions online
- Improves patient understanding and engagement
- Speeds up FU visits


# Data analysis

- Condition treated / differential effect
- Dose and distribution
- Response
  - Likert scores
  - VAS analysis
  - Adverse effects
- Could be compared to any disease-specific scale data also collected routinely

# Interested in principle?

- Please indicate using screen button
- Will hold a further webinar: time tbc
- Any thoughts / ideas welcome
- Propose a collaboration clinical centres and patient groups

[mindthegap@thewaltoncentre.nhs.uk](mailto:mindthegap@thewaltoncentre.nhs.uk)

A nighttime photograph of the Liverpool city skyline, featuring the illuminated Liverpool City Hall and other buildings, reflected in the water of the Mersey River. The scene is lit with warm yellow and orange lights, creating a vibrant reflection on the dark water.

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