

Engaging with your elected representatives

Big Conversation
Wednesday 2nd April 2025

Welcome and introductions

Katie Reade, Head of Policy & Public Affairs
Hospice UK

Housekeeping



Please keep your mic muted unless you are asking a question



Please note that the presentations (excluding the Q&A) are being recorded.



The recording and slides will be shared with you after the event, and we'll notify you by email



Please use the Chat function to ask any questions



AI bots are not permitted in these meetings and will be removed

Agenda

11:30	Welcome and Hospice UK's parliamentary engagement	Katie Reade, Head of Policy & Public Affairs Hospice UK
11:35	Greater Manchester Hospices' Grand Day Out to Parliament	Martin Foster, Programme Lead Greater Manchester Hospices Provider Collaborative
11:45	Working with elected members... ...to keep funding on the political agenda	Gareth Pierce, Forget Me Not Children's Hospice CEO
11:55	The Good, the Bad and the Ugly- the risks and rewards of political engagement	Kenny Steele, Highlands Hospice CEO
12:05	Q&A	All
12:20	Group discussion	All
12:55 - 13:00	Close	Katie Reade, Head of Policy & Public Affairs Hospice UK

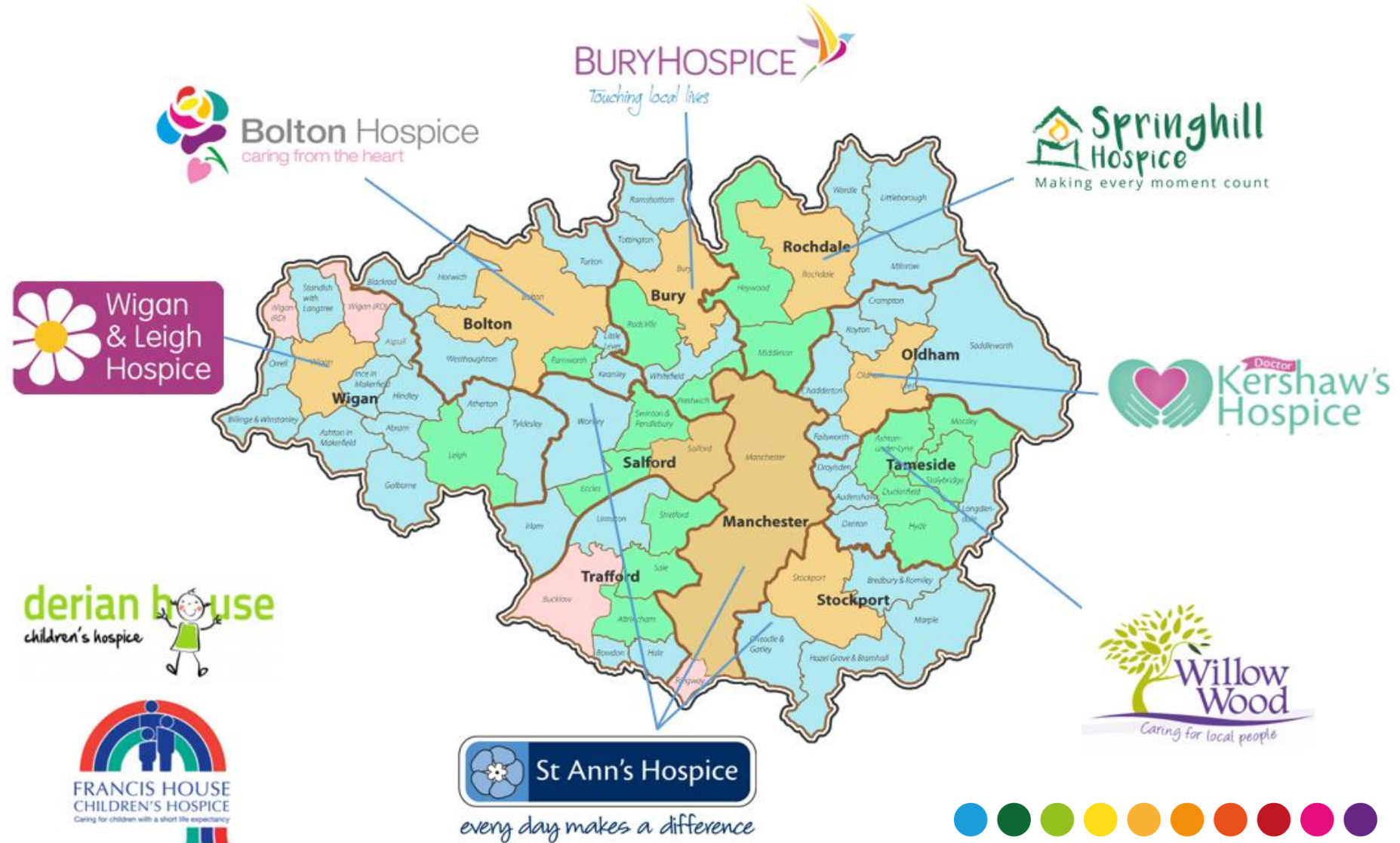
Hospice UK's parliamentary engagement

- The strength of the movement – local and national
- A team of six – different approaches in different nations
- Why do elected representatives want to speak to us?
 - Convening the sector
 - A national voice for national issues
 - Not 'just' a constituency issue
 - Capacity to act fast, work at scale and an understanding of Parliaments
- What can we help with?
 - Consistent messaging and hospice presence
 - Ensuring representatives are briefed
 - Creating links with local hospices
 - Advice and support
- Here to help – policy@hospiceuk.org




Greater Manchester Hospices'
Grand Day Out to Parliament

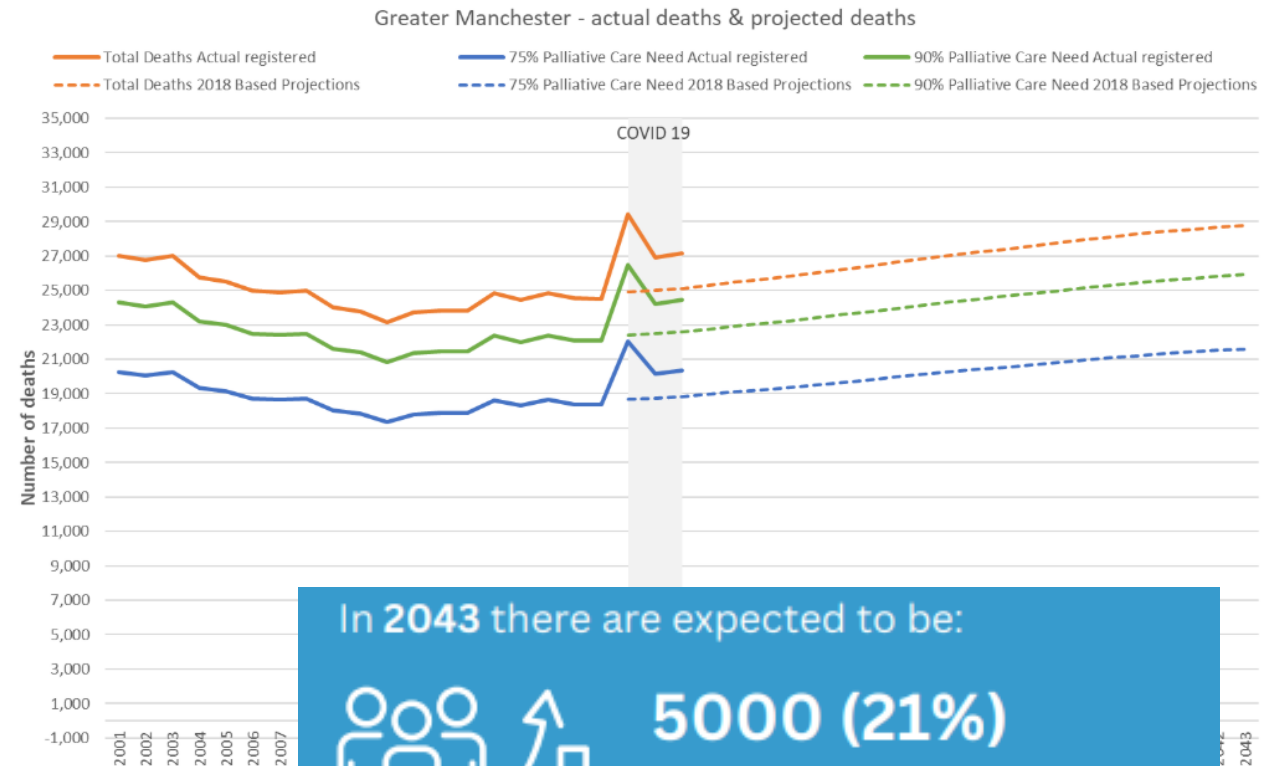
Greater Manchester – 10 localities, 27 MPs



Inequitable care; rising demand

$\frac{1}{3}$ 

In Greater Manchester, 1/3 of people in last year of life have three or more admissions to hospital ⁵



In 2043 there are expected to be:



5000 (21%)

more deaths

3500 (17.5%)

more deaths requiring palliative care

each year in Greater Manchester than in 2019 ⁶



Financial sustainability challenge



Great traction with GM ICB – but their hands are tied



- GM Hospices Collaborative has made great strides engaging our GM ICB colleagues
- Moment of hope last Spring: in spite of huge deficit of its own, ICB agreed to one-off financial boost in 24/25 for all Hospices (uplift = 3.5% total costs)
- Also agreed to ICB-led review of SPC provision in GM, to explore more sustainable model for 25/26+
- Some success around the edges, e.g. min 3-year contracts for all Hospices, commitment to match inflationary NHS uplift (albeit only on % contribution)
- But ultimately all Hospice contracts/financial decisions have returned to locality level – feels back to square one: inequity baked in / “there’s no money”



Funding reform needed – is national the only way?

- Funding model is simply not sustainable – and something has to give
- Government's commitment to £100m in additional capital spend over next 2 years is welcome, but offers a short-term solution
- Long-term reform is needed to prioritise PEO LC and protect Hospice services – maybe only Government can make that happen, via 10 year plan?

**NHS 10 YEAR
PLAN
CONSULTATION**



MPs can be great allies / Gov't influencers

National influence:

Powerful advocates for Hospice movement nationally

Strong relationships can strengthen calls for national funding reform and national prioritisation of palliative care



Local influence:

Could be powerful advocates for our Hospices locally

Strong relationships could perhaps support ICB commissioning negotiations and local prioritisation of palliative care



2024/25: good chance to influence new batch of MPs

- 2024 election ushered in a whole new batch of fresh-faced MPs, many of whom may not have met their hospices before, or even know what hospice care is...
- GM Hospices Collaborative keen to proactively explore a coordinated approach to meeting and influencing this new batch of MPs
- Could we get all 27 GM MPs together, in one place at one time, to hear from us with one united voice?



Event in Parliament idea – thanks, Toby

- Toby Porter suggested Hospice UK could easily support this, e.g. host a round-table event for GM MPs to drop in to
- We dismissed a North West event due to likelihood of low attendance
- Better to host a GM Hospices reception in Westminster itself in mid-week
- Unlikely to get all MPs there at the same time, “but 60-70% maybe”
- Chance to put on a memorable, credible, united front as a Hospice movement



Added momentum from £100m capital announcement

Press release

Biggest investment into hospices in a generation

£100 million boost for adult and children's hospices and £26 million to support children and young people's hospices.

From: [Department of Health and Social Care](#), [Stephen Kinnock MP](#) and [The Rt Hon Wes Streeting MP](#)

Published 19 December 2024

- Dec 2024: news about extra £100m for Hospices
- Doesn't fix our long-term problem, but does show some political investment
- Slightly more open door to sustainable funding reform for Hospices
- Possibly more likely for Ministers to attend



So off we went, 18 March...



So off we went, 18 March...



Key messages (1) – Importance of sustainable SPC

Speech: Senior Clinical Lead for Palliative Care in GM

- Introducing the importance of equitable access to high-quality palliative care
- Setting out the wider strategic context in Greater Manchester, incl rising demand for Specialist Palliative Care / rising complexity of patients etc
- How sustainable investment in SPC is a key part of delivering the shift of care from hospital to community / prevention agenda etc



Key messages (2) – Vital role of Hospices

Speech: Chair of GM Hospices Collaborative



- Why Hospices are such a vital solution to some of the system's key challenges
- Critical investment for wider health & care system
- Lead role of Hospices in shift from hospital to community / prevention agendas
- Significant added social value of Hospices for our communities

HOWEVER...

- Current funding model is broken
- Hospice services being lost just as they're needed the most
- We welcome the clear political & financial investment in Hospice care from the new Gov't - but recurrent, long-term funding reform is still needed to sustain these vital services



Key messages (3) – Lived experience

Speech: Deputy Chief Nurse, GM ICB – and bereaved mother

- Speaking of her own lived experience of Hospice care (her daughter), and what it means to her
- Experience of the alternative in acute services
- Able to link to wider strategic themes and make them feel real



Key messages (4) – CALL TO ACTION

Over to the MPs...

Ask / Action:

- Commitment to letter to Health Ministers...
- From Chair of APPG for GM MPs, and signed by as many GM MPs as possible...
- Seeking a meeting with Minister for DHSC to ensure palliative care & funding reform for Hospices are prioritised



Attendance?

- Only 10 MPs, plus Baroness Ilora Finlay – out of our 27 MPs, relatively low number, but:
- We expected this anyway – busy diaries, so I expected a quick pop-in-/pop-out at best from most of them
- It's about quality, not quantity! Real engagement from MPs who were there
- Although Stephen Kinnock MP couldn't show up on the day, he was engaged with the event beforehand and is tuned in to whatever actions come out of it



Impact? Next steps?

Actions:

- Letter from all GM MPs to Wes Streeting / Stephen Kinnock

Impact?

- Touch wood, impact on 10 year plan / prioritisation of PEO LC
- Keeping national momentum going



The Rt Hon Wes Streeting MP

Secretary of State

Department for Health and Social Care

39 Victoria Street

London

SW1H 0EU

Jo Platt MP

Member of Parliament for Leigh and Atherton

House of Commons, London SW1A 0AA

Email: jo.platt.mp@parliament.uk

Telephone: 020 7219 3657

March 2025



Working with Hospice UK



- Invaluable support from HUK at every step of the way
- Katie Reade, who (along with Liv/Charlie) has been brilliant in helping us to convene and host this event

Key advice

- Identifying & securing a sponsoring MP
- Securing a good, affordable space and time for the event (mid-week afternoons good for attendance, cheaper than evening receptions)
- Who to invite (local MPs, national APPG supporters, other stakeholders)
- Invitations (format, language, chasing RSVPs)
- Aligning regional with national messaging to amplify (shared 10 year plan consultation submission / recent briefings to MPs etc)
- Review of our materials (leaflet etc)
- Support on the day (logistics / media / meeting MPs)





Any questions?



**forget me not
children's hospice**



Working with elected members...
...to keep funding on the political agenda

The keys to success...

- Communicate, communicate, communicate
- Working with you or for you
- Your turf
- Their turf
- WIIFT, WIIFY
- The game



Communicate, Communicate, Communicate

- Key stakeholders
- Not just problems
- Be brave
- Tell it as it is
- Frequency
- HUK / TFSL
- Time

GP Fri 28/03/2025 18:02
Pierce, Gareth
Built to Last? The State of Children's Palliative Care in 2025

To: Pierce, Gareth
Cc: 'Imran Hussain, mp@parliament.uk'; 'CUMMINS, Judith'; 'naz.shah, mp@parliament.uk'; 'yosh.fentonglyn, mp@parliament.uk'; 'Paul Davies MP'; 'iqbal.mohamed, mp@parliament.uk'; 'Kate Dearden MP'; 'harpreet.uppal, mp@parliament.uk'; 'yoblie.moore, mp@parliament.uk'; 'alex.sobel, mp@parliament.uk'; 'anna.dixon, mp@parliament.uk'; 'Yabon Hamilton, mp@parliament.uk'; 'katie.white, mp@parliament.uk'; 'bennh@parliament.uk'; 'mark.sewards, mp@parliament.uk'; 'yachef.reeves, mp@parliament.uk'; 'trickett@parliament.uk'; 'jade.botterill, mp@parliament.uk'; 'cooper@parliament.uk'; 'Zair

This is the most recent version, but you made changes to another copy. Click here to see the other versions.
You forwarded this message on 28/03/2025 18:02.

Dear West Yorkshire MPs,
Forget Me Not Children's Hospice supports seriously ill children and their families across the whole of West Yorkshire.

I am writing to you today to draw your attention to a recent report; **'Built to Last? The State of Children's Palliative Care in 2025'**, published by the UK's children's palliative care charity; Together for Short Lives.

I find this report particularly concerning, in light of the actions that we have recently been forced to take here at Forget Me Not. The report further supports the need for a long term, sustainable model of funding, not just for children's hospices, but palliative care sector as a whole.

The report has been covered by the [Daily Mail](#), [the Independent](#), [ITV News](#) and LBC and shows there is significant variation in the extent to which high quality children's palliative care is being formally planned, funded and provided across England.

According to Together for Short Lives, the postcode lottery is particularly stark in children and families' access to 24/7 end of life care at home, provided by nurses and supported by advice from specialist consultants in paediatric palliative medicine. Improvements have been made in the past year, it is shocking to hear that only 19% of integrated care boards (ICBs) currently commission these services on a formal basis.

The unjustified variation in care is largely driven by workforce shortages, a lack of accountability among local NHS bodies and councils, and a substantial funding gap. Alarming, the report estimates that the shortfall in NHS children's palliative care funding would therefore be grateful if you could please write to ministers and/or take action in Parliament to encourage the UK Government to take the actions recommended in this report. Specifically, Together for Short Lives is calling on the Government to consider the following action:

- Review the way in which children's palliative care is planned and funded, to identify how the £310 million annual gap in NHS spending on children's palliative care in 2025/26 can be filled.
- Fill the £2.4 million annual funding gap in GRID and special interest (SPIN) training in palliative care for paediatric consultants—in addition to other funding gaps in educating and training other professionals, including community children's nurses.
- Use the existing children's palliative care workforce more equitably—and increase the number of professionals who are educated and trained with the skills and experience to provide palliative care to children with life-limiting conditions across a range of different roles.
- Fund frontline voluntary sector providers—including children's hospices—equitably and sustainably for the long-term as their costs increase. In England, this should include a commitment to maintaining ring-fenced, centrally distributed funding for children's hospices beyond 2025/26 as part of a transition to a sustainable funding system.
- Hold ICBs and local councils to greater account for implementing the existing policy frameworks relating to children's palliative care.

With the number of children with life-limiting or life-threatening conditions increasing and becoming more complex, I am concerned that if action is not taken now, more seriously ill children and their families will be denied choice and control over their palliative and end of life care.

I hope you agree that this is unacceptable. Time is short for them, and they cannot wait any longer. Seriously ill children deserve to be supported by a system that is built to last.

Yours sincerely,
Gareth Pierce - CEO - Forget Me Not Children's Hospice
Call me: 07391 011358
Email me: gareth.pierce@forgetmenotchild.co.uk
Find us: Russell House, Fell Creave Road, Huddersfield, HD2 1NH



With you or for you?

- Joint campaigning
- Awareness raising
- Questions in the house (written / oral)
- Questions to ministers
- Local questions
- Voting
- Fundraising



Harpreet Uppal MP • 1st
Labour MP for Huddersfield
1mo •

During DHSC questions this week, I highlighted the pressures facing [Forget Me Not Children's Hospice](#) and [The Kirkwood](#), and called for palliative care to be a central part of the NHS's forthcoming 10-year plan.

I welcome the Minister's response in confirming they are working with the hospice sector but I will continue to call for more support for our hospices locally at what is a challenging time.



Steph Parker (née Hartley) and 24 others

2 reposts



Like

Comment

Repost

Send

Your turf or their turf?

- Hospice visits (persistence)
- Parliament mon-thurs
- Round tables
- Virtual
- Phone / text / whatsapp
- Parliamentary assistants



What's in it for them?

- Awareness
- Kudos
- Positioning
- Air time
- Media
- WIIFM? – Not just the bigger picture stuff



The Game

- Govt. or opposition
- Public / supporter agitation
- Working together – narrative
- Thank you
- When to agree and when to push back
- Reciprocal persistence
- Not in my area



Gareth Pierce MCIOF(AdvDip) · You

CEO at Forget Me Not Children's Hospice

1mo · 🌐

🙏 Thank you [Harpreet Uppal MP](#) for your continued support in keeping this important subject on the table!

[#hospicecare](#) [#palliativecare](#)



Harpreet Uppal MP · 1st

Labour MP for Huddersfield

1mo · 🌐

During DHSC questions this week, I highlighted the pressures facing [Forget Me Not Children's Hospice](#) and [The Kirkwood](#), and called for palliative care to be a central part of the NHS's forthcoming 10-year plan.

I welcome the Minister's response in confirming they are working with the hospice sector but I will continue to call for more support for our hospices locally at what is a challenging time.



👍❤️ Steph Parker (née Hartley) and 24 others

2 reposts



👍 Like

💬 Comment

🔄 Repost

➦ Send

The Good, the Bad and the Ugly- the risks and rewards of political engagement

Kenny Steele, Highlands Hospice
CEO

Q&A

Group discussion

Big Conversations

The Big Conversations series comprises webinars, workshops, and roundtables that enable our members to:

- learn more about key issues
- share knowledge and experience to inform our work
- discuss problems and solutions with peers
- get practical guidance to move work forward

We invite you to continue engaging with us in the months ahead, as we explore a range of important topics.

Scan Me



Feedback Survey

Engaging with you elected representative - Big Conversation 2 April
25



Please consider sparing a few minutes to answer this survey, so that we can continue to improve future Big Conversation events:

<https://forms.office.com/e/1maiJgQqk9>

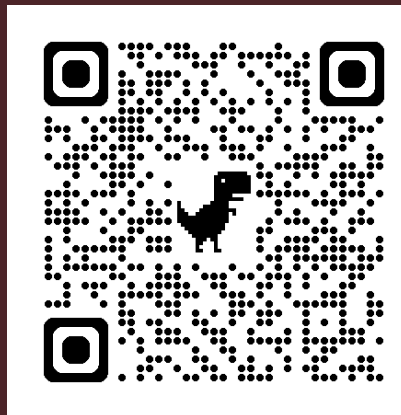
Jobs Board March 2025 Sale

All job listings on our Jobs Board are half price from 1st March to 31st March.

Check out our packages starting from just £74 for a standard listing.



Scan Me



Stay up to date



Scan me

Our [Member Update page](#) is updated regularly so you can keep up with our key work and priorities from week to week.

The page is hidden from the public and will not come up in web searches, so we'd recommend bookmarking it!

Thank you