Select Committee on Charities – Call for Evidence

About Us

At the heart of The Brain Tumour Charity is our vision to see brain tumours defeated. They are the biggest cancer killer of our children and adults under 40. Because of where they are, they are difficult to treat and steal life. Their impact is far reaching – for the person that they affect, their family and friends, the wider community and on our economy. There’s been very little progress in their treatment and survival rates have barely changed over the last 40 years. As a charity we are committed to having the biggest possible impact for every person affected by a brain tumour, to defending the most amazing part of the human body, so that getting a diagnosis no longer means a death sentence.

Responses to consultation questions

1. What is the role and purpose of charities in civic society in England and Wales?
   - How has this changed?
   - What makes them distinct from other organisations doing similar work?

1.1 The purpose of charities is to meet need that is not met by the state. In the health and social care sector this could be through direct service provision and advocacy on behalf of patients and their families. It is also the case that charities meet need by furthering our understanding of causes and trialling new models of meeting need (i.e. new services, new treatments and medical research).

1.2 The Brain Tumour Charity was founded by parents who had lost their child to a brain tumour, and wanted to make sure that support was available so no one would face brain tumours alone. They saw the need to reduce diagnosis times, speak up against inequalities in brain tumour research funding and lack of progress in improving survival. The charity has grown into the largest dedicated funder of brain tumour research in the UK, investing over £18.3million to date and providing support to thousands of people personally affected each year. We actively provide the patient voice in any arena where it is vital that they are heard – whether in developing services, campaigning for change or shaping research.

1.3 Over the last two decades, the role of charities in health and social care has broadened, with many charities now investing heavily in research as well as being active in campaigning, lobbying policymakers in the NHS, NICE and Government on behalf of the patients they represent on issues like improving earlier diagnosis of cancer. This trend is evidenced in The Brain Tumour Charity’s own journey as we have sought to improve the quality of life of people living with the disease. Overstretched statutory services just don’t have the resources to address the isolation that people experience, or to provide support when relationships are pushed to the limits, or even represent their patients amongst policymakers – we do. Because those that give generously to fund our work, we are able to fund research giving hope for the future, as well as providing support for life today.

1.4 Finally, charities can help to raise public awareness of conditions (and their symptoms) that have not been prioritised by central or local government bodies tasked with building understanding of health and social care conditions.
For example, as a charity we have a duty to raise awareness of the symptoms of brain tumour amongst the general public\(^1\) – early diagnosis means treatment may be available sooner and long term outcomes may be better. Our HeadSmart campaign, which raises awareness of the signs and symptoms of brain tumours, was developed with the University of Nottingham and the Royal College of Paediatrics and Child Health (RCPCH) in response to a lack of public awareness of the disease. Since its launch, the campaign has helped to reduce average diagnosis times from 9.1 weeks in 2011 to 6.7 weeks in 2014.

Despite attempts to include evidence from HeadSmart in national public health campaigns such as Be Clear on Cancer, much of the focus of these campaigns has been on more common cancers and symptoms, meaning that charities representing rarer cancers will continue to play a prominent role in raising public awareness.

- **What role can charities play in community cohesion and civic action?**

1.5 Charities play a vital role in bringing people together for a common cause, building communities that transcend geographical boundaries. We also speak out on behalf of our beneficiaries and campaign for change when statutory services let them down, holding healthcare providers to account.

1.6 A brain tumour diagnosis, and the ensuing symptoms, can have a devastating impact on the social fabric of a person’s life, causing them to retreat from social and leisure activity\(^2\). By recruiting volunteers who have been personally affected by a brain tumour, we have helped to reduce social isolation, providing people with an opportunity to use their skills and make a contribution to the Charity’s work.

1.7 Community and corporate partnerships between charities and businesses can also promote civic action, engaging employees in charitable activity to raise funds for a cause. In some cases, the choice of charity to partner with is based on the experience of an employee who has been affected by a particular condition or life experience. Many of these partnerships help a charity to directly meet its strategic objectives - in our case, a recent fundraising challenge completed by a major donor and colleagues from Goldman Sachs has funded a new paediatric brain tumour research centre.

1.8 Other partnerships are based around the sharing of equipment or expertise, which are provided to a charity at a lower cost or no charge at all – for the last four years, our partnership with Bluecube Technology Solutions has provided IT support (to a value in excess of £120,000 per annum) at no cost which has helped the Charity to focus spending on research and services.

1.9 Since 2013, The Brain Tumour Charity has organised annual 10km “Twilight Walks” in town centres across England, which engages local people from the regions around Warwick, Windsor and Chester to walk together for a cause. We have gone into greater detail about how partnerships between local charities can build community cohesion in answer to question 2.

- **How does the sector benefit from volunteering?**

1.10 Volunteers increase our capability to deliver on our objectives, taking on roles that allow for paid staff to focus on their key areas. They can also increase the quality of our services by offering skills and experience which paid staff may not have, or in some situations, where a charity is unable to recruit someone for a paid position.

1.11 At The Brain Tumour Charity, volunteers provide administrative support for our research, support and information and fundraising teams, and help to pack merchandise orders which are distributed

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\(^2\) [https://www.thebraintumourcharity.org/media/filer_public/94/6d/946d8473-3e1a-4f36-ac2a-0a989f176226/losing_myself_the_reality_of_life_with_a_brain_tumour.pdf](https://www.thebraintumourcharity.org/media/filer_public/94/6d/946d8473-3e1a-4f36-ac2a-0a989f176226/losing_myself_the_reality_of_life_with_a_brain_tumour.pdf)
across the UK. Volunteers also represent the Charity at major fundraising events, allowing us to run those engagements successfully and safely.

1.12 The majority of our volunteers are personally affected by a brain tumour, and their contribution to our work brings paid staff closer to the cause.

1.13 At The Brain Tumour Charity, we have a number of specialist volunteers who use their expertise to further provide feedback on specific elements of our work. For example our Scientific Advisory Board is responsible for assessing and rating research applications, and is formed of 10-14 academic members and two patient representatives, who are all volunteers. The Board’s membership provides us with access to specialists whose experience helps us to assess the quality of research projects, and gives the Charity the credibility of being aligned with experts in the field. These volunteers also hold the recipients of our research grants to account, monitoring their progress and that the research continues to represent the best value usage of donor funds.

1.14 Finally, trustees and board members of most charities are volunteers, and as a governing body that holds the leadership of charities to account, their service is crucial to the impact of a Charity’s work.

- How has the status of volunteers changed?

1.15 Volunteering is becoming increasingly professionalized, a development that can be compared to fundraising as competition for time and money has increased across the charity sector. However, as the consultancy NFP Synergy has pointed out, there is no trade body equivalent to the Institute of Fundraising for volunteering which offers opportunities for professional development and qualifications.

1.16 For younger people starting out in the job market, more importance is attached to volunteering experiences that provide skills desired by employers for permanent employment. Evidence from younger workers in the Millennial Impact Reports has highlighted how companies that provide an opportunity to get involved in community outreach or “cause work” are more likely to retain staff over the longer term. Charities must be receptive to these needs and tailor volunteering opportunities accordingly.

- What challenges do charities face in trying to fulfil their role in civic society?

1.17 Media attention on fundraising practices of major charities over the past year has contributed to a decline of public trust in charities, falling from 71% in 2014 to 57% in 2015. The risk is that in rectifying these issues, charities will have to devote more time in future ensuring compliance with regulation, allowing fewer resources to drive innovation in the sector or meeting need.

1.18 There has also been more scrutiny around staff pay, particularly at a Chief Executive level, with calls for a greater proportion of donations from the public to be spent on frontline services. This scrutiny could provide challenges in charity recruitment for highly talented staff, given that the sector already faces competition from private sector employers who can offer higher salaries.

1.19 The Lobbying Act has created legal uncertainty for charities about the extent to which they can campaign in the run-up to regional and national elections. Our supporters and donors want us to be active in campaigning for change, whether it be in encouraging the Government to promote awareness of brain tumour symptoms or by increasing access to new and innovative treatments. This legislation, whilst well intentioned, has created an additional regulatory burden on many

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3 https://www.thebraintumourcharity.org/our-research/for-researchers/grant-review-and-monitoring-committee/
1.20 Charities must also be responsive to the changing support needs of beneficiaries, something that is particularly challenging with the pace of technological change, which affects the way people wish to access support and information services. Given the limited resources that charities have compared to the private sector, there is a real challenge in attracting the right people who can help the third sector to meet those changing needs.

1.21 As charities grow in staff numbers and their fundraising base, they naturally have to change their operations, and there is the risk that they become more removed from the cause and their donors at a grassroots level.

• How can these challenges be overcome?

1.22 One way that charities can help meet the changing needs of beneficiaries is by consistently seeking feedback about what matters to them. Over the last year, The Brain Tumour Charity has launched two studies, looking at the impact on quality of life that a brain tumour has on adults and young people. This has helped to identify areas like access to financial advice where we need to change our services to meet unmet need. With people increasingly looking online to find community and support, we have been developing our digital platforms to engage more people, such as Facebook groups and webchat which can be tailored to the individual's situation. With effective monitoring, these groups can provide people with the space to raise questions or concerns, receiving support from Charity staff and the online community.

1.23 Secondly, an effective, committed board of trustees is important to helping charities fulfil their purpose. Recruiting trustees with experience of reputation management could help to identify potential risks to a Charity's integrity and trust among its supporters. In larger organisations, trustees must make an attempt to participate in the life of a Charity's work by meeting with beneficiaries and staff, something that will help to build their knowledge of its operations and allow for more considered decision making.

2. What are the main pressures faced by charities currently, and what impact have these had?

• What opportunities do charities have in the current environment?

2.1 Against a background of funding cuts to local and national services, charities have the opportunity to fill the gap in service delivery to meet unmet need. Within health and social care, the NHS faces major challenges in workforce planning and recruitment for different healthcare professionals in different positions as the demand for health and social care increases, and budgets are constrained.

2.2 In this climate, the voluntary sector has an opportunity to take on a greater role in health and social care workforce provision, filling some of those gaps by directly recruiting healthcare professionals. Macmillan Cancer Support currently has 3,942 nursing posts across the UK, both in hospitals and the community, and even though some of those healthcare professionals are eventually funded by NHS Trusts, the charity is an established part of the NHS workforce.

2.3 To address unmet need in our own community over the next year, The Brain Tumour Charity is considering whether to provide funding for a limited number of healthcare professional posts, so that more patients have access to the support they need. Without this investment from the charity sector, many patients would not benefit from the experience and advice of healthcare professionals who can help to coordinate their care.

2.4 However, policymakers need to clarify the correct balance between central government provision and voluntary sector provision. This is particularly important in areas such as workforce, where the expectation behind charity investment in staff (i.e. clinical nurse specialists) has often been that
Trusts or Clinical Commissioning Groups will provide a greater share of funding after a defined period.

2.5 Other opportunities lie in expanding support and information services, responding to unmet need and forging partnerships with other organisations. For example, surveys of those personally affected by a brain tumour showed that many brain tumour patients felt there is a lack of support around financial advice and relationships.²

2.6 In response to this, we have recognised the need to better support people in these areas, and have forged partnerships with other charities such as the Citizens Advice Bureau and One Plus One. Bringing on board external expertise in an area like financial advice means that we can help beneficiaries with benefit applications and obtaining additional support that improves their quality of life. By delivering services in an innovative way, these partnerships between charities can positively influence the way the public sector delivers services.

- Are there specific pressures affecting particular types of charity (for example, service delivery charities; charities reliant on fundraising income; charities with a rural focus; smaller or larger charities; or charities promoting a particular cause) that you can highlight?

2.7 As a Charity that funds medical research, the result of the EU referendum in June has created uncertainty on access to EU research funding streams and fundraising. Whilst the UK Government has committed to guarantee EU research grants for Horizon 2020 (FP7), there is concern that the UK’s ability to influence the shape of the next Framework Programme (due to start in 2021) will be reduced, and changes to free movement could have a negative impact on the ability of researchers to access funding.

2.8 To use one example, the Samantha Dickson Brain Cancer Unit at the UCL Cancer Institute was able to leverage £1.7 million further funding from the European Research Council after initial investment from The Brain Tumour Charity into their projects. By expanding the capacity of research work at the Unit, the team at UCL has been able to translate their findings into a clinical trial.

2.9 As the AMRC has highlighted, charities could make up this shortfall, and there is concern that the UK Government would not be able to guarantee the level of funding currently leveraged by HEIs and researchers from the EU. In an area of research like brain tumours, international collaborations between institutions is critical to delivering progress, and these collaborations have been underpinned over the last decade by the European Union.

2.10 The referendum result could also have on the ability of medical research charities to raise sufficient funds to continue research projects and expand funding calls. For many of our supporters, the attraction of giving a donation to The Brain Tumour Charity comes from the understanding that it will help to fund the research work carried out in the UK and abroad.

3. How do charities seek to innovate, particularly in the digital arena?

- What more can be done to promote innovation, and by whom?

3.1 The vast pace of technological change and innovation, particularly in areas like apps and virtual reality makes it very challenging for charities to respond early enough to understand and apply the technology in a way that will assist beneficiaries. Therefore, tech companies should be encouraged by greater tax reliefs and incentives from Government to collaborate with charities to design health applications that can help improve quality of life for patients.

3.2 One recent example of such collaboration in action has been the partnership between Oxfam and the augmented messaging app Traces. This new campaign will see reality portals placed at 650 UK

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² https://www.thebraintumourcharity.org/media/filer_public/94/6d/946d8473-2e1a-4f36-ac2a-0a989a176226/losing_myself_the_reality_of_life_with_a_brain_tumour.pdf
retail locations, allowing people to use their mobile phones to learn more about the charity’s work or even make a donation.

- What barriers are there to being innovative?

3.3 Although the rise of digital marketing has meant that it has never been easier to get your message out and be visible, the charity sector faces challenges in the recruitment of staff with digital skills, given salaries on offer compared to similar jobs in the private sector. In the past, there was more defined roles in both sectors which meant that charities rarely competed for employees within the same recruitment pool.

3.4 There is also a need to develop digital skills among existing charity workforce, particularly in the use of social media, so that staff members can deliver content on the networks that beneficiaries are using online. For smaller charities, this is challenging, with less capacity to train staff in these skills.

3.5 In the case of social impact bonds, New Philanthropy Capital has suggested that investors and commissioners have tended to pursue proven interventions, rather than back something new and innovative. This leaves the bonds open to charge they are an expensive way of pushing through known intervention or programme.

3.6 Additionally, greater scrutiny about charitable spending from the general public and the need to evidence impact of the work that charities do could reduce the willingness of the sector to take risks and try new ideas, especially where large, up-front investment is required.

6. How can charities ensure that they are properly accountable to their beneficiaries, their donors, and the general public?

- What, if any, changes might this mean for current arrangements?

6.1 The main way that charities can ensure accountability is by having a robust budget in place which is reviewed on a regular basis, maintaining a respectable cost ratio (with 80p out of £1 raised going towards charitable objectives) and complying with the Fundraising Code of Practice.

6.2 Charities need ensure that supporters understand the direct impact of their donations and that they are transparent about spend. They can do this through online channels and by promoting documents such as annual reports which evidence where money is spent and how it makes a difference. This may also mean educating beneficiaries, donors and the general public about what non-charitable spend goes towards, for example by highlighting the valuable role of office staff to a charity’s work.

6.3 Upcoming changes to fundraising regulation are creating uncertainty for charities, particularly around the ability of donors to exercise greater control over opting in and out of fundraising communications. There is great concern that more people are likely to not tick the “opt-in” box, reducing the overall number who can be contacted again. This reduction could be exacerbated by the launch of the Fundraising Preference Service next year, where people can elect not to be contacted by a charity at all, which would likely mean that as well as not receiving fundraising specific communications, they will not receive potentially helpful information about services or information for campaigning purposes. We are concerned that the changes will mean that greater resources will be required to comply with regulation, particularly on the requirement that charities having able to evidence more strongly that they have taken steps to avoid contacting vulnerable people.

6.4 For charities like ours which fund research, accountability means following recognised processes such as the peer review methods recommended by the Association of Medical Research Charities (AMRC). Peer review helps to eliminate any potential conflicts of interest and requires researchers from across the World to evaluate the quality of research proposals gives us credibility in the field, ensuring that we extract the greatest value for money for our supporters and donors.
6.5 Likewise, our accreditation with membership bodies such as the Information Standard helps to build confidence and credibility in the support and information services we provide.

6.6 Recently, we have conducted a study of over 1,000 people to understand the impact that a brain tumour has on quality of life. The feedback on the support and information that those personally affected have received, or would like to receive, has informed some of the changes that we have made to aspects of our support and information services.

7. What are the current challenges to financial sustainability, as well as efficient resource and risk management for the sector?

- How can these challenges be overcome?

7.1 A measure that would have significant impact in terms of financial sustainability would be the removal of the requirement to pay VAT.

- What can best practice and information be shared across the sector?

7.2 Information is best shared through member organisations such as the Institute of Fundraising, who can have the capacity to monitor the landscape around regulation, and more specialist bodies like the Association of Medical Research Charities (AMRC), who have a stronger understanding of the needs facing charities who invest in medical research.

- What lessons can be learnt from past mergers or dissolutions of charities?

7.3 Over the last twenty years, gradual consolidation among brain tumour charities has helped to enhance the scope of research, support, information and fundraising for the cause of helping people personally affected by a brain tumour and finding breakthroughs to tackle the disease.

7.4 In its current form, The Brain Tumour Charity was forged by a merger of three smaller charities based in different parts of England: Brain Tumour UK, Samantha Dickson Brain Tumour Trust and Joseph Foote Trust. This merger ensured that we are the largest charity dedicated to fighting brain tumours in the UK, but there are still over 50 charities for this purpose still in existence.

7.5 With regards to dissolutions of charities, the recent example of Kids Company highlighted that there is very little consequence of failure within the sector beyond reputational damage. In the case of Kids Company, there is a real sense that the organisation was simply too high profile for the Government to withdraw funding, despite major questions around its operations and leadership. Such scandals affect the reputation of the whole sector, making donors more reluctant to give towards charitable causes and sceptical about charities spending effectively.

7.6 As a regulator, the Charity Commission could not hold the leadership of the charity to account for its practices which helped to lead to its financial failure. Even before its demise, the leadership of Kids Company made big claims about the impact and reach of the charity's work. But without an equivalent to the Trading Standards Board within the charitable sector, claims made about the work of certain charities cannot be challenged legally.

- How can charities effectively deliver services and be assured that their work achieves successful outcomes?

7.7 The main ways that charities can ensure this is through constant evaluation and monitoring of existing projects, and setting clear performance indicators at defined periods. To ensure good value for money, if a service is consistently underperforming, charities should be prepared to change either the method it is delivered or remove it altogether.
7.8 Effective use of database programs like Salesforce can also help analyse the level of supporter engagement with a charity’s work, and the quality of that engagement. This can help charities to tailor their marketing and fundraising work in a more effective way to accomplish their chosen outcomes. Linking objectives in staff member appraisals to initiatives in a Strategy document can also help to highlight specific outcomes for the Charity that an employee is working on.

8. What is the potential of social investment and social impact bonds?

8.1 Social investment has the potential to accelerate research for a range of different conditions which charities fund. The Dementia Discovery Fund was launched last year after receiving investment from a charity, Alzheimer’s Research, the Department of Health and major pharmaceutical companies.

8.2 The objective of the Fund is to explore new ideas in dementia research, accelerate the discovery and development of new treatments for dementia and encourage further global investment in dementia research. This form of investment has the potential to drive forward medical research and ultimately benefit patients with better treatment options. Drawing on this example, The Brain Tumour Charity is currently launching our own Venture Capital fund in an attempt to accelerate brain tumour research globally.

8.3 Social impact bonds have the potential to reduce costs and improve the social outcomes of public services, based on the “payment by results” contract. It provides an up-front funding mechanism for the charity that should incentivise the partnership to work, and allows a charity to expand its funding base – attracting those looking for both a financial return and philanthropic benefit.

- What are barriers to fulfilling their potential?

8.4 In the area of health, social impact bonds need to demonstrate a measurable improvement to the NHS in a short space of time, and this could be a barrier to such projects being approved. This pressure to deliver an almost instant return on investment would make it challenging to providing upfront funding and creating the “payment by results” element of the contract.

8.5 However, even when successful interventions are found through social investment, there is the challenge of scaling up projects, something most charities struggle with, with the challenge of raising more grants and donations to do so. Rigorous evaluation to measure the progress of social impact bonds is vital to understanding how effective a programme is, with proper control groups or baselines needed to compare progress.

8.6 Finally, there is a need for best practice and information about the use of social investment and social impact bonds to better shared across the charity sector. This will help charities to learn from the experience of others and successful models that already exist. For example, in response to issues of homelessness, there have been a number of projects bringing together social investors and charities to increase the capacity of their work.

9. What should the role of Government be with the sector?

9.1 The main role that Government should play is to provide incentives (including tax reliefs and deductions), and develop institutions to empower charities and social enterprises to flourish as independent organisations in civil society. This should be driven by the Office for Civil Society in the Cabinet Office.

9.2 There are two key examples of where Government action has assisted charities in the last six years. Firstly, the creation of Big Society Capital, a financial institution (now independent) which provides finance to charities and other not-for profit organisations to help them scale up projects with a social purpose. This has helped to expend the social investment sector in the UK and allowed charities and social enterprises to increase the capacity of their work.

9.3 Secondly, the introduction of social investment tax relief, a Government tax relief for social investment meant to encourage individuals to support social enterprises and help them access new sources of finance. The Office for Civil Society should consider ways to further incentivise charitable giving and philanthropy through the tax system.
9.4 In respect of research, the Charity Research Support Fund (CRSF) is a good example of where Government spending has helped charities to leverage additional investment in research at UK universities. This investment, which provides support to institutions that are successful in winning grants from charities of all sizes, helps to ensure that universities are incentivised to seek charity investment.

9.5 We would also like to see Government departments establish a consistent approach to engaging with charities in consultation on different policy proposals. As organisations that consistently work with patients affected by health conditions, we are well placed to understand how public policy will impact on those who will be directly affected by changes to NHS services.

9.6 An example of this was when reforms to the Cancer Drugs Fund were proposed back in 2014. NHS England highlighted its desire to work closely with the charity sector to help shape the proposals, and a CDF Charity Coalition was set up to facilitate this. Before a public consultation was launched, a number of work streams were established to focus on different aspects of the Fund, with membership including NHS England staff, pharmaceutical industry personnel and charities.

9.7 Whilst there were shortcomings in this process, with some charities feeling that their input was disregarded in the final proposals, it did demonstrate how Government agencies can work in partnership with the charity sector can be constructive, and departments should learn from this experience.

- **What should be the role of local Government?**

9.8 The role of local government should be to partner with charities to ensure that statutory duties to promote public health are delivered. With budgets constrained, Directors of Public Health need to work with local and national charities to avoid duplication ensure that charity information resources, either seeking to raise awareness of a condition or advice about seeking treatment, are supplied in local health centres and GP surgeries.

9.9 There is also a need for more local authorities to make use of the Social Value Act 2012, which requires commissioners of public services to consider the social, economic and environmental benefits when buying services above a certain financial threshold. This means consulting more with the users of local services and charities that represent them on where funding for services should be spent.

- **What should be the role of the Charity Commission?**

9.10 At present, the Charity Commission is able to open inquiries into allegations of illegality, but we would like to see strengthened powers for the Commission to hold charities to account for their actions. In a similar way to Ofsted or the CQC, this would mean the ability to recommend further intervention in the running of an organisation or change in leadership following complaints of mismanagement or misappropriation. Indeed, as stated above, an equivalent of the Trading Standards Board within the charitable sector would mean that erroneous or exaggerated claims made about the work of charities could be challenged legally.

- **What is the likely impact of greater local devolution on the charitable sector, or particular types of charity?**

9.11 One of our strategic aims is to ensure that all brain tumour patients have equal, universal access to the best treatment and care across the UK. However, navigating four different healthcare systems in the UK, along with varying structures within the English NHS means that it is increasingly difficult for charities to influence change for patients on a truly national scale.

9.12 At present, the different structure of the NHS in Scotland, Wales and Northern Ireland, and different metrics used to measure patient experience and outcomes makes it very challenging to
compare healthcare systems from one country to another. Greater devolution of health and social care in England could make it even harder to compare outcomes across the country.

9.13 Despite this, it is clear that under a more centralised healthcare system in England, there is significant variation in the quality of care provided and the health outcomes achieved. Over the last three years, brain tumours have regularly ranked in the bottom four cancer types on a range of metrics in the National Cancer Patient Experience Survey.

9.14 If decision-making powers over the allocation of health and social care budget are devolved to more city regions/combined authorities, this could provide service charities with an opportunity to influence where money is spent, and make the case for unmet need to be addressed at a local level.

9.15 Combined authorities will be comprised of directly-elected politicians, rather than healthcare professionals (as is the case with CCGs and Health and Wellbeing Boards), which may provide greater accountability for those bodies to be responsive to the views of voluntary sector groups in the local region on where spending priorities lie.

9.16 There are also national frameworks that are designed to ensure that patients have equal access to care wherever they live. For example, the NHS Constitution, which enshrines patient rights in the NHS wherever they live in England, places an accountability on all healthcare providers to provide a minimum standard of care on certain measures.

- **What are the opportunities and challenges associated with local devolution?**

9.17 For the charity sector, the key challenge of local devolution will be how to engage with the new structures to influence policy. The delegation of powers over health and social care budgets in Manchester has created a new level of bureaucracy (the Combined Authority), and it remains to be seen whether those structural changes can deliver better efficiency or health outcomes.

9.18 Within health and social care policy, charities have been used to working with national stakeholders and greater devolution will require engagement at a more local level, something that could be harder for smaller charities with less capacity. To influence policy in combined authorities/city regions, charities will have to build alliances at a regional level in England and develop a common set of asks to the health and social care system. This would only be replicating alliances that have been developed by charities to influence policy at Westminster, Holyrood, Cardiff and Stormont.

9.19 The biggest challenge for policymakers is how much freedom local areas should have to differ from national policy, and whether accountability of the health and care system to national regulation will shift to regional bodies over time. Evidence-based guidance from NICE is meant to be applied by all Trusts and CCGs across England. However, if structures are changed, NICE should try and adapt its guidance to reflect the changing realities of NHS care in different regions.

9.20 Devolution of health powers would provide more opportunities if local city regions had the power to raise revenue themselves, so that they can invest in prevention. One of their recommendations is that local authorities should have the ability to establish devolved health taxes to raise revenue, and also incentivise certain behaviours if a region is affected by a particular disease.

9.21 At present, a major restructuring of local government in England is taking place. Some county councils, such as Oxfordshire and Hampshire are considering a move towards unitary status, which could have an impact on charities shaping local public health services. Should there be further fragmentation of public health provision, this could affect the capacity of smaller, local charities to affect change for a disease area on a wider scale.