Cancer Research UK response to the Civil Society Strategy

May 2018

Cancer Research UK is the largest fundraising organisation in the UK. As a charity, we receive no funding from the Government for our research and our ground-breaking work is therefore only possible because of the generosity of the public. In 2016/17 we spent £432 million on research in institutes, hospitals and universities across the UK, funding over 4,000 researchers, clinicians and nurses. In 2016/17 alone, over 40,000 volunteers gave over four million hours of their time. Our ambition is to accelerate progress to see three in four patients survive cancer by 2034.

The charity sector is made up of a wide range of organisations which vary greatly in size and cause – but all work for public benefit. For the sector to thrive, government must provide a favourable environment: through favourable fiscal and legislative measures, as well as contributing to a supportive public narrative about the vital role that charities play. We are therefore pleased to have the opportunity to respond to this important consultation.

Charities must also demonstrate that they are worthy of the public's trust, through communicating effectively about their mission and demonstrating best practice. As the largest fundraising charity in the UK we believe we have a responsibility to play a leading role when it comes to good governance, and to share our learnings with others. We would be pleased to discuss any of the issues raised in our response further, if helpful.

Key points:

- Civil society is vibrant, diverse and strong. Charities play a vital role in driving social change, both nationally and in communities.
- Government could increase the impact of civil society by promoting a favourable fiscal and legislative environment. More could be done to encourage Government to engage with charities and to embed consideration of civil society in routine policymaking. This would ensure that new policy does not have unintended consequences for the sector and allow the sector to thrive.
- Charities are facing increasing pressures, increasing scrutiny and increasing financial burdens to comply with regulatory requirements. Accountability and transparency are important, however Government could do more to support the sector through promoting policy that could help compensate for these pressures and promote innovation.
- It is only through achieving best practice and communicating effectively about what we do, that charities can build public confidence in the sector. CRUK has a responsibility to play a leading role in the sector, in terms of good governance and fundraising operations – and so have recently moved to a system of opt-in for all marketing communications.
- There is also a role for Government in building public trust: by telling the positive stories about the impact of charities as well as the negative stories, and encouraging a positive public narrative about the role of civil society. Government must also ensure that the sector's regulators are adequately resourced to cope with their growing demand.

1. What are the strengths of civil society today?

Civil society can represent, champion and understand the needs of people with specific challenges, and then connect them to those with the capabilities to find solutions. It can give individuals purpose, through providing opportunities to donate, volunteer and be part of a community.

Civil society can act as an independent voice, speaking truth to government on behalf of our beneficiaries and of people who are unable to advocate for themselves. In the case of Cancer Research UK, we support the prevention of cancer, act as a champion for everyone diagnosed with cancer, fund life-saving research and advocate for policy change – all so that we can bring forward the day that all cancers are cured.

2. How can Government help to increase the impact of civil society?

Government can help increase the impact of civil society by promoting a favourable environment for charitable giving in the UK. Government can do this through supportive fiscal measures and legislation, as well as championing the vital role of civil society more broadly and building a culture of philanthropy.

Building a favourable fiscal environment

A supportive fiscal environment for charities allows our supporters' generous donations to have the greatest impact possible on our research. An ideal environment would include sector-wide measures, such as maintaining or even extending Gift Aid, as well as more specific fiscal incentives to encourage partnership between charities and other organisations – in our case, research partnerships.

Gift Aid is a highly valued form of tax relief for charities. As it is income forgone for public benefit, it is not subject to tax and provides a reliable stream of income for charities that do not receive funding directly from Government, such as Cancer Research UK. It is reassuring that Government are taking steps to encourage people to declare Gift Aid on their donations. Recent research by HMRC shows a third of eligible donations did not add Gift Aid, meaning that charities are losing out on nearly £600 million a year collectively[1].

Cancer Research UK is a significant claimer of Gift Aid, claiming £32.8 million in the year to 31st March 2018 – almost our annual spend on breast cancer research[2]. Gift Aid is therefore a crucial funding stream that must be protected if we are to achieve our ambition of reaching three out of four patients surviving their cancer by 2034.

There are also more specific ways that Government could increase the impact of civil society, through fiscal measures that would incentivise partnerships between charities and industry. The specific solutions may be very different for different charities; we are eager to find fiscal measures that could encourage collaboration in medical research.

R&D tax credits enable companies that incur costs in developing new products, processes or services to receive a cash payment or tax deduction. Universities and large charities were originally able to claim relief through the Research and Development Expenditure Credit (RDEC), but in 2015 the legislation was changed to close this scheme to charities 'in line with the original intention of the policy'[3].

Government should consider opening the RDEC scheme to independent charities not based at a Higher Education Institute. This would meet the scheme's original policy intention and, since any funds recuperated by medical research charities must be reinvested in research activity, would stimulate further R&D growth in the UK.

The extent to which charities and universities can currently collaborate with industry on medical research is limited by VAT rules on sharing of facilities, equipment and buildings. Publicly-funded research institutes are restricted to 5% commercial activity if they opt not to pay VAT, or face

significant tax costs co-locating their researchers with industry colleagues. Collaboration between industry and publicly funded researchers is crucial to research input – and the inability to collocate and share resources is a major barrier. Government should therefore review current rules on VAT exemption on sharing of buildings, equipment and facilities for the purposes of R&D, to support collaborations and attract inward investment.

We will submit a more detailed picture of our perspectives on charity tax to NCVO's Charity Tax Commission consultation later this year.

Building a favourable legislative environment

Civil society can be affected by a broad range of legislation, either directly or indirectly. While many charities play an active role in monitoring and influencing the development of legislation relevant to their charitable purpose, there is also a much broader scope of legislation that can impact charities' operations. This can be managed by a broad range of government departments.

For example, gifts left in wills make up more than a third of Cancer Research UK's funding, and so we would have been significantly impacted by changes to the legislation surrounding fees for grants of probate which were proposed in early 2017 by the Ministry of Justice[4]. This would have diverted over £780,000 away from gifts given to Cancer Research UK each year and would have cost the sector £18 million a year – however there was no specific consideration of the impact on civil society and no exemption proposed to mitigate the impact[5]. Thankfully, following an official petition and media coverage of the proposed reforms, these proposals were dropped.

Similarly, many larger charities are being significantly impacted by the Department of Education's Apprenticeship Levy, which is likely to cost Cancer Research UK around £500,000 this year. Because of a lack of time to prepare, and a lack of appropriate apprenticeship standards, this year we have only been able to spend about 20% of the levy. Even after the 10% of the fee that can be transferred, this means Cancer Research UK will lose roughly £350,000. This fund will be spent on other organisations' apprenticeships – which may not be in accordance with our charitable objectives, as our donors would quite rightly expect.

In both cases, government policy has significant unintended consequences for the charity sector, diverting both time and funding away from charities' core purpose. While Cancer Research UK is fortunate to have the resource to monitor these developments, respond to consultations and work with others in the sector to coordinate a response, we are very conscious that many charities do not.

Government could do much more to embed consideration of civil society into all policymaking, across all departments. This is increasingly important given the growing role of civil society. There should be a consistent approach across government, with civil society seen as an important stakeholder group, given due consideration and not overlooked. The Office for Civil Society have an important role to play in driving forward this culture change, to ensure the importance of civil society is recognised by all.

The financial burden of regulatory compliance

Finally, over recent years the sector has experienced pressures that are challenging our ability to effectively spend funds – donated by our supporters - in a way that maximises their impact in our fight to beat cancer. There is also an increasing financial burden placed on charities to comply with regulation and governance requirements.

For example, CRUK's annual expenditure on the Apprenticeship Levy is around £500,000 and to date, we have spent over £460,000 on complying with the General Data Protection Regulation (GDPR). There are numerous other requirements in addition to this, for example pension regulations and the introduction of the national living wage.

These policies are important and as a large employer, we have a responsibility to implement these in full. However, charities – unlike businesses – cannot pass these increased running costs onto consumers. On the contrary, these requirements mean that less money is available to spend on meeting charitable objectives; this is also a matter of public interest, with significant attention placed on calculations such as "pence in the pound" spent on charitable activities. There is therefore a strong argument for government to introduce policy that can help compensate for these pressures and promote charity innovation.

Plans to increase further charging for charities are often touted, including requiring charities to contribute to the funding of the Charity Commission. It is of course vital that the sector is supported and governed by an adequately resourced body, especially given recent concerns about safeguarding. However, the route of the issue is that the Commission's funding has been reduced by roughly 50% over recent years. We are also concerned about the message that charging charities would send to the sector and to the public about the Commission's independence and credibility. We therefore encourage the Government to reconsider these proposals.

More broadly, we are concerned about this trend of increasing the financial burden placed on charities, especially in the context of an uncertain economic outlook and often growing responsibilities for charities. There must be a balance between ensuring sufficient resource to support charity governance and maintaining an agile, diverse and innovative charity sector.

3. How can public trust in civil society be built and maintained?

We know that only through achieving best practice and communicating effectively about our work can we secure public confidence. We are in the service of our supporters and must work to earn and maintain their trust, through everything that we do, and so aim to operate to the highest standards of best practice. This includes being prepared to raise money in the right way, even if that sometimes means raising less money. As the largest fundraising charity in the UK, we believe we have a responsibility to play a leading role when it comes to good governance. We are always happy to share our learnings and aim to be as transparent as possible in the decisions we make. However, transparency should be seen as a tool to highlight good practice; transparency is not a goal in and of itself.

Over recent years, how charities communicate with their supporters has been heavily scrutinised. There have also been significant changes in the sector's regulation and legal framework, for example the introduction of the General Data Protection Regulation (GDPR). For many charities as well as ours, these changes have driven us to reflect on our relationship with our supporters. This has been one positive effect of the increasing scrutiny placed on charities in recent years.

CRUK has therefore made the decision to move to an opt-in model for all our marketing communications with our supporters. We expect that this change will impact our fundraising income, but we believe it's the right thing to do and will protect our supporters' trust in us in the long-term. This change has also meant that we are now being more cost-effective with who we contact, and has given us a head-start in our GDPR compliance. We have submitted a case study of our move to opt-in to the Fundraising Regulator and would be happy to share further learning with other charities and government as this move matures[6].

However, there is also an important role for Government in building trust – through telling the good stories as well as the bad, and speaking about the impact of charities. It is important to speak openly about cases of misconduct, but this should not be used to tarnish the whole sector.

There is also an obvious and important role for the sector's regulators. We are supportive of the Fundraising Regulator and believe that recent changes to self-regulation will help build public confidence. However, there is still more to be done to ensure that the public is aware and engaged in its work. This includes improving public awareness of the Fundraising Preference Service.

4. **How can civil society be supported to have a stronger role in shaping government policy now and in the future?**

Lobbying and campaigning is a hugely important tool for charities, whether used to encourage change or maintain a positive status quo, raise awareness, provide expertise to strengthen strategy, or otherwise help to achieve their vision. Charities should absolutely be non-partisan, however they must also feel free to be positive and constructive campaigners. Following the Lobbying Act, we would welcome recognition from Government of the value that charity campaigning adds.

Cancer Research UK works to keep cancer a priority on the political agenda, and have had many campaigning successes[7], including successive campaigns on tobacco control legislation and our "Test Cancer Sooner" campaign, which led to a commitment in the 2015 Spending Review for £300m a year in additional funding to speed up cancer diagnosis[8].

There is also a strong case for meaningful involvement of civil society in government policymaking. Charities have broad expertise, as well as strong links to local communities, frontline services and service users – all of which is hugely valuable in informing policy, especially during times when the civil service is lacking in capacity or resource. While we have had brilliant engagement with government on some of our specific policy priorities, we know that across the sector this can be inconsistent. There is a role for the Office for Civil Society in championing the role that charities can play in supporting government policymaking.

People

5. **How have people successfully taken action to improve things for themselves and their communities? Please tell us why it has worked well**

As well as a strong national presence, Cancer Research UK also has a presence in communities around the UK: in our network of shops, our research, through local fundraising groups and our work to communicate health information. We aim to join this work up and integrate CRUK into local communities. For example, our shops can act as local hubs; they can also help disseminate health information and information about cancer screening programmes. Central to all of this is our ambition to engage and empower the public to take positive action for their health; this is led by our health community engagement team. We therefore have several strong examples to share of how people have taken action to improve their local cancer outcomes, set out below.

Health Community Engagement

Cancer Research UK's Health Community Engagement team works on the ground through a team of trained nurses, skilled trainers and brilliant volunteers, helping to prevent more cancers and support earlier diagnosis, particularly among disadvantaged groups.

As part of this activity, we run a Cancer Awareness Roadshow and Hubs, nurse-led activities in the community. The Cancer Awareness Roadshow and Hubs reach around 60,000 people every year. Key evaluation results, some of which have been published[9,10], include:

- Significant increase in awareness of risk factors
- 92% reported that their visit was very good (highest level of satisfaction) and 95% said that they are likely to make a positive change for their health following their visit
- 48% of smokers attempted to quit smoking at 2-month follow-up with 71% attributing this to the Roadshow
- Reduction in most barriers to seeing a doctor; 33% of people who spoke with our nurses about going to the GP reported they had done so at 2-month follow-up, with 80% attributing this to the Roadshow

As well as engaging the public directly, we run *Talk Cancer* training workshops to equip trainees to talk to their own communities about cancer. Workshops are led by skilled CRUK trainers with nursing backgrounds and years of experience talking to the public through the Roadshow. We have delivered around 200 workshops to over 3,000 people to date. We've published evaluation results and our lead trainers have authored invited opinion articles based on their insights[11,12]. Results from our most recent evaluation include:

- Increase in risk factor awareness, including physical activity (52% pre to 95% post) and obesity (79% to 97%)
- Increase in awareness of screening programmes, e.g. bowel cancer screening (64% to 96%).
- Increase in confidence to talk to the public, e.g. signposting to info and services (61% to 100%) and about screening programmes (43% to 97%)

To increase our reach further, we've developed a massive open online course (MOOC): *Talking About Cancer: reducing risk, early detection and mythbusting*. This draws on some of the core principles of our Talk Cancer training workshops, giving learners an introduction to having simple, effective conversations about cancer and health with the public, colleagues, friends and family. Since launching in June last year, we've had over 7,500 learners from 168 countries taking part in the course. Learners are wide-ranging, including health workers, members of the public, patients and carers, and researchers. While the majority are from the UK, these figures show that this topic and approach has international relevance and reach. Our evaluation shows a shift in confidence to talk about cancer with the public from 64% to 94%.

<u>Campaigning</u>

Cancer Research UK also have 343 local Cancer Campaigns Ambassadors, who are all volunteers. Our Campaigns Ambassadors save lives by meeting with their local MP and campaigning on our behalf, but often go above and beyond by collaborating with others to make change in their local area.

> *Working as an Ambassador has opened my eyes to how it is possible for people like me to improve the outcomes of cancer in ways other than fundraising... I am also more confident about putting across issues to my MP, Council, friends or other organisations.* - A CRUK Campaigns Ambassador

This programme works well because our Campaigns Ambassadors are passionate, motivated and committed. We also make sure that our Campaigns Ambassadors are given enough support to

succeed, for example through equipping them with a toolkit of actions they could take, peer support from other Campaigns Ambassadors and central support from CRUK's Campaigns team.

Partnership

6. Reflecting on your own experience or examples in the UK or abroad, how are partnerships across sectors improving outcomes or realising new potential?

Partnerships with industry on medical research

Research is at the heart of our ambition to improve cancer survival. One of the strengths of the UK's science base is its diversity of funders and their collaboration. CRUK fund 45% of cancer research activity in the UK[1]. We work with 42 NHS hospital trusts, support research in over 70 institutions and work with many commercial partners to drive forward progress in the right against cancer.

CRUK's Centre for Drug Development (CDD) sponsors, manages, funds and executes preclinical and early phase clinical development programmes from both academia and industry. CDD's aim is to accelerate the development of promising new treatments, ultimately bringing more treatment options to patients. CDD has an active portfolio of around 20 agents and a strong track record, having taken over 150 agents into clinical trials. These partnerships have led to several important treatment options being brought to patients, including abiraterone for prostate cancer and temozolomide for brain cancer.

CDD partner with pharmaceutical and biotechnology companies who have a promising product, but need resource, capabilities or expertise to take it forward. By forming a partnership, we can get that product through the most difficult step of drug development. These partnerships bring together the drive of pharmaceutical and biotech companies with CRUK's network of world-leading scientists and our in-house expertise.

For example, we can use our network of 18 Experimental Cancer Medicine Centres (ECMCs) to deliver translational clinical trials for new medicines. ECMCs are themselves a partnership; they are a joint initiative between CRUK and the Health Departments for England, Scotland, Wales and Northern Ireland.

Case study: our partnership with Bicycle Therapeutics
Together with Dr Udai Banerjee, Chief Investigator for the trial, our Centre for Drug Development (CDD) is sponsoring and funding the first-in-human clinical trial for BT1718. The first patient joined this trial in February 2018.

We partnered with Bicycle Therapeutics in December 2016. While we are sponsoring the early-phase development, Bicycle Therapeutics can license the results of our trial in return for success-based milestone and royalty payments to CRUK, as well as an equity stake in the company.

> *"This relationship is an example of a situation where one plus one is greater than two… It is clear that by combining forces we can deliver potential benefit to patients more rapidly than we could by working alone."* – Kevin Lee, CEO of Bicycle Therapeutics

In November 2017, our partnership won the Best Partnership Alliance Award at the industry's prestigious Scrip Awards, highlighting the genuinely collaborative nature of our model.

[1] *Calculated from NCRI Cancer Research Database (CaRD) 2014 expenditure figures. Figure excludes industry-funded research.

An innovative approach to corporate partnerships

Cancer Research UK has several corporate partners, as do many charities. In 2015 CRUK launched a 'Cancer Awareness in the Workplace' programme, which involves working with our corporate partners to engage and empower people to take positive action for their health and raise awareness of cancer prevention and early diagnosis. This helps us to enable behaviour change and tackle health inequalities, contributing to our goal of increasing cancer survival to 3 in 4 by 2034.

We do this through a range of evidence-based activities, ranging from delivering on-site workshops to producing tailored health messaging. In 2017 alone, we worked with over 35 different partners and in the last two years we have reached over 600,000 employees with health information. Our successes include:

- Delivering nine cancer awareness workshops in 14 hours to over 400 night-shift workers at a food processing factory. Results show that our workshops increased staff's awareness of the UK's bowel cancer screening programme from 42% to 89%.
- Creating UV warning posters for 150+ construction sites to help workers stay safe in the sun.
- Delivering health stalls at construction sites. Our site contact said:
  "It was positive to see individuals sharing their own experience of how cancer has impacted their lives… it is my hope that to some extent this has broken a barrier that will now prompt further communication between our teams in the future to provide support to one another, which is sometimes lacking in a male dominated workforce"
- An online prevention game with a communications company which encouraged over 6,000 staff to make a public health pledge in a four-week period.

Case study: Cancer Research UK, British Heart Foundation, Diabetes UK and Tesco

This partnership, "Little helps for healthier living", brings together the skills of the four organisations to help lower the risk of heart and circulatory disease, cancer and Type 2 diabetes. Over the next five years, the four organisations will work together to help Tesco's 300,000 UK colleagues and millions of UK shoppers by removing barriers to healthier habits, including:

- Developing the UK's leading workplace health programme for Tesco's 300,000 UK colleagues
- Aligning communication campaigns in store and online with national health campaigns
- Training Tesco pharmacists to help them better support customers in the prevention and management of heart and circulatory disease, cancer and Type 2 diabetes
- Sharing anonymised sales information to help develop insight on health policy and public health programmes
- Fundraising for more health research – innovative and engaging fundraising initiatives that help customers and colleagues raise money for the three charities.

Our partnerships with the public sector

We also work in close partnership with the public sector, for example through engaging with local health services and supporting primary care. Cancer Research UK's facilitator programme involves facilitators working directly with local health systems to support improvement programmes, provide training and influence priorities.

Our facilitators currently work with over 5,700 GP practices around the UK and deliver around 700 engagements per month. A core part of this is conducting practice visits to discuss their performance

on cancer; these result in 96% of practices taking action, for example introducing systems to track uptake of screening programmes for their patients. Practices have reported increases of up to 17% in bowel screening rates as a result of our interventions – so these partnerships are saving lives.

> *"I understand where how we are performing in relation to screening and have good ideas on how to try and increase uptake."* - Practice Nurse

Our approach is successful because it is unique: the NHS does not, and has never had, an effective method for engaging practices in quality improvement – and this is especially true given current pressures. CRUK is also able to offer an independent expert voice, connected to a national programme and national organisation – and can offer consistent resource. In this instance, there is a distinct advantage to this coming from civil society, rather than being part of the system. The challenge we continually face is capacity, however – there is a clear demand for deeper support, and so meeting that demand is difficult.

7. **Are there any additional factors that would enable more impactful partnerships across sectors? How could these factors be addressed now and/or in the future?**

Working in partnership with local authorities would be more impactful if there was adequate funding for local authorities. This is felt most acutely in terms of cuts to public health grants, however this is compounded by the wider context of extremely stretched local government sector, which restricts the ability of local authorities to plan long-term and invest for the future, for example by retaining investment in Smoking Cessation Services. This effect is compounded by uncertainty surrounding the future funding model for local authorities throughout the ongoing reforms[13].

Responsible business

Reflecting on your own experience or examples you are aware of in the UK or abroad, how are businesses unlocking new partnerships and potential within civil society? Please tell us how this is different to other types of organisations

Please see our earlier responses.

Place

How have local people, businesses, voluntary and community organisations, and decision-makers worked together successfully to break down barriers in our communities and build a common sense of shared identity, belonging and purpose?

The most prominent example for CRUK is in Greater Manchester (GM), where we have several activities, including with local government and the broader health systems – the Health and Social Care Partnership, GM Cancer and the GM Cancer Vanguard.

Our policy and information activity in Greater Manchester, led by our Local Public Affairs and Campaigns team, has included contributing to the development of several local and regional plans for cancer and cancer prevention. We have also recently launched a joint research project with Greater Manchester Health and Social Care Partnership, to explore new models for pricing cancer drugs in the NHS[14]. This partnership helps realise new potential by combining our policy and research expertise with an opportunity in Greater Manchester to think in new ways about how to challenge the key challenges in health policy. The outputs from this work can then

constructively challenge existing policy thinking, potentially driving better outcomes for patients and the public – as is fundamental to the goals of both CRUK and GMHSCP.

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