

# **SUPPORTING GOOD HEALTH: THE ROLE OF THE CHARITY SECTOR**

A discussion paper & topics for future research

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# EXECUTIVE SUMMARY

Good health is at the top of most wish lists—for governments and individuals alike. Physical and mental well-being makes it easier for people to pursue opportunities to work and study, to remain financially secure and physically independent, and to maintain strong relationships. A healthy population is also a productive workforce, and one that would relieve considerable strain on the public purse by keeping well.

The statutory system is central and hugely important to guaranteeing adequate healthcare across the UK, but conversations about health need to look beyond the doors of hospitals and GP surgeries.

Early reports indicate that the NHS is struggling to meet efficiency targets, which may create a deficit of £30bn a year by 2020/21. At the same time, an ageing population and a significant rise in the number of people living with long-term conditions are placing additional pressure on resources. Continuing cuts without changes to the way in which our health system operates will compromise the quality of services and the ability of the NHS to meet demand. Moreover, the NHS system is built around thinking within specialisms and approached through a clinical lens, enabling it to deliver complex treatments and respond to crises, but leaving little room to think about non-clinical solutions and support.

Charities can play a significant part in meeting these challenges, providing expert healthcare, conducting research, raising awareness, supporting patients, and promoting mental health and well-being. Health is the third largest charity sub-sector by expenditure, with 6,626 health charities spending £4bn in 2011/12. In 2012/13, Cancer Research UK, one of the sector's largest charities, spent £351m on research activity designed to understand the causes and biology of cancer and to create treatments to tackle it—funding clinical trials that involved more than 35,000 patients and the work of more than 4,000 doctors and scientists.<sup>1</sup>

Charities also play a hugely important coordinating role. Acting as a broker between beneficiaries, clinical professionals, local authorities, national policymakers and the general public, they bridge the gap between different parts of the system, and ensure that patients interact with it effectively and efficiently.

The sector's ability to consider the 'whole person' is central to fulfilling this role effectively. While the statutory system provides clinical and specialised care, charities are able to think more holistically, taking into account physical, emotional and environmental challenges and tackling the root causes of health inequality. This approach lends itself to—and could not exist without—a detailed understanding of need based on knowledge, skills, and patient insight.

Charities are at the heart of the communities they support: some directly deliver health and social care services; many work with a range of beneficiaries to provide care around daily problems. This perspective could more actively inform commissioning practices, which would have enormous practical significance—not only improving the quality of care people receive but also contributing to a more efficient use of state resources. It even has the potential to allow a greater shift in focus onto the causes rather than the symptoms of problems, lessening the onset of preventable diseases and potential demand for treatment in future. This is essential at a time when only 4% of the NHS budget is allocated to public health.

Despite this contribution, NPC believes the potential of the charity sector has not yet been realised. This is because the offer of charities is not properly understood or embraced by those outside the sector; nor is it fully agreed and articulated by charities themselves.

We believe there is work to be done here—not necessarily to carve out an expanded role for the voluntary sector, but to recognise and encourage those areas where charities might add the greatest value to the good health of the nation.

## Key strengths of the charity sector

- **Occupies a unique position between the system and the beneficiary.** It can therefore act as a trusted, independent intermediary and deliver improved coordination between different parts of the system. This role also affords greater freedom to focus on non-clinical issues, and to respond flexibly and creatively to changing needs. Key to this is supporting beneficiaries to understand their condition and choose the right care pathway, as well as empowering them to have a say in their treatment.
- **Ensures greater understanding of need.** Specialist charities advocate for and support particular patient groups or those suffering from specific conditions; others work in local, community settings in a personalised way. As a result, charities are often best placed to understand the needs of the UK's increasingly diverse population. This is supported by considerable research and expertise.
- **Provides joined-up, holistic support.** Charities care for the 'whole person'—whether their needs are medical, emotional or social—and provide support throughout a patient's journey to recovery. It is not just about fixing a problem, but building resilience so individuals feel able to make positive health choices. This includes preventative action and early intervention, and work to address the social determinants of health.
- **Influences the design and delivery of services.** A large proportion of charities are involved in the delivery of health and social care services. Another important part of their work is to influence how services are designed and commissioned by developing new ideas and sharing best practice.
- **Creates significant opportunities to save money.** By taking advantage of complementary charity activities, the NHS could reduce costs and reinvest the proceeds to improve the quality of patient care and develop preventative approaches.

## Key barriers

- **The health system is becoming increasingly complex.** Clinical Commissioning Groups are still relatively new and considerable funding, including public health budgets, has been transferred to local authorities—with this landscape set to change further as we approach the General Election. Getting used to new and complex arrangements will make refining the voluntary sector's offer more challenging.
- **The role of specialist providers is unclear in the new commissioning environment.** As approaches to commissioning move towards larger contracts, and look to bundle services relating to specific groups or conditions under single contracts, providers that carry out an array of services will take preference over those that have particular thematic or local specialisms.
- **Spending cuts make it difficult to know how to influence commissioners and shift money to prevention.** It is difficult for commissioners operating in a highly pressurised environment to look to preventative and holistic solutions; funding must first and foremost guarantee a minimum standard of care. Charities that focus on preventative action and whole person care may struggle to win public contracts.
- **Charities struggle to make the case for their impact on health and lack the data to do so.** It becomes harder and more expensive to evidence effectiveness when impact is less direct. This is true for many charities focusing on the social and environmental causes of poor health, and is further hindered by difficulty gaining access to existing data that could help build their case. Initiatives, such as [NPC's Data Labs programme](#), seek to address this challenge.<sup>2</sup>
- **Clinicians still need convincing that charities offer complementary expertise.** The attitudes of clinicians towards charities present a considerable barrier to improving coordination between the voluntary and statutory systems. Our research has shown that charities may be viewed as less professional and rigorous than health professionals. Until clinicians are convinced of what the charity sector has to offer, opportunities to improve coordination will be limited.
- **A blueprint for the redesign of the health system does not exist.** Charities and commissioners alike are still finding their feet in the new system. As a result, the levers of influence are not always clear, and are likely to vary between different issue areas and localities. This makes the task of charities seeking to influence the design of services and the shape of the health system much more difficult.

# INTRODUCTION

In this paper, we present seven key areas in which charities have the potential to improve the quality of UK health services. For each, we outline the current state of play and the benefits that stand to be made through charity involvement at a national and local level. We also explore current barriers to progress and suggest topics for further research. The seven areas divide broadly into the role that charities play in helping individuals, and their contribution as part of a wider health system. We use a broad definition of health that encompasses physical health, mental health and well-being.

## **Role with individuals**

1. Representing patient voice and advancing patient involvement
2. Helping individuals to understand their condition and navigate the system
3. Shaping prevention and early intervention
4. Addressing the social determinants of health

## **Role within the system**

5. Delivering services
6. Influencing the design of services
7. Making scarce state resources go further

For this paper, we have taken observations and examples from our events and roundtable discussions<sup>3</sup> and our work providing advice to individual charities, drawing also on conversations shared during the course of this and other research.<sup>4</sup> It is the first consultative step in what we hope becomes a longer research process, and we look forward to engaging with charities on some of the issues it presents.

# 1. REPRESENTING PATIENT VOICE AND ADVANCING PATIENT INVOLVEMENT

Patients are often best placed to judge how well treatments are working, as well as the quality of care they receive. Yet, as individuals, they lack the power and profile to put these views across, and are therefore unlikely to have any influence over their treatment. Though efforts have been made to tackle this problem in the public sector<sup>5</sup>, it represents a significant challenge for a statutory service that is already stretched thin (see section 7). As a result, these initiatives have generally faltered.

The charity sector faces a dual challenge here: to act as an effective conduit for patient voice and involvement in healthcare, but also to relay the diverse needs of its beneficiaries in a unified way. Health charities listen to patient voice, but they also have a voice themselves.

## What do we stand to gain from improving this?

It is impossible for an outsider to fully understand the day-to-day challenges that health conditions present—whether an employer, a family member or even a medical professional. Patients carry this unique insight, and incorporating their experiences into conversations about the design of services will more effectively meet their needs. Where patients are heard, medical professionals can better ensure that the right services are available to take them through to a sustainable recovery.

Equally, services risk overlooking certain needs where patients are not involved in this process. People with learning difficulties, for example, may have particular requirements that are not properly recognised. Directly involving patients in the design of services ('co-design') and in decisions regarding their treatment ('co-production') would help improve the quality of services even further.

Enhancing patient voice and involvement would bring three key benefits:

- Getting people better, faster<sup>6</sup>
- Improving patients' experiences of healthcare<sup>7</sup>
- Helping to redress inequalities in the quality and availability of treatment<sup>8</sup>

## What role does the voluntary sector currently play?

Charities use knowledge and expertise gained through the complementary activities of service delivery and research to represent particular patient groups or those suffering from specific conditions. Some, like the Neurological Alliance and Macmillan Cancer Support advocate for a group of conditions, while organisations such as the Alzheimer's Society and Pancreatic Cancer UK focus on a specific condition. Others represent particular patient groups to ensure they receive equal access and treatment. Mencap's *Getting It Right* charter, for example, calls for the health service to become more hospitable to people with learning difficulties.<sup>9</sup>

Charities also act for beneficiaries on issues beyond the clinical realm. For example, the national mental health charity, Mind, campaigns for a fairer benefits system, better workplace rights, and an improvement in public attitudes towards the mentally ill, and also helps individuals find "personal advocates" to represent their interests at a local level.

## What does the voluntary sector bring to the table?

Charities are often said to occupy the middle ground between the health “system” and beneficiaries, whilst remaining separate from each. Indeed, they are often uniquely placed to act as a ‘conduit’ between the two—as charities command higher levels of public trust and confidence than many public and private institutions.<sup>11</sup> This puts them in a strong position to gauge the opinion of beneficiaries, and to represent those views at a local and national level. At the same time, many have developed closer relationships with the state via their role in public service delivery. It is their unique and in-depth knowledge of need, combined with an understanding of local authority systems and relationships with commissioners and policymakers, which gives charities the opportunity to act as independent, informed and trusted intermediaries.

### Challenges

**It is difficult to define a unified vision of what the health system should look like.** In representing such a diverse range of interests, can health charities ever present a unified account of the voluntary sector’s vision for, and demands of, an evolving system? In order to find a common voice, charities working in this space will need to prioritise common themes.

**In seeking to relay patient voice, health charities may end up shouting over one another.** Given that health charities are in competition for finite resources, the ability of powerful voices to shout above the rest may distort funding flows and the focus of policy decisions. The need to make the best use of limited resources may be problematic where certain patient groups require services that are less cost effective than others. How far can patient voice ever win out over cost considerations?

**The extent and success of patient involvement is unknown.** NPC has so far been unable to determine if parts of the sector are better placed than others to incorporate the views of beneficiaries, or whether particular models, approaches, funding sources, or attitudes contribute to success. Without a clear picture of what ‘good’ looks like and where it is happening, designing effective approaches and models will be difficult.

**The case for increasing patient involvement needs to be strengthened.** Studies have shown that patient involvement has a positive effect across a variety of outcomes, including reduced A&E attendances, hospital admissions and length of stay; quality of life, patient experience and patient satisfaction; and even medical improvements such as glycaemic control.<sup>10</sup> However, the magnitude and confidence of the results varies considerably. Equally, whether these ideas can be implemented is not well understood. Patients are not clinical experts, nor is it necessarily true that all patients will *want* to contribute to these decisions, and there is a need to ensure that views are representative.

### Questions for future research

- What is the sector-level theory of change for charities that contribute to the nation’s health? Is a discussion at this level the most productive way to approach things? What would best represent the interests of health charities and their beneficiaries in the manifestos of 2015?
- Can, and should, health charities have a single voice? How can patient voice be prioritised without health charities undermining each other as competing voices in lobbying? Does relaying patient voice create too many different ‘asks’ from health charities, which ultimately drown each other out?
- Is inviting greater patient involvement equally possible, and desirable, for all charities? Are barriers to co-production more pronounced for charities adopting certain models and approaches? Can these variations be understood and mapped to provide a better understanding of best practice?
- What is the evidence for the positive effects of patient involvement? Do different levels and types of involvement have different results?

## 2. HELPING INDIVIDUALS TO UNDERSTAND THEIR CONDITION AND NAVIGATE THE SYSTEM

In order for patients to navigate the health system in the best way possible, they need to know which services and treatments are available, how to access them, and what to expect in terms of quality and results. Given the separation of medical health treatment and social care arrangements, patients often struggle to properly assess their options—a challenge that will only increase as the system becomes more complex. This could result in patients missing out on the most appropriate treatment or having to cope with additional emotional burdens.

Acting as a broker between beneficiaries, clinical professionals, local authorities, national policymakers and the general public, charities bridge the gap between different parts of the system, and ensure that patients interact with it effectively and efficiently. They produce guidance to help individuals choose the right care pathway, and provide emotional support as they follow it.

### What do we stand to gain from improving this?

#### **Better services**

Helping patients to understand their condition enables them to have the right conversations with health professionals and to volunteer information that might affect the course of their treatment. Knowing which services are available—and which are well evidenced—also allows patients to contribute more meaningfully to their design. Patients need to be well-informed about what is possible, what is effective, and under what circumstances, for the benefits of patient involvement to be realised (see section 1).

#### **Greater efficiency**

Efficiency in healthcare provision has never been more important. To this end, a number of models are already being tested to minimise unnecessary contact between patients and clinicians.<sup>12</sup> Efficiencies can also be gained if patients are well-informed; because by seeking the right help early, and coming equipped with a certain level of understanding, they are likely to move faster through the system.

Healthcare professionals are naturally concerned that improved navigation will result in an explosion in demand. However, our research suggests that this does not play out in practice; better navigation creates a *more efficient* use of the system, rather than greater use.<sup>13</sup>

#### **Improved patient well-being**

Better understanding of their condition improves patient experience in a number of ways. Knowing what to expect can help relieve some of the emotional pressures associated with any difficult life situation. It can also have a positive effect on people's willingness to engage with health professionals at an early stage and their ability to self-manage their condition, which will ultimately support their recovery. Feeling empowered to take personal responsibility for their own care choices is strongly connected with patients' well-being.

### What role does the voluntary sector currently play?

Some charities provide information relating to specific conditions—on the treatment options available, the evidence and research that surrounds them, eligibility criteria and entitlements. The MS Society, for example, produces

material to help those with MS navigate relevant services, make complaints, and access financial and emotional support. A number of advice-focused charities, such as the Citizens Advice Bureau, also offer advice on healthcare more generally.<sup>14</sup> Preparing and sharing this information is no small task; it is often very specific to particular conditions and circumstances, and therefore needs to target and reach the right people. It is conveyed to patients in a variety of ways, through online resources and helplines, face-to-face sessions and patient forums.

Charities also provide a check on the quality of care delivered by statutory bodies by offering advice on redressing grievances and even taking up issues with relevant authorities on behalf of their beneficiaries.

## What does the voluntary sector bring to the table?

Charities have the necessary understanding of *both* beneficiaries and the system to help people understand their options and make decisions about their treatment. More so than clinical professionals, they have space and freedom in their remit to focus on non-clinical issues—the emotional and practical impacts arising out of patient care day-to-day—which engenders a more holistic understanding of need. Many are also engaged in commissioning processes, speaking to local authorities and health professionals, and interpreting and carrying out research about the way in which the system functions and how conditions are best treated.

Being one step removed from the clinical aspects of treatment means that charities can provide support to individuals and their families throughout their journey, maintaining this role even as patients move from one part of the system to another.

### Challenges

**Charities may not fully understand the system themselves.** Given the extent and complexity of reforms to health services, many charities do not yet have a complete understanding of how things work and where levers of influence lie. This may obscure information about patient entitlement, redressing grievances, and the likely trajectory of care pathways.

**Increasing complexity may mean that information is not enough.** It may be the case that charities need to undertake more resource-intensive activities to properly guide patients through the system, using models such as ‘patient navigation’ from the USA, by which patients are assigned a personal advisor to advocate on their behalf and assist in finding information and support.<sup>15</sup>

**Charities can only go so far in helping people to navigate an imperfect system.** Can charities be a player in the game *and* solve wider systemic problems, or does a decision need to be made about where to focus efforts and resources?

### Questions for future research

- Can the UK charity sector adopt a ‘patient navigator’ model?
- How can systems that aim to create flexibility in personal data, whilst maintaining patient control (such as MyDex\*), be used to create a more streamlined system and reduce the resources required to ensure effective navigation?
- Are charities effectively communicating the extent and importance of patient burden in debates around the evolving system? What is the state of evidence to support this case?

\* Mydex CIC aims to put individuals in control of their personal data. All personal data is stored in one place, and individuals decide with whom it is shared. This is one way to ensure that data stays with patients as they move through different parts of the system. <https://mydex.org>

### 3. SHAPING PREVENTION AND EARLY INTERVENTION

Prevention and early intervention activities aim to prevent or limit the effect of a specific health condition before it becomes a serious problem. They can be grouped into three areas:

- Preventing or minimising the risk of problems arising, usually through universal programmes; for example, the Diabetes UK Healthy Lifestyles Roadshow
- Early intervention targeting those at high risk or as symptoms begin to show; for example, the Place2Be's mental health counselling interventions helping children adjust to the transition from primary to secondary school
- Early remedial treatment to stop a condition from getting worse; for example, participatory arts interventions for older people with early-stage dementia in residential homes, helping them to stay intellectually active and connected to their environment.

Within statutory health services, prevention and early intervention fall primarily into the remit of public health, although it is also a concern for GPs and health and wellbeing boards. However, health reform in the UK has typically focused on managing needs, not on preventing them, with only 4% of the NHS budget allocated to public health.<sup>16</sup>

#### What do we stand to gain from improving this?

Preventative action and early intervention can be effective in reducing the incidence or severity of conditions relating to unhealthy lifestyles, which are becoming the dominant cause of death and disability worldwide. Poor diet and lack of physical activity are linked to cardiovascular disease, obesity and type two diabetes, which cost the NHS £11.5bn;<sup>17</sup> while smoking and alcohol consumption are now the second and third leading risk factors for disease.<sup>18</sup> Overall, research estimates that 60-70% of premature deaths are caused by behaviours that could be changed.<sup>19</sup> Other non-lifestyle health conditions can also be treated with greater success if detected and treated early, including mental health conditions such as psychosis,<sup>20</sup> and physical health conditions including glaucoma and cancers. So, not only does preventative action stand to extend and improve the quality of life for a large portion of the population, it could also bring about long-term savings in public spending (see section 7).

#### What role does the voluntary sector currently play?

Charities play an important role alongside statutory services in communicating information about health risks and the importance of screening for health conditions. Government leads on some public health campaigns, but condition-specific charities also have a role in sharing specialist knowledge and raising awareness of the risk factors associated with certain conditions. The British Heart Foundation, for example, runs national *No Smoking Day*, which aims to encourage people to stop smoking by reminding them of the health benefits it can bring.<sup>21</sup> Where charities are in contact with people affected by a condition, they ensure patients understand best practice in treating their condition and know what to ask of their clinicians (see section 2). The National Osteoporosis Society has found that this kind of education can create a demand for appropriate early intervention, as patients ask clinicians to assess their fracture risk, and thereby improve practice and health outcomes.<sup>22</sup>

Charities not focused on health but working with specific beneficiary groups can play an important role here too. For example, chronic health conditions such as obesity and cardiovascular disease are closely linked to social deprivation; and Afro-Caribbean and South Asians have a higher risk of cardiovascular disease.<sup>23</sup> Charities

working with these specific populations can provide more personalised information and training in healthy lifestyles to avoid preventable diseases or identify health conditions early.

## What does the voluntary sector bring to the table?

Charities often work in community settings, which provides an opportunity to communicate health messages to populations at greater risk of health problems in a more targeted way than national level public health activity. For example, the African Health Forum works in Southwark, Lewisham and Lambeth to promote greater community awareness of health issues, and improved provision and uptake of services through community mobilisation, signposting, and networking. Health is also a top priority for many homelessness charities<sup>24</sup>, with many working to ensure that homeless people are supported to access and sustain treatment for health problems. Groundswell, for example, provides homeless people with peer advocates who provide one-to-one support in accessing health services. Groundswell sends reminders about appointments, provides transport to and from treatment locations and sends peer advocates to accompany people on the day of their appointments. This approach is designed to ensure that homeless people are confident in seeking help early for any health problems.<sup>25</sup>

Condition-specific charities often fund research into risk factors and warning signs associated with a particular condition, and then communicate that information. Some also have additional resources—money and volunteers—with which to undertake awareness-raising activities. The voluntary sector also works to promote and support self-management of health conditions, so that people can stay well and avoid health crises. For example, Diabetes UK helps individuals to develop health plans so they know when and how to access high quality information, emotional and psychological support, and advice from healthcare professionals.

### Challenges

**Increasing patients' levels of activation.** The concept of 'patient activation' relates to an individual's knowledge, skill and confidence in managing his or her own healthcare. People who show higher levels of activation are more likely to engage in preventive behaviours such as attending immunisations, check-ups and cancer screenings. This is also relevant to helping patients use their voice to exercise control over their care (see section 1). Effectively encouraging patient activation requires a considerable commitment of resources to coordinate engagement, outreach, research and support. It also relies heavily on patient attitudes and their experiences of the system.

**The roles charities play in early intervention.** How easy is it for condition-specific charities to reach those who have not yet been diagnosed, and what are the most effective routes to doing so (public awareness, communication with local health bodies, or coordination with public bodies)? Conversely, what are the opportunities for non-specialist charities to deliver health messages to the people they work with?

### Questions for future research

- Can we understand and share lessons about where the charity sector has performed this role effectively and where it has not worked? How easy is it for the charity sector to work together with publicly-funded health services and ensure they are communicating consistent messages?
- This approach is suited to the way charities work and is a clear place they could add value. Which charities are already doing so? Are there opportunities to do more?
- How can charities work together in these areas?
- Is there a way to use data on health outcomes (eg, visits to the GP, hospital admissions and length of stay) to demonstrate the effectiveness of services that work preventatively? Would this data help charities to build a case for support?

## 4. ADDRESSING THE SOCIAL DETERMINANTS OF HEALTH

There is a social gradient to health, meaning that the lower a person's socioeconomic position, the worse his or her health.<sup>26</sup> Healthcare has traditionally under-emphasised these social determinants of health, instead focusing on the biological, but there is growing recognition that supporting good health starts long before any contact with the statutory system.

The social determinants of health are the circumstances in which people are born, grow up, live and work, and are in turn shaped by wider economic, social and environmental factors. All of these interact with and influence an individual's attitudes and behaviours.

The leading report on this subject, *Fair Society Healthy Lives*, suggests we need a shift in attitudes to make the link between social conditions and health the main focus of conversation. It remains influential, but progress has been slow because it is difficult to prove the links between disparate causes and their effects on health, and interventions aimed at addressing inequality take a long time to produce results.

### What do we stand to gain from improving this?

Differences in social status can result in health inequalities—a gap between the health outcomes of the wealthiest and the most deprived communities. In our society there are ten-year and eight-year gaps in life expectancy for men and women respectively,<sup>27</sup> and even larger gaps in healthy life expectancy.<sup>28</sup> People with a higher socioeconomic status are likely to have greater life chances, to live in healthy and stable environments, and—with fewer everyday concerns about employment, finances and security—to focus on healthy behaviours. Conversely, those with a lower socioeconomic status are more likely to choose unhealthy behaviours such as smoking, poor nutrition and physical inactivity. Living a higher quality of life also makes it easier to act when problems arise because a feeling of ill health does not generally feature day-to-day.

Inequality of health outcomes is also associated with differences in quality of care across different locations, and for different groups of people. For example, it is still the case that 93% of people with mental health problems in black and minority ethnic communities experience discrimination.<sup>29</sup>

Any serious attempt to create a sustainable health system must deal with the factors that determine the nature and scale of our health needs. Indeed, addressing behaviours that are associated with socially determined health inequalities is part of the core remit of public health bodies, as they work to reduce the burden of ill health associated with smoking, high blood pressure, obesity, and poor diet. However, there are a wide range of factors contributing to health, beyond individual choices and behaviour, which are not conventionally thought of as part of the health sphere but can have a huge impact on health outcomes. *Fair Society Healthy Lives* explains that reducing health inequalities will require action on six policy objectives:

- Give every child the best start in life
- Enable all children, young people and adults to maximise their capabilities and have control over their lives
- Create fair employment and good work for all
- Ensure healthy standard of living for all
- Create and develop healthy and sustainable places and communities
- Strengthen the role and impact of ill health prevention

## What role does the voluntary sector currently play?

The charity sector's impact on health is far wider than is often appreciated, not least because much of charities' work on wider social issues like housing, domestic violence, substance misuse, poverty, and parenting also contributes to this agenda. Whether their services provide rape counselling or shelter from domestic violence, build confidence among disengaged young people or improve health knowledge among BME communities, all are heavily focused on social determinants and in this way work to tackle some of the root causes of health inequality.

As local health and wellbeing boards begin to better exert their influence over local health priorities through instruments such as Joint Strategic Needs Assessments (JSNAs), charities could use these fora to put the social determinants of health further up the government and health agendas. Charities also advocate for health equality at a national level, including the BHA,<sup>30</sup> and within particular communities, like the Afiya Trust.<sup>31</sup>

## What does the voluntary sector bring to the table?

The current health system is highly specialised and institutionalised; relatively few actors take a holistic view of health. Local charities working in health, well-being or community development often engage with people through a range of activities and support, taking a less medical view. Aside from charities explicitly addressing health, many support under-served populations—the economically disadvantaged or those experiencing discrimination—which contribute to the social determinants of health. In either case, these services may be part publicly funded, but will often draw other charitable income and volunteer resources into the health field.

### Challenges

**Positioning charity activity in terms of its positive effects on the social determinants of health.** A range of charities delivering services that contribute to the health equality agenda are not articulating their work in these terms. This is an extremely difficult task since it involves a wide range of activities and the health outcomes may not be the most immediate or easy to evidence.

**Improving the ability of charities to influence local health priorities.** Fewer than half of charities feel they have the opportunity to influence local health and social care priorities.<sup>32</sup> As long as this poor relationship persists, charities and decision-makers will be left unable to fully understand the challenges that the other faces and will struggle to build a common vision, let alone find solutions.

### Questions for future research

- Would a theory of change for addressing health inequalities help charities to articulate their role, or are the different elements too disparate for this to be meaningful? What are the alternatives?
- What are the main barriers to influence in this area, and have charities successfully overcome them? Can we share this success so others can replicate it? Is the proper incorporation of patient voice into the sector's voice a precursor to any advances in this area (see section 1)?
- What number and range of charities currently sit on health and wellbeing boards? Could improvements be made to better represent voluntary sector interests? How influential are these bodies likely to be in the future?
- Who is taking a leadership role for the sector in collecting and collating evidence that their input makes a difference to health outcomes?
- What information do charities need to present to demonstrate the impact of their interventions? Where does longitudinal data exist that could inform the evidence base for prevention? Do charities have the analytical skills to use it effectively?

## 5. DELIVERING SERVICES

Charities that deliver services need income to do so, not only to carry out quality work, but to create sustainable and integrated models of support in their communities. However, emerging market structures present barriers to this delivery. Contracts are being tendered at great scale, bundling together whole pathways on the basis of disease or demographic.<sup>33</sup> This means prevention, community, primary, and acute care of an issue or patient group are crowded under one headline contract.

This bundling can bring efficiencies for the commissioner insofar as it has fewer contracts to oversee, and can hand over the contract risk and responsibility for achieving outcomes to the provider. However, it is not always clear that these contracts are realistic and workable from a commercial or charity perspective—especially given the cost savings expected—and any problems in the design of the contract between the commissioning body and the prime (often commercial) provider are likely to be passed down to subcontractors, which may include charities.

To date, NHS standards of procurement reference sustainable procurement practices, but NHS contracts do not reference the Social Value Act by name. The Act requires commissioners to consider the social, economic and environmental value delivered by contracted services.

### What do we stand to gain from improving this?

For commissioners, building diversity into public services ensures that providers bring varied skills and experience to delivery, that community and social interests are represented, and that healthy competition breeds innovation and quality. It can also help them avoid some of the negative public perceptions around outsourcing public services solely to organisations motivated by profit.

In theory, 'whole pathway commissioning' provides a better patient experience by linking the different points of contact an individual has with the health system all the way along. However, it does not always result in a holistic care experience; it can deliver a narrowly focused vertical pathway concentrating on one health condition (eg, diabetes care) that neglects other conditions or factors affecting an individual's health. Alternatively, a horizontally structured pathway (eg, older people's health) can work against effective coordinated working for conditions affecting patients of different ages. Taking a more holistic approach to commissioning is likely to achieve better results across the board, removing the duplication of efforts, tackling problems in their entirety through a coordinated approach, and ensuring that no groups are left behind.

### What role does the voluntary sector currently play?

Many charities deliver health and social care services directly, comprising 31% of the public services run by charities in 2007.<sup>34</sup> They may provide care for the elderly, for patients leaving hospital or those with particular needs such as learning difficulties or mental health problems. Some are specialist providers, and often the only appropriate provider within a local authority. Others deliver services that have less direct implications for health. The Gloucestershire Clinical Commissioning Group (GCCG), for example, works with Create Gloucestershire to incorporate arts and culture into commissioned health and well-being services in Gloucestershire.<sup>35</sup>

### What does the voluntary sector bring to the table?

Charities working at a local level can bring important local specialisms to public service markets as well as a commitment to social values to counterbalance the financial focus of commercial providers. Breadth in knowledge,

skills and experience in health is key to providing high quality, inclusive services; and ensuring that a wide range of providers are able to participate effectively in the market is the only way to secure this breadth.

In addition, many charitable providers believe the mission-driven nature of their work brings an advantage over other types of provider; their motivation comes from a desire to fulfil the needs of beneficiaries, and they therefore aim to provide the best possible service, potentially going above and beyond the service specification required by the contract. By contrast, commercial companies are incentivised to make a profit for shareholders, and are less likely to channel resources back into improving service delivery.

Profit considerations aside, service delivery charities are often able to use voluntary income to undertake a broader range of activities than those covered by the contract. For example, only 25-30% of hospice funding comes from statutory sources, with legacy funding and donations accounting for most of the rest. Under some circumstances, charities may even use voluntary income or volunteer time to bring down the costs of the service and offer a more competitive bid—a move which may be controversial with other stakeholders.

Charities also supplement the healthcare that beneficiaries are entitled to through statutory provision by building a wider array of services around it. For example, Age UK provides residential social care for older people who qualify for statutory support, but uses the same premises to run day services funded through voluntary sources for those with lower levels of need who do not qualify for public support.

## Challenges

**Devising appropriate contracting arrangements.** Some charities simply cannot compete in the light of large contracts, minimum turnover requirements and complex bidding processes. Though whole pathway tendering stands to simplify contract management and coordinate healthcare provision, contracts must be designed to allow smaller or specialist providers to participate.

**Charities need to evidence their additional social value.** Charities are socially motivated and often see this as their added value when approaching commissioners. But with very tightly-budgeted commissioned work, they may have limited resource with which to deliver this added value. To make this argument effectively, charities need better evidence of the difference a social mission makes in contract delivery.

**Charitable funds may be diverted into contract management.** For hospices, the financial impact of data reporting requirements for the new NHS contract is estimated to be £3.2m. And yet on average only 34% of hospice costs are covered by the NHS, with most coming from charitable sources. Individual fundraisers and local communities have every right to expect hospices to account for their spend, including money spent on the administrative burdens of contract management.

## Questions for future research

- What are the costs of whole pathway tendering to specialist providers? Is there a more effective way to accommodate specialist providers, for example, through prior negotiations with the commissioner?
- When charities deliver contracts, are the results any different to other types of provider? Does a social mission influence delivery method or quality?
- How are new commissioning arrangements impacting charity service providers? What types of organisation are winning tenders in the new health landscape? How consistent is CCG behaviour between different localities? What are charities' perceptions of the new arrangements?<sup>35</sup>
- What are the effects and risks of failing to acknowledge the needs of other stakeholders? What are the opportunities to negotiate with commissioners on contracting arrangements?
- Can the charity sector do more to encourage a holistic approach to commissioning healthcare services? How can it exert influence on commissioners to learn from its experience?

## 6. INFLUENCING THE DESIGN OF SERVICES

Whether or not they directly deliver services, many charities are concerned with the types of services provided by the public sector or outsourced to other providers. It may be that the best way for a charity to support the health of beneficiaries is to spend its energy ensuring that the services provided by government are as effective as possible.

At present, it is not always the case that services are designed based on sufficient consultation with relevant stakeholders (such as beneficiaries and the charities that represent them). Public services, as a result, may often be designed with a primary focus on cost, rather than effectiveness, and in a way that is not useful to all beneficiaries.

### What do we stand to gain from improving this?

It is vital that services are designed to accurately reflect the needs of the populations they serve, regardless of who delivers them. Arguably, if those designing services understand the needs of users and best practice in addressing them—as well as drafting contracts or service delivery agreements to reflect this—it becomes less important who delivers the service (ie, public, private or voluntary organisations), as quality is to a certain extent ensured by good service design.

This is especially important for rare health conditions. Health professionals may only encounter these very occasionally, creating a risk that people with frequently occurring needs are well served, while those with rarer conditions are neglected or misunderstood, and therefore vulnerable to inappropriate support. Charities provide a counterbalance to this.

### What role does the voluntary sector currently play?

For many charities focusing on a specific health issue, an important part of their work is to influence how policymakers and healthcare professionals commission and deliver services. To do this relies on the effective communication of their expertise, based on research, and their experience in working closely with those affected. Organisations focus on influencing different points in the system through a number of approaches:

- **Training:** The National Osteoporosis Society identifies 'local champions' to act as advocates in osteoporosis hotspots. The champions are osteoporosis specialists who work with local GPs, health and wellbeing boards, MPs and patient groups to encourage demand for commissioning effective osteoporosis services. The charity also provides training for primary care practitioners, making them aware of the early signs of osteoporosis and enabling them to monitor and support patients and those at risk.
- **Pilot projects:** Macmillan concentrates on developing and funding pilot projects to test different approaches and learn what works. It then shares this knowledge to insert successful approaches into the health system.
- **Communities of interest:** Parkinson's UK is developing an 'Excellence Network', which involves influential clinicians and other professionals building communities of practitioners who develop and share best practice in supporting people with Parkinson's disease.

## What does the voluntary sector bring to the table?

Charities focused on specific medical conditions can use voluntary income to provide a ‘research and development’ service to the health sector, drawing on clinical research and frontline experience to understand best models of care and treatment. In this way, charities bring a significant amount of funding to the design and delivery of services. Medical research, for example, attracts the highest proportion of donors, receiving donations from 33% of individuals in 2011/12 (accounting for 15% of the total amount).<sup>37</sup> The insights that this kind of research brings are crucial to designing services that are as effective as possible. As the government struggles to meet targets on NHS spending, it is timely to consider what would happen if charities working closely with the NHS commanded a more significant and acknowledged role.

In addition to this, health charities can bring to bear expertise and experience from working with directly affected individuals, and their carers and families, in the design of effective good services. Again, it is the holistic perspective of charities that allows them to design services in a way that caters to the full range of factors that can influence a person’s health.

### Challenges

**The best way to change health practices is unknown.** Charities use their expertise to change health practices but it remains unclear which of the three approaches (detailed above) yields the best results under what circumstances; there is little guidance for charities on how to exert this influence.

**Changing health practices requires a critical mass.** The example charities mentioned above are recognised leaders in their field. Macmillan is a very large charity with significant capacity to fund innovation. Cancer is one of the best funded health causes from charitable sources, and this capacity is not matched in other health fields—certainly not for rarer health conditions.

**The opinions of stakeholders are difficult to integrate or may not be fully respected.** As discussed in section 2, there are many difficulties involved in effectively taking on board the views of a diverse range of beneficiaries. More worryingly, our research also suggests that non-clinical approaches are not well-respected or valued by medical professionals, meaning that these perspectives are not taken seriously during service design.

### Questions for future research

- Which of the three models of influence identified work best, and under what circumstances? Are different approaches successful for different conditions, or do you need a combination of all three? Should we be looking at other methods or approaches? Could this be done in a more coordinated way across sub-sectors or geographical areas?
- How big does a charity need to be to make effective changes using the different approaches? Can small, specialist charities influence some situations?
- What kind of changes is the public sector able to make in response to charity specialist influence? It may be easier to effect change by improving clinicians’ understanding of a problem or encouraging them to look for warning signs.
- When influence requires larger-scale change, does the public sector have the resource needed to mainstream new innovation? Under what circumstances is this likely to be successful?

## 7. MAKING SCARCE STATE RESOURCES GO FURTHER

Early reports show that the NHS is struggling to meet targets in efficiency savings.<sup>38</sup> Monitor, NHS England and independent analysts have calculated that this could produce a mismatch between resources and patient needs of £30bn a year by 2020/21.<sup>39</sup> At the same time, the population is growing and people are living longer and with complex needs, putting greater pressure on the system. Continuing cuts run the serious risk of compromising the quality of health services and their ability to meet demand.

Decision-makers should look to make the most of the resources and expertise already in place within charities. Whilst a discussion of resources is unavoidable, the focus should always be on service improvement, as short-term cost cutting may store up further costs in the future if services suffer as a result. Fortunately, improving services in this way often leads to a more efficient deployment of resources—achieving better and more sustainable improvements in people’s health.

### What do we stand to gain from improving this?

Making better use of resources outside the NHS and the statutory system could lower the cost of health services without sacrificing quality. The activities of the charity sector and the public sector in relation to health are complementary and mutually reinforcing. By making the most of this synergy, there may even be an opportunity to redirect some state funding towards prevention and early intervention, rather than simply struggling to meet demand. In the longer term, the ability to switch resources towards these kinds of activities would reduce cost pressures created by increasing demand.

### What roles does the voluntary sector currently play?

Of charities delivering public services, a large proportion are involved in the provision of health and social care.<sup>40</sup> As well as those that deliver these services such as palliative care, which often subsidise public money with the addition of voluntary income, other charities work to ensure that the provision of social care is well coordinated. Care-focused charities, such as the Carers Trust and Sue Ryder Care, provide support, guidance and professional development opportunities for carers.

Charities like Independent Age ensure individuals receive adequate care upon leaving hospital, helping them to stay well and avoid re-admission. Others provide information on how to manage particular conditions, so that people feel more in control of their health and are therefore less likely to rely on statutory services for support. Charities that focus on building communities or tackling social isolation can also help in an indirect and non-clinical way, by reducing the number of GP visits resulting from loneliness and uncertainty, for example.

### What does the voluntary sector bring to the table?

Charities have the ability to leverage extra value by providing volunteer-run services. Volunteers provide an extra layer to services that mean people have a better chance of staying well, and can do so at minimal cost. In some cases, these services may directly replace or supplement statutory services, whilst in others the voluntary sector activities *complement* existing services, rather than simply running statutory services on voluntary income.

Charities provide low-level care outside hospital to help, for example, reduce hospital admissions and keep beds free. In this way, some health charities aid the wider health system by minimising the need for people to access

NHS services. The Newquay Pathfinder pilot run by Kernow Clinical Commissioning Group and Age UK focuses on bringing voluntary, health and care services together. Age UK supplies highly trained volunteers to act as a link between these services, with the aim of helping older people stay healthy; early evaluations suggest that the pilot has reduced emergency hospital admissions by as much as 35%.<sup>41</sup>

Charities can also bring extra funding to the sector. The specific causes that voluntary organisations pursue and their campaigning efforts are able to harness personalised reasons for giving, and attract funding that may not otherwise have found its way into the sector. Medical research, for example, has been the leading recipient of individual giving since the CAF<sup>42</sup> UK Giving survey began in 2004/5, whilst giving by high-income individuals to medical research is even higher than average.<sup>43</sup>

The rich network of projects and organisations within the voluntary sector also makes it an environment that breeds innovation. Organisations like Macmillan focus their efforts on testing and piloting new innovations to prove whether they are cost effective, replicable and scalable. They then aim to ensure these new and proven approaches are adopted by the statutory system, injecting efficiency and quality improvements.

## Challenges

**The voluntary sector needs to make the case for reducing the burden on the state.** Whilst the ability of voluntary organisations to complement and reinforce statutory services can be easily sketched in theory, the task of proving the extent to which this is the case presents a serious challenge. Given the nature of their work, impact on health is not always readily measurable, and the longitudinal data needed to demonstrate impact over time is not generally accessible. Even where data is available, isolating the specific contributions of the sector from internal efficiencies within the statutory system is no small task.

**Standards of evidence may inhibit the contribution of the voluntary sector.** In some areas, standards of evidence (driven largely by NICE guidance) run the risk of cutting out good providers. This directly influences which charities are able to directly deliver state-funded services, and also obstructs links between the two systems. Some services, for example ‘arts on prescription services’, find that referrals from the statutory system are not forthcoming given strict attitudes to evidence<sup>44</sup>.

**Poor relationships between clinical professionals and charities undermine synergies.** Our research has shown a tendency for clinical professionals to undervalue the contribution of charities. It may be that the non-clinical approaches of charities are seen as inferior to well established and evidenced medical interventions, or even that some clinicians see charities as amateurs.

## Question for future research

- Making the case for individual organisations is difficult enough, but the real challenge is to estimate the *collective* impact of the sector. Even in the case of more accessible metrics, a collective picture of the voluntary sector’s contribution has not yet been created. It is not clear how far the state is being directly subsidised by voluntary activities, and the sector would benefit from updated research into the extent how far, for example, charities delivering public services are able to fully recover costs.<sup>44</sup>
- It is not clear how far voluntary services *replace* statutory services and how far they *complement* them. How much voluntary revenue, for example, is put towards subsidising the delivery of services that are publicly funded?
- Where is the boundary between complementing state services and excessively subsidising them? Is it the charity sector’s role to fill the gaps in welfare provision?
- Could projects designed to open up centrally held administrative data help charities to make this case for their contribution?<sup>2</sup>

# CONCLUSION

Charities are a key part of our health and social care system. Their work can help relieve pressure on mainstream NHS and social care services and provide cost effective joined-up care in the community. However, the seven roles outlined in this paper are not always well understood or communicated by charities individually or collectively, nor fully appreciated by those outside the sector. If we can make improvements in these areas, there are substantial gains to be made in healthcare and for the economy as a whole, as summarised here:

Areas for focus	Potential gains
<b>Roles with individuals</b>	
Representing patient voice and advancing patient involvement	<ul style="list-style-type: none"> <li>• Get people better, faster</li> <li>• Improve patients' experiences of healthcare</li> <li>• Redress inequalities in the quality and availability of treatment</li> </ul>
Helping individuals to understand their condition and navigate the system	<ul style="list-style-type: none"> <li>• Greater efficiency</li> <li>• Improved patient well-being</li> <li>• Better services</li> </ul>
Shaping prevention and early intervention	<ul style="list-style-type: none"> <li>• Prevent health problems arising</li> <li>• Stop symptoms getting worse</li> <li>• Protect high-risk groups</li> </ul>
Addressing the social determinants of health	<ul style="list-style-type: none"> <li>• Avoid the perpetuation of disadvantage</li> <li>• Provide individuals with an equal chance of a high quality of life</li> <li>• Ensure improvements in health are sustainable</li> </ul>
<b>Roles within the system</b>	
Delivering services	<ul style="list-style-type: none"> <li>• Greater diversity of skills in the market</li> <li>• Representation of community interests in public services</li> <li>• Offer a holistic approach to healthcare</li> </ul>
Influencing the design of services	<ul style="list-style-type: none"> <li>• Services reflect the views and needs of patients more accurately</li> <li>• Services suit the needs of all groups (including the marginalised) and all conditions (including rare conditions)</li> </ul>
Making scarce state resources go further	<ul style="list-style-type: none"> <li>• Meet efficiency requirements without sacrificing the quality of services</li> <li>• Redirect resources to make further savings in the long term, through prevention and early intervention</li> </ul>

We would like to bring together charities to discuss and refine this offer as part of a complex and evolving system, so that they can ultimately play a more significant part in supporting good health. We welcome any feedback and would be interested in hearing your thoughts on the questions raised and future priorities. Get in touch via [info@thinkNPC.org](mailto:info@thinkNPC.org) or tweet us [@NPCthinks](https://twitter.com/NPCthinks).

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## TRANSFORMING THE CHARITY SECTOR

NPC is a charity think tank and consultancy which occupies a unique position at the nexus between charities and funders, helping them achieve the greatest impact. We are driven by the values and mission of the charity sector, to which we bring the rigour, clarity and analysis needed to better achieve the outcomes we all seek. We also share the motivations and passion of funders, to which we bring our expertise, experience and track record of success.

**Increasing the impact of charities:** NPC exists to make charities and social enterprises more successful in achieving their missions. Through rigorous analysis, practical advice and innovative thinking, we make charities' money and energy go further, and help them to achieve the greatest impact.

**Increasing the impact of funders:** NPC's role is to make funders more successful too. We share the passion funders have for helping charities and changing people's lives. We understand their motivations and their objectives, and we know that giving is more rewarding if it achieves the greatest impact it can.

**Strengthening the partnership between charities and funders:** NPC's mission is also to bring the two sides of the funding equation together, improving understanding and enhancing their combined impact. We can help funders and those they fund to connect and transform the way they work together to achieve their vision.

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