



Bliss strategy: 2022-25

Bliss
for babies born
premature or sick



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Introduction from our Chief Executive



During our last strategy period, from 2019 to 2022, Bliss marked our 40th anniversary – an opportunity to reflect on developments in neonatal care, and the significant improvements in life chances for babies born premature or sick which have resulted from our work, since we were founded.

The onset of the COVID-19 pandemic in early 2020, however, had a dramatic impact on neonatal care, on Bliss' work, and on the families touched by a neonatal experience. The most significant change to neonatal services throughout the pandemic was the introduction of rigid access restrictions for parents to neonatal units; a dramatic change from the 24/7 access that parents typically have to their babies on units. This reinforced the importance of Bliss' work, over many years, in advocating for parents to play a central role in their babies' neonatal care and decision-making, as we concentrated our campaigning on the removal of access restrictions. At the same time, we refocused our support for families on helping them through this particularly challenging and distressing time, and our support for health professionals and neonatal units on providing up-to-date guidance and helping them to adapt to new ways of working.

The pandemic has affected different groups in the population in different ways, with those already facing disadvantage often experiencing its worst effects. This has strengthened Bliss' commitment to driving for equity in neonatal care and outcomes, recognising that babies born into families already facing health inequalities may need more, or different, support in order to have the best chance of survival and quality of life. As an early COVID poem put it, *"We are in the same storm, but not in the same boat"*.

Looking ahead to this strategy period, 2022-2025, we are therefore taking a bolder stance in identifying and addressing poor experiences and unequal outcomes amongst the population of babies born premature or sick, and their families.

Our vision remains simple – for **every** baby born premature or sick to have the **best** chance of survival and quality of life.

We know that we have work to do to understand the sometimes complex and multi-faceted barriers facing some babies within our population, and to deliver our work differently in order to overcome these.

We also know that we will only be able to achieve this bold ambition through working collaboratively. Most importantly, this means grounding everything we do in the insights and involvement of our beneficiaries, service users, supporters and other stakeholders, with whom we want to build stronger and longer-term relationships. It also means deepening our existing partnership work with fellow pregnancy and baby charities, as well as forging new and innovative collaborations with other charities and grassroots organisations with whom we can make more of a difference together.

This strategy sets out how we plan to deliver this bold ambition across five strategic objectives, with our plan for the next three years set in the context of our longer-term ambitions in each area.

I am mindful, as ever, that we can only deliver this with the generous help of our incredible supporters, so I want to extend my heartfelt thanks to all of you who have supported Bliss to date; and to all of you who will do so in the future.

A handwritten signature in black ink, which appears to read 'Caroline Lee-Davey'.

Caroline Lee-Davey,
Chief Executive

Our vision, mission and values



Our Vision

That every baby born premature or sick in the UK has the best chance of survival and quality of life.



Our Mission

Bliss champions the right for every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.



Our Values

We are trusted, supportive and ambitious.

Who are we here to help?

For all babies born premature or sick, throughout their neonatal journey

When Bliss was founded in 1979, our charitable objective was described as “*to support the life of babies in distress at birth*”. Throughout our history, our focus has remained on the whole neonatal population of babies either born prematurely, or those born at full-term but needing admission to neonatal care.

Every year, over 90,000 babies¹ are cared for in neonatal units in the UK because they have either been born prematurely (before 37 weeks of pregnancy), or full term (after 37 weeks) but sick. This means one in every seven babies born in the UK each year is admitted to neonatal care. More than 60% of these babies are born at full term, however Bliss’ research shows that their families often feel less visible and less supported in neonatal care. This is why we have launched a full-term awareness campaign, which now takes place annually each February, and are committed to doing more throughout this strategy period to better represent and support full-term neonatal journeys.

We will continue to focus our work for all babies most closely on the period of time from the start of a family’s neonatal journey – including support for those families whose baby sadly dies in neonatal care – through to the early months after returning home; recognising that it is in this time that we can make the biggest difference based on our expertise and experience.

For those who need us the most: recognising and addressing health inequalities

Health systems across all four nations of the UK recognise the need to reduce health inequality, and are beginning to implement a range of programmes to reduce unwarranted variations in care, experience and outcomes. While it is not within Bliss’ charitable remit to try to address all health inequalities, our starting point must be to acknowledge that these inequalities exist, and that our neonatal population is born into and cared for within a health system and society which is structurally unequal.

Many of the ways that these inequalities manifest within neonatal care are clearly identifiable: for example, babies from certain ethnic or socio-economic backgrounds have a significantly higher risk of pre-term birth, and of perinatal mortality; and parents from lower socio-economic backgrounds are likely to face financial barriers which prevent them from spending as much time in neonatal care with their baby as they would like. There is also much that we don’t yet know about how inequalities affect neonatal care and babies’ and families’ lives, including how the outcomes of a neonatal stay may vary for babies from different backgrounds, or how differential experiences of neonatal care may affect some parents’ ability to be involved in their babies’ care.

Throughout this strategy, therefore, we are committed to using the lens of health inequality to identify how we can make the biggest difference for babies born premature or sick; both through seeking to address the evidence gap in what we know about the experience, delivery and outcomes of neonatal care for different groups; and, significantly, through working closely with specific communities within the neonatal population to develop and deliver our work in ways which better meet everyone’s needs.

¹The number of babies admitted to neonatal care fluctuates slightly each year; this statistic is based on latest information from 2021 when around 92,700 babies were admitted to neonatal care, according to various sources including the Office for National Statistics and Imperial College London’s Neonatal Health Intelligence Tool.

Our approach to language

We strive to be transparent in how we use language. Throughout this strategy and across our work, we refer to health inequality (or health inequalities). These terms refer to the **unequal access to and experiences of healthcare services**, support and information, and the **unequal healthcare outcomes** which are apparent across the UK population, and across the population of families who experience neonatal care.

These inequalities exist due to many different and often interconnected factors. These include ethnicity, socio-economic status, characteristics which are protected by the Equality Act 2010, such as age, sex, religion or belief, and sexual orientation; as well as factors such as digital access and skills, literacy, education, and employment status. There are regional differences – and differences across the four nations of the UK – in care access, experiences and outcomes. Often these inequalities are experienced as barriers to families' involvement in care and decision-making for their babies while on the neonatal unit.

This strategy is written in 2022 and throughout the strategy period we will continue to build our understanding of health inequalities in the neonatal field. We will be working in partnership to do this, and by increasing our engagement with more people affected by these inequalities, so that they are more involved and better represented in our work. It is likely that our understanding of inequalities will improve, and that language will be used differently over the three years of this strategy period. We acknowledge the importance of language to the experience of families and to tackling these inequalities. We will endeavour to reflect best practice, acknowledging we will not always get it right, and we commit to involve and learn from people who are affected by health inequalities to improve outcomes for **all** babies born premature or sick.

Our approach

Supporting the babies of today, and improving care for the babies of tomorrow

Across this strategy we aim to strike a balance between the work that we are doing to improve outcomes for the babies born premature or sick and being cared for today; and the work that we are doing to improve outcomes for babies born premature or sick in the future.

We are taking this approach so that we can deliver tangible benefits and improvements to babies in neonatal care now, while also working towards securing improvements to the quality of neonatal care – and therefore the outcomes for babies – delivered over the long-term.

Research with and insight from service users informs both policy development and service delivery, through which we in turn capture new insights to drive further change. During this strategy period we are committed to driving innovation through this cycle, through testing and learning as we develop and deliver our work, in particular to enable greater digital innovation.

Embedding insight and involvement across our work

At Bliss, we have always involved our service users, supporters and stakeholders to inform and develop our programmes of work; from our foundation by parents with personal experience of neonatal care through to more recent work to engage our service users in shaping new service developments. However, our involvement work so far has not successfully engaged with a fully representative group of neonatal families; nor have we yet embedded involvement across every aspect of our work.

In this strategy period, we are committing to put babies' and families' voices at the heart of everything we do.

Building partnership and collaborative ways of working to achieve even more

We know from longstanding experience that we are able to deliver more for babies born premature or sick when we work together with others: whether this be through joint policy and campaigning work with fellow pregnancy and baby charities; working with neonatal academics and researchers to identify new breakthroughs in neonatal care; or partnering with professional bodies and health professionals to drive change. This is how we can make the biggest difference for all vulnerable babies.

In addition to continuing and strengthening our existing partnership work, we are keen to build even greater collaboration across our programmes of work throughout this strategy period – for example working with grassroots organisations with whom we may better reach different communities; joining more closely with other neonatal-specific charities to meet more of families' information and support needs and to build a stronger voice for the neonatal sector overall; and building relationships with a broader range of corporate partners whose audiences and aims align with ours.

Our 2022-2025 goals



Campaigning for change



Supporting all neonatal families



Improving care for babies



Putting research into practice



Working with our amazing supporters and staff

Our strategic objectives



Campaigning for change

Ensure that national and local policy changes are delivered which improve the staffing, systems and investment in neonatal care; and which enable more parents to be at their baby's bedside and to play a hands-on role in their care and decision-making

"My biggest regret was that I wasn't there more for Joseph and felt that I missed so much, but I couldn't afford it. Having neonatal leave and pay is so important."

- Thomas, dad to Joseph, born at 25 weeks and four days

Long-term ambitions

- For neonatal care to be adequately funded and staffed with a full multidisciplinary team across every nation of the UK, to ensure every baby has access to consistent high-quality care
- For there to be national leave and pay and financial support policies in place which enable every parent to spend significant quality time with their baby in neonatal care
- For the central role of parents in neonatal care to be consistently embedded in national policy and guidance, and delivered on the ground
- For every baby to receive equitable neonatal care.

We will:

- Prioritise securing the delivery of ongoing policy commitments to deliver lasting change for babies and families, including legislation to bring in Neonatal Leave and Pay; and the delivery of existing commitments in England and Scotland through full implementation of the Neonatal Critical Care Review and Best Start programmes
- Work closely with partners across the pregnancy and baby charity sector to identify and address the factors that will make the most difference to reducing rates of neonatal mortality and pre-term birth
- Develop greater insights into the health inequalities within neonatal care, working with external partners to make best use of evidence to drive policy change where needed
- Do more campaigning through which our supporters can get directly involved in influencing meaningful change, and through which we can leverage the voices of parents and families to deliver more.

We will know we are successful when:

- Neonatal Leave and Pay is enacted across the UK
- The Neonatal Critical Care Review is implemented in full across England, including committed capital spend to improve cot capacity, accommodation and facilities for parents
- More families across the UK have access to a package of financial support when their baby or babies are receiving neonatal care
- The Best Start Review is implemented in full across Scotland, including the delivery of evidence-based service reconfiguration
- Neonatal mortality and pre-term birth rates are declining, across all groups within the population.



Supporting all neonatal families

Provide information and support for all families with a baby in neonatal care which helps them to be better informed, more confident, less isolated, and more involved in their babies' care and decision-making

"Bliss really helped me and my husband - we had a Zoom call with a Bliss Champion while we were on the NICU. We came off the call feeling more ready to face what we had to come, knowing we weren't alone and that so many others had struggled in similar situations."

- Emma, mother to a full-term baby who spent time in neonatal care

Long-term ambitions

- For every parent of a baby or babies admitted to neonatal care to find out about and be able to engage with Bliss' information and support at the start of their journey
- To provide accessible and inclusive information and support which meets the needs of all neonatal families, focussing especially on families facing inequalities
- To build relationships with parents and families throughout their neonatal journey, making best use of data and digital, to provide the support families need, when they need it
- For every parent to receive equitable support to help them be equally involved in their baby's neonatal care and decision-making.

We will:

- Invest in accessible on-unit and online resources to drive awareness of Bliss' information and support among all families at the point they start their neonatal journey
- Engage with and understand our service users, their experiences, needs and the barriers they face in order to develop new services, and improve existing services, so that we can reach, engage and support every family
- Increase engagement of volunteers, focussing on recruiting volunteers who have faced health inequalities, to support more parents in ways which understand and adapt to their needs
- Build partnerships to increase engagement across the neonatal population, improve support pathways, and reach families from backgrounds and with experiences which are currently under-supported.

We will know we are successful when:

- At least 80% of parents accessing our information and support tell us it helps them be more involved in their babies' neonatal care
- At least 90% of parents tell us they are better informed, less isolated and more confident as a result of our information and support
- We are continuously improving and innovating, based on a strong understanding of families' needs, to deliver personalised information and support in multiple formats
- Our information for families is viewed 500,000 unique times per year, and by a representative number of people who face barriers to access
- We engage families with support services 10,000 times per year, including by a representative number of people who face barriers to access.



Improving care for babies

Drive excellent and equitable care for every baby in every neonatal unit

“Being accredited for the Bliss Baby Charter is recognition of all the hard work and determination from every member of staff in the neonatal unit. We will continue to strive to do our best for all of our families and babies coming through the unit.”

- Claire Adamson, Lead Nurse and Baby Charter Lead at Luton and Dunstable

Long-term ambitions

- For the Bliss Baby Charter to be embedded nationally so that high-quality family-centred care is consistently and comprehensively delivered in every neonatal unit
- For Bliss to be a trusted guardian of best practice in both family-centred care and Family Integrated Care
- For Bliss to support significant numbers of neonatal healthcare professionals to improve their practice and awareness of inequalities in healthcare provision
- For healthcare professionals on every neonatal unit to help parents to engage with Bliss consistently at the start of and throughout their neonatal journey.

We will:

- Deliver tangible improvements in family-centred care at unit level through the further roll-out and delivery of the Bliss Baby Charter across the UK
- Influence practical change and improvements to neonatal care at unit, network and national level
- Develop our understanding of and support for Family Integrated Care to provide a consistent framework to improve best practice, alongside supporting family-centred care
- Develop a programme of communications, training and events for health professionals with a particular focus on sharing best practice, and on sharing insights from a diverse range of parents and families to improve health professionals' understanding of and support for different needs; working with corporate partners where possible to maximise reach.

We will know we are successful when:

- A minimum of 40 units have reached gold accreditation with the Baby Charter
- We engage and support best practice through providing communications, networking and learning and development opportunities to a new cohort of neonatal health professionals each year
- We have built a common understanding across the sector of the shared goals of Family Integrated Care and the Baby Charter, and are actively supporting units to put families at the heart of their baby's care through excellence in the delivery of both models of care.

Put parents' and babies' voices at the heart of research, and use new evidence to inform tangible improvements in care on the ground

"I like to think that because of all the research my little boy is here today. He was born at 29 weeks and is now three and a half. Studies can only improve things further."

- Hannah, mum to a premature baby who spent time in neonatal care

Long-term ambitions

- For new research findings about the role of parental touch in reducing pain to be translated into daily practice in neonatal units across the UK
- For all Bliss-supported research projects to involve meaningful consideration of inequalities in research design and delivery
- For more parents of babies admitted to neonatal care to understand the role of research in improving care.

We will:

- Conclude and publish results from our grant-funded research work with Oxford University on the measurement and management of pain in premature babies; and work with their research team to develop and disseminate a suite of parent resources on the importance of parental touch in neonatal care informed by the research findings
- Conduct a full evaluation of our grant-funded research, to share its impact as well as to inform any future decisions about research funding
- Prioritise our non-funding research support on facilitating parent/patient involvement and voice in research projects, to maximise the benefit to babies of research findings; in particular promoting a more inclusive approach to research projects to improve the engagement of diverse communities in research
- Undertake further work to understand more about neonatal care delivery, outcomes, and parent experiences across different groups of babies and families, and use this insight to inform work to address inequalities identified.

We will know we are successful when:

- Research findings from our funded research project with Oxford University have informed accessible information resources which are widely disseminated to parent and practitioner audiences
- There is a more comprehensive evidence base on how health inequalities affect the delivery of care and outcomes for babies receiving neonatal care, and on how best to address these.



Working with our amazing supporters and staff

Build the organisational infrastructure and workforce to enable Bliss to make the biggest difference for babies born premature or sick

“The best thing about working for Bliss is knowing that the work I do helps families to be more informed and well supported. I’m so proud that we are helping families know that they are not on their own, and that we can speak up for them too.”

- Bliss staff member in our annual staff survey

Long-term ambitions

- To develop our culture and ways of working to ensure that Bliss is an attractive, inclusive and family-friendly employer, able to recruit and retain a committed and diverse workforce
- To have the internal skills and capacity in place to make best use of digital and data, and be able to respond nimbly to emerging technology opportunities and risks
- To have the skills, partnerships and capacity to engage our service users and those with lived experience of neonatal care meaningfully in all aspects of our work
- To build the foundations for fundraising which deliver sustainable long-term income diversification and growth, and also support broader strategic objectives through reaching new audiences, raising brand awareness, and engaging supporters.

We will:

- Build a programme of activities to attract, retain and support a motivated and diverse staff, trustee and volunteer body
- Develop and embed policies and practices which are effective in ensuring that all the people within the organisation – our staff, volunteers, trustees, and involvement participants – feel valued and experience a genuine sense of connection to our mission
- Facilitate an agile approach within all our ways of working to enable us to take advantage of new funding and service delivery opportunities, to test and learn in our development of technological and infrastructure improvements, and to equip staff with multi-disciplinary skills and experience
- Expand our digital capacity and upskill our staff to ensure we can effectively resource the development and delivery of appropriate technology solutions to meet the needs of our service users and supporters, as well as to drive internal efficiency, whilst balancing the need for cost effectiveness
- Build the foundations of a sustainable fundraising programme through the implementation of the fundraising strategy, to deliver long-term growth
- Embed supporter involvement and insight across all aspects of our fundraising to build long-term engagement and relationships with our supporters
- Develop a suite of online and offline fundraising products and opportunities which meet the needs and expectations of existing and potential supporters
- Embed an organisational impact framework through which we can capture and report meaningful data about the impact we deliver, to inform investment and decision-making as well as fundraising activity

- Take practical steps across our organisation to understand and reduce our environmental impact.

We will know we are successful when:

- 80% of our staff recommend Bliss as a good place to work
- Service user involvement informs all of our work and decision-making
- Our annual income reaches £2.9M by the end of the strategy period
- We are able to report regularly on the impact of our work for babies and families using robust and routinely-collected data

Join the family

If your baby is on a neonatal unit because they were born premature or sick, you're not alone. Find practical information, emotional support and a community of families with a neonatal experience at bliss.org.uk

Join the family, search Blisscharity



Registered charity no. 1002973 Scottish registered charity SC040878

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