

BMA Patient Liaison Group Symposium 2024

Valuing diversity, co-design and intersectionality in policy formation

On Wednesday 1 May 2024, the [BMA Patient Liaison Group \(PLG\)](#) held a symposium attended by a wide range of speakers and delegates from different sectors and backgrounds that included people with lived experience, to discuss the importance of diversity, co-design and intersectionality in health policy formation. This document summarizes what each speaker discussed and the delegates' key takeaways.

See Appendix 1 for a list of organisations that attended the symposium, and Appendix 2 for the full programme.

An introduction to creating inclusive policy

Lord Victor Adebowale, Chair of NHS Confederation

Lord Victor Adebowale identified that factors such as intersectionality, co-design, and ethnicity were often seen as add-ons rather than central components of the policymaking process, which posed a significant issue. During the pandemic, Lord Adebowale established the Race and Health Observatory after realising that the first eight people to die of Covid-19 were people of colour (POC) working for the NHS. The health leaders that provided the public face to the crisis response, except for Professor Jonathan Van Tam, were White. Lord Adebowale noted that repeated conversations had taken place with health leaders about the lack of inclusive data and policies, despite well-understood facts such as:

- Black women being four times more likely than White women to die in childbirth in the UK.
- South Asian and Black people being two to four times more likely to develop diabetes than White people.
- African British men being twice as likely to develop prostate cancer as White men of the same age.
- Despite 26% of the NHS workforce being Black, and 50% of nurses in London being Black, leadership in the NHS remained predominantly White.

David Williams, a professor at Harvard University, suggested that addressing race first would benefit all other protected characteristics. Lord Adebowale posed that addressing race inherently dealt with intersectionality. Historical progress, such as the abolition of slavery before women's emancipation and women's rights before LGBTQ+ rights, supported this view.

As a leader, Lord Adebowale considered his race irrelevant; what mattered was his ability to lead all people, everywhere, at all times. David Williams's research into unconscious bias training and other methods revealed that the most powerful intervention in any system was a leader's behaviours and actions—what they said, when they did it, and how long they sustained it. The NHS was criticised for

its poor establishment of acceptable management standards to which leaders could be held accountable.

Lord Adebowale believed that the future was often dictated by the topics we avoided discussing rather than those we addressed. It became evident that intersectionality was not an additional challenge but the central challenge of our health system. The life expectancy of poor people had increased after the founding of the NHS, but this trend was now reversing. Reversing this trend required engaging with communities.

Key principles identified for leaders to improve community health included:

- Diverse groups in organisations make better decisions;
- The importance of local collaboration;
- Understanding community assets;
- Ensuring local people led place-based preventative care.

If any intervention does not improve equity or improve access, why we are doing it should be questioned. One further provocation from Lord Adebowale served as a useful takeaway: think about the things that made one uncomfortable, ask why, and keep probing until the answer is found. This introspection should lead to actionable insights for individuals, organisations, and communities. Attendees were encouraged to leave with this question and continually revisit it.

Recipes for Engagement: Involving Children and Young People (CYP) in policy formation

Emma Sparrow, Head of Children, Young People & Engagement, Royal College of Paediatrics and Child Health

Emma Sparrow emphasised the importance of understanding the rights of CYP, referencing the [United Nations Convention on the Rights of the Child](#) (UNCRC) and the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD). The Royal College of Paediatrics and Child Health used these rights to appropriately involve CYP in policy formation.

Relevant Articles from the UNCRC included:

- Article 12: Voice and Views – Ensured that CYP’s perspectives were heard either individually or collectively.
- Article 23: Living a Full Life – Ensured that disabled children could access all healthcare services.
- Article 24: Best Health Care – Ensured the best healthcare services for CYP.
- Article 27: Standard of Living – Involved CYP in addressing health inequalities around the country, such as the inability of some people to afford public transport to their appointments.
- Article 28: Education – Recognised the right of CYP to attend school and gain experiences that would benefit their future, and emphasised minimising school absences due to medical appointments.
- Article 31: Rest, Relaxation, and Play – Highlighted the importance of CYP enjoying their youth.

Emma identified several key foundations for engaging CYP in policy formation:

- Understanding why this was the right thing to do;
- Determining how it would make a difference;
- Identifying what was needed to be successful;
- Being inclusive, creative, and honouring existing work.

It was noted that the Royal College's [website](#) offered resources and practice examples based on feedback from CYP, which could be beneficial to others. For example, the "Worried and Waiting" [page](#) provided advice and support for CYP who had been referred to a specialist but were facing several months of waiting for their appointment.

Panel discussion: Involving Children and Young People (CYP) in policy formation

Lauren Gilbert, Award-Winning Disabled Activist, Content Creator & Writer

As a member of the Health Inequalities subgroup of the NHS Youth Forum which conducted it, Lauren Gilbert presented a survey that examined the personal healthcare experiences of marginalised CYP, emphasising the critical need to value these voices in policy formation. The survey first explored individuals' characteristics, including age, medical conditions, race, gender, ethnicity, and religion.

Survey questions included:

- *"Do you feel there are enough resources and services available to fulfill your needs?"*
The majority of respondents were unsure or disagreed. One individual shared that they had to wait a year for surgery.
- *"Have you been discriminated against or treated differently by NHS staff when accessing healthcare?"*
Most respondents answered "yes" and recounted negative experiences.
- *"How hopeful are you that your health concerns will be addressed within the next two years?"*
Over two-thirds of respondents were unsure or not confident that their health concerns would be addressed within the next two years.

Recommendations from the survey included:

- Implementing staff training developed and delivered by marginalised people;
- Agreeing that the Oliver McGowan mandatory training on learning disability and autism was beneficial;
- Developing similar training to educate healthcare professionals on transphobia, medical racism, and ableism;
- For trans healthcare specifically, incorporating more insights provided by trans people;
- Addressing negative experiences caused by outdated and ableist attitudes from staff or by physically inaccessible services, as many disabled and chronically ill patients avoid seeing medical professionals due to the high risk of poor treatment.

Lauren identified the following important considerations for future CYP policy formation:

- Active listening: Ensuring lived experiences are centred throughout, and feedback is acted upon;
- Transparency and accountability: Building trust and openness with young people involved, clearly communicating solutions, and providing updates on progress;
- Support: Recognising that using lived experiences to drive change can be emotionally taxing; thus, young people need to be supported throughout the process.

Aishah Farooq, Member of the NHS Assembly and Board Member on Children and Young People's Transformation Programme at NHSE

Aishah Farooq explained that good practice required involving CYP people *directly* in policy formation. She emphasised that including them in guideline formation from the beginning was critical, as this was where power shifted towards people with lived experiences. Aishah highlighted the fine line between hearing and listening; true listening involved not just hearing, but also taking action. Without listening, it was difficult to genuinely understand someone's lived experience. She also stressed the importance of co-production and its value; noting that it takes a lot of courage for young people to share their own experiences. She emphasised how imperative it was to ensure that the views of young people are woven into policy creation and healthcare service design to encourage young people to continually engage in co-production. Additionally, Aishah dispelled the existing stigma that young people did not want to get involved in policy formation, explaining that young people were keen but appropriate and sufficient support, permission and opportunities were needed.

Haris Sultan, Board Member on Children and Young People's Transformation Programme at NHSE

Haris Sultan identified several principles as key to good practice in CYP policy formation:

- Permission: He emphasised the importance of giving young people the permission to enact change in their areas, such as through youth forums, ensuring their involvement from the start.
- Partnerships: For true co-production, Haris stressed that young people needed to be treated as equals to the adults working on these issues; it should not feel tokenistic.
- Power: He advocated for bringing young people onto the boards of organizations, which would facilitate true co-production. Haris believed that granting power would make young people feel more comfortable and empowered to be advocates.

Taking an intersectional approach to healthcare and policy

Dr Amali Lokugamage, Clinician, Academic, Medical Educator, Author

Dr Amali Lokugamage discussed the concept of intersectionality, its significance, and the importance of applying an intersectional approach to healthcare. Intersectionality was shown to serve as a lens for studying the social determinants of health, reducing health disparities, and promoting health equity and social justice. It provided a framework for understanding how social identities, such as gender, caste, sex, race, ethnicity, class, sexuality, religion, disability, age, weight, and physical

appearance, overlapped and interacted to create unique experiences of privilege and oppression. By considering these intersecting identities, researchers and practitioners could gain a more nuanced understanding of social inequalities.

Dr Lokugamage emphasised the necessity of working with individuals who had lived experience, acknowledging the overlapping layers of discrimination and oppression, and the crucial role of intersectionality in equitable policy formation and implementation. Dr Lokugamage explained that intersectionality aims to counteract analytical systems that treat each axis of oppression in isolation, giving the example that discrimination against Black women cannot be explained merely as a combination of misogyny and racism; it is more complex for instance when socioeconomic class is also considered.

Intersectionality was underscored as a means to understand the core problems faced by marginalised groups, and by addressing the needs of the marginalised, society as a whole could benefit. Although critics argued that intersectionality could be vague, Dr Lokugamage clarified that it remained a powerful tool for promoting social and political egalitarianism. Furthermore, she noted that intersectionality links individual, institutional, and structural levels of power in a given sociohistorical context which is necessary for advancing health equity and social justice.

Panel discussion: An intersectional approach to policy formation

Dr Gabby Matthews, Children and Young People's Advocate and junior doctor. Member of the NHS Assembly and King's Fund General Advisory Council

Dr Gabby Matthews noted that she had the privilege of witnessing policy formation both as a young patient involved in charity work and later as a junior doctor trying to lobby the government to put policy into action. She highlighted the challenges in achieving intersectionality and co-production, attributing these difficulties to the fear of not knowing how to implement them effectively. She pointed out that the charity 'Children In All Policies 2030' was advocating for the consideration of children in all policies by 2030. Dr Matthews questioned what needed to be done to meet this goal, acknowledging that although significant work was underway, the deadline of 2030 was rapidly approaching, and involving children's voices in policy was often challenging.

Dr Matthews also questioned whether the right voices were being heard and emphasised the necessity of working across the appropriate sectors to implement policy effectively. She suggested that listening and using data to reflect on work across these sectors were crucial steps in achieving these aims.

Fazilet Hadi, Head of Policy at Disability Rights UK

Fazilet Hadi identified that the views of disabled people were often mediated through others. She emphasised the importance of making every effort to hear their voices directly. Leaders needed to see everyone, avoiding selective comfort with some individuals while excluding others. Inclusion and viewing society from multiple dimensions should be systemic. While anti-discriminatory practices

should be the default, Fazilet noted that people often held biases and assumptions that went unchallenged.

Fazilet stressed the need to ask disabled people what adjustments they required to create a trusting space. Understanding communication needs and creating a safe environment where disabled people could share power and be equals were crucial. Fazilet questioned how people could make themselves truly present in the moment and listen without imposing their assumptions. She also asked how to ensure that no one leaves feeling worse, how to connect individuals with the rest of the group, and how to provide friendship and support.

Kieron Blake, BMA PLG member, Mental Health and Respiratory Diseases Advocate

Kieron Blake emphasised that policy needed to address power imbalances and suggested that disrupting the status quo could be a form of positive disruption. He highlighted the importance of centralising the patient voice. For example, as a Respiratory Diseases Advocate attending a workshop, he got there as a member of the PLG and might be the only Black person present. He noted that many others like him faced similar situations, raising the question of how to bring more diverse voices to the table.

Kieron pointed out that while there were solutions in policy and intersectionality, the challenge lay in reaching them. He stressed that a one-size-fits-all approach was ineffective and that policies needed to be tailored to meet diverse needs. Additionally, he highlighted the simple yet crucial need to be kinder to one another, observing that many people had forgotten this basic principle.

Closing remarks

Charlotte Paddison, BMA PLG member

The Symposium was noted to be a first step in opening up space for conversation.

- For medical education, it was essential to challenge biases in the curriculum that perpetuated prejudice. Health professionals needed training that integrated considerations of health inequity and intersectionality into core thinking, rather than treating these issues as mere add-ons.
- For CYP specifically, it was crucial to create opportunities for them to speak up while ensuring they received adequate support when they did so. The process of speaking up could make them feel vulnerable, especially when discussing negative experiences with healthcare. Planning for their psychological safety and valuing their time appropriately was imperative for professionals seeking their input. Additionally, space needed to be made for CYP to directly contribute to leadership and policy, such as by involving them as governors or board members. Given that CYP comprised 25% of the population, imagining a scenario where they had 25% of the activity and effort in policy terms was advocated.
- Health leaders at national and local levels were called to understand their own identities and how their characteristics influenced their thinking and problem-solving approaches. They

were urged to start with the facts, bring them into discussions, and cultivate reflexivity both individually and institutionally.

- The value of being a positive disruptor was also embraced. For instance, in response to the shift to digital primary care, it was necessary to speak up and question whether it would improve equity and access for the most disadvantaged. If the answer was no, it was essential to reconsider such shifts.

Delegates' perspectives

In breakout groups we asked delegates to share their experiences/reflections on CYP and intersectional approaches to policy formation; what would 'good' look like when involving CYP in policy making; and what actions could be taken forward after this symposium? Key takeaways included:

Involving Children and Young People (CYP) in policy formation

- Young people should be included in decision making as a gold standard within representative structures like committees and boards, both locally and nationally (e.g., every Trust should have a youth forum representative).
- Schools should be involved through outreach activities to engage young people and spark their interest, beyond those already considering a medical career.
- The definition of a child in the UK is variable, unlike most other European countries with clearly defined ages (e.g., Gillick competence at 12, some services up to 16, others 18 or later).
- A particular concern is the transition between child and adult services, which varies significantly across locations and services. It is essential to hear from young people about their experiences with these transitions.
- Social media platforms like TikTok should be utilised to engage young people, as these are often their primary sources of news.
- CYP should be more involved in general practice.
- Freedom of information requests should be sent to integrated care boards to understand their levels of engagement with CYP and to identify good practices.
- PLG is key in the British Medical Association (BMA) as a critical friend and is involved in policy making. Consideration should be given to involving CYP in BMA policy making (e.g., at the Annual Representative Meeting), especially on issues that directly affect them.
- National government backing and creating space for CYP involvement in policy making is crucial. The government creates many policies affecting CYP but often does not involve them in the process. For instance, the policy on gender-questioning children faced significant criticism for not engaging with CYP, despite being directly relevant to them.

An intersectional approach to policy formation

- Ensure that medical training included transformational learning and intersectionality.

- Emphasise the importance of language, noting the need to avoid excluding people from the conversation.
 - Advocate for listening to people and asking them what they needed in policy making, rather than assuming what they wanted or what was best; encouraged challenging one's own assumptions.
 - Actively work with employers within the NHS to understand the intersectional needs of their staff and to tackle prejudice in this way.
 - Consistently share learning and best practices, and create supportive environments for improvement.
 - Address barriers that prevented new voices from being involved in policy making processes, questioning what aspects of the current processes led to the same voices being heard repeatedly.
-

Appendices 1 and 2 listing all the organisations who were represented at the symposium, and the programme respectively follow.

Appendix 1

Attendees at the symposium represented the following organisations:

1. Academy of Medical Sciences
2. Barts Health NHS Trust
3. Big Society Winslow
4. British Medical Association
5. Change Grow Live
6. Circle Group
7. Council For Disabled Children
8. CPWC
9. Dartford and Gravesham NHS Trust
10. Essex Partnership University NHS Trust
11. Faculty of Pharmaceutical Medicine
12. Healthwatch England
13. Healthwatch England
14. Imperial PCPH
15. Macmillan Cancer Support
16. National Children's Bureau
17. National Deaf Children's Society
18. National Confidential Enquiry into Patient Outcome and Death
19. NHS Digital
20. NHS England
21. Northern Care Alliance
22. National Society for the Prevention of Cruelty to Children
23. Peninsula Medical School
24. Royal College of Paediatrics and Child Health
25. Royal College of Physicians of Edinburgh
26. Royal College of Anaesthetists
27. Royal College of Physicians
28. Sandwell and West Birmingham Hospitals NHS Trust
29. Social Benefits Consortium CIC
30. Southern Health and Social Care Trust
31. St Mary's Hospital NHS Trust, Isle of Wight
32. Student Minds
33. Swansea Medical School
34. The Children's Society
35. The Doctor magazine
36. The Health Foundation
37. The King's Fund
38. University of Cambridge
39. Versus Arthritis
40. West Sussex LMC
41. Young Lives Vs Cancer

Appendix 2

Patient Liaison Group Symposium 2024 programme:

Valuing diversity, co-design and intersectionality in policy formation

- 09.30 – 09.35** **Welcome**
Christine Douglass, BMA PLG chair
- 09.35 – 10.00** **An introduction to creating inclusive policy**
Lord Victor Adebowale, Chair of NHS Confederation
- 10.00 – 10.30** **Q&A**
With Lord Victor Adebowale, Chair of NHS Confederation
- 10.30 – 10.45** **Recipes for Engagement: Involving Children and Young People (CYP) in policy formation**
Emma Sparrow, Head of Children, Young People & Engagement, Royal College of Paediatrics and Child Health
- 10.45 – 11.15** **Panel discussion: Involving Children and Young People (CYP) in policy formation**
Chair: Emma Beeden, BMA PLG member
- Lauren Gilbert, Award-Winning Disabled Activist, Content Creator & Writer
 - Aishah Farooq, Member of the NHS Assembly and Board Member on Children and Young People's Transformation Programme at NHSE
 - Haris Sultan, Board Member on Children and Young People's Transformation Programme at NHSE
- 11.15 – 11.45** **Breakout groups**
- 11.45 – 12.00** **Breakout groups feedback**
- 12.00 – 12.15** **Break**
- 12.15 – 12.30** **Taking an intersectional approach to healthcare and policy**
Dr Amali Lokugamage, Clinician, Academic, Medical Educator, Author
- 12.30 – 13.00** **Panel discussion: An intersectional approach to policy formation**
Chair: Rowena Skinner, BMA PLG member
- Dr Gabby Matthews, Children and Young People's Advocate and junior doctor. Member of the NHS Assembly and King's Fund General Advisory Council
 - Fazilet Hadi, Head of Policy at Disability Rights UK
 - Kieron Blake, BMA PLG member, Mental Health and Respiratory Diseases Advocate
- 13.00 – 13.30** **Breakout groups**
- 13.30 – 13.45** **Breakout groups feedback**
- 13.45 – 14.00** **Closing remarks**
Charlotte Paddison, BMA PLG member