Response to the Health Devolution Commission's Call For Evidence 2020

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Macmillan's response

In what ways does health devolution enable the building of healthier communities and promote the prevention of ill-health?

Integration of health and social care is widely acknowledged as a key factor in building healthier communities and delivering a sustainable health and social care system. While devolution is not a prerequisite for an integrated health and social care system, it can play an important part in providing the political will, momentum, collaborative working and a whole system approach that makes integration easier to achieve.

Areas with devolved health powers have often used an integrated response to health and social care to provide a focus on addressing health inequalities. Macmillan has a lot of evidence to indicate that when the NHS and local authorities collaborate around reducing inequalities and use their shared knowledge, powers and resources. This creates the potential for greater investment, more targeted policies and better actions for deprived communities.

Macmillan's Time to Talk report (2019) highlights the importance of partnerships amongst different stakeholders, to address the unmet needs of excluded communities.

For example, in rural or remote areas limited transport infrastructure often means health systems have less capacity to meet their population's range of health and care needs. A lack of infrastructure is likely to impact people on lower incomes the most, as their financial means may limit the transport options available to them. Integrated care therefore needs to be designed to help the most deprived groups get timely access to vital cancer support to ensure that they have the best chance of surviving cancer and living well after treatment.

We know people in the most socio-economically deprived areas in England are 20% more likely to have their cancer diagnosed at a late stage than people in the least deprived areas, and people living with cancer in the most socio-economically deprived areas face almost 25% more emergency admissions in their last year of life compared to people from the least deprived areas.[i]

In London, the Greater London Authority Act 2007 gave the Mayor a statutory responsibility to produce a health inequalities strategy for London. The 2018 London Health Inequalities Strategy acknowledges that prevention and early diagnosis goes some way to limiting health inequalities. To combat inequalities in the cancer pathway the strategy ensures good access to major preventative programmes such as screening for cancer, fairer access to effective treatment and promoting a healthier lifestyle by reducing the use of, or harms caused by tobacco, illicit drugs, alcohol.

The Strategy recognises that the Mayor does not have powers to commission or provide some of these services, therefore he must work with other parties to ensure health inequalities are minimised in London. For example, to reduce the use of tobacco, drugs and alcohol he is working in partnership with London boroughs, the NHS, Public Health England and other sectors to support and deliver this outcome.

A 2017 Macmillan survey into cancer health inequalities in London found that white respondents reported the most positive cancer experiences, compared to other ethnicities. 42.4% of patients of mixed ethnic background felt like groups of doctors and nurses talked in front of them as if they weren't there, compared to 19.2% of white patients, and 58.9% of Black patients said that that they understood the explanation of what was wrong with them compared with 72.7% of white patients.[ii]

Following our report and campaigning by Macmillan these differences in care experiences were recognised by the Mayor in his 2018 Strategy. Plans with local communities including marginalised groups have been developed through continuous engagement to reduce these types of inequalities occurring in London. It also aims to empower Londoners to improve their own and their communities' health and wellbeing, by giving a strong voice to the public in the decision making, design and delivery of services.

Our Macmillan Local Authority Partnership Programme (MLAPP) has demonstrated that local authorities taking a lead role in planning cancer support in the community, helps to facilitate joint working to maximise the impact of community asset mapping, Joint Strategic Needs Assessments and service delivery for people with cancer.

Although it is difficult to evidence the impact of a whole system population health approach, devolution certainly allows for a stronger and more ambitious vision for health and social care, reinforcing collaborative working and ensuring that good practice, successful approaches and programmes are spread effectively through policy direction.

In what ways does health devolution enable the marshalling of a wide range of services and partners across local authorities, the NHS, community and charity bodies, and the private sector to address the wider drivers of ill-health in local communities?

In the devolved nations, legislation such as Well-being of Future Generations (Wales) Act 2015 has created a legal requirement for public bodies in Wales to think about the long-term impact of their decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.

Although devolved bodies in England can't legislate for this, they can help to develop and drive a strong policy, ambition and mindset to improve the way that organisations work together.

In Greater Manchester, the devolution and integration of health and social care across the city-region has boosted an already existing culture of collaboration which is evident even at a place-based level. The ambitious approach in Tameside, for example, has been one of inclusion and partnership across sectors to address the wider drivers of ill-health in the local community. Macmillan has been working in partnership with Tameside and Glossop Integrated Care NHS Foundation Trust for many years to support people from the point of diagnosis right through their cancer journey. The Tameside Macmillan Unit provides a single point of access for all appropriate cancer assessment, treatment and support services for people living locally. Co-location of services in the unit has meant that support is integrated and wrapped around the individual. Community assets have been mapped and important links with local organisations and groups across the borough have been built in order to increase the support available to those living with cancer. Facilities available include Macmillan clinical nurse specialists, information and support services offering practical and emotional help, chemotherapy and outpatient services, complementary therapies, welfare rights advice, access to personalised community support and dedicated spaces for prosthesis and wig fitting as well as support groups. Since opening in 2017, the information and support service alone has had over 7,000 contacts with people affected by cancer and the integrated Macmillan benefits officer has helped people to claim over £163,000 in benefits and charitable grants.

Are there any barriers to the potential benefits of health devolution being realised; and if so how could these be addressed?

Financial pressures upon health and care systems represent a very significant barrier to the benefits of health devolution being realised. Major system changes like devolution of health powers need to be properly financed and the delivery of that spending must be at the right time, when the system and the infrastructure are ready to support it. While there has been a welcome increase in funding for the NHS recently, there is still a long way to go before the NHS will be able to deliver the level of care and support that people with cancer, and the wider population deserve. This is before the added pressures of immense system transformation and integration under devolution are accounted for.

The 2018 10-year programme of NHS investment amounting to an addition £20.5 billion by 2023/4 was widely welcomed, however it followed significant underfunding of the NHS in the previous decade. Because of rising inflation, the additional funding amounts to less than the 3.4% annual increase announced by the Government. The financial position of many local authorities is a grave concern and is a substantial impediment to realising true integrated services at a local level. Central government funding for local authorities in England fell by nearly 50% between 2010/11 and 2017/18. The funding gap in adult social care is estimated to be £1.5 billion pounds, which could rise to £6 billion pounds by 2030.[iii] Public health and local authority funding is critical if people with long term conditions are to receive all the services and support they need. This is particularly true in cancer care, where public health and social care investment is necessary to achieve genuinely integrated care.

The growing crisis in the health and social care workforce is increasingly affecting cancer services and support, highlighted in Macmillan's 'Voices from the Frontline' report. The NHS nursing workforce is being pushed to breaking point, with vacancies reaching 40,000 and

near intolerable pressure being placed on many professionals. Without enough workforce capacity, it is much harder to deliver successful system change. Furthermore, it has been predicted that the NHS will be unable to optimise the extra funding outlined in 2018 because of staffing shortages[iv].

Workforce challenges vary throughout the UK. For example, in some areas in Wales the vacancy rate for registered nurses is as high as 25% and a recent Royal College of Nursing (RCN) survey found that 57% of nurses surveyed wanted to leave London in the next five years.[v] Humber, Coast and Vale STP has enormous difficulties in recruiting and keeping skilled and experienced staff in smaller, rural areas and argue this is the root cause of many problems their system faces[vi]. When it is difficult to recruit and retain staff this can affected the quality and availability of healthcare being offered in an area. Some devolved powers can be used to correct underlying staffing shortages and retention rates. For example the RCN recommends rent controls and free travel for nurses and key workers in London. However, despite the reason for workforce shortages differing from area to area, devolved powers will only go some way to tackling the national workforce crisis.

Accountability and transparency of the system are also key to the success of devolution, and how it is viewed by the public. On existing evidence, a devolved health and care system such as Greater Manchester has sought to be much more transparent than is common practice in most other Integrated Care Systems, leading to greater engagement and acceptance from the public in Greater Manchester.

How does health devolution affect the outcomes and experience of care for people with specific conditions such as cancer or mental illness, or specific population groups such as older people with conditions such as dementia?

While most Integrated Care Systems will have specific programmes of work for conditions such as cancer, health devolution in Greater Manchester has allowed their system work on cancer to be integrated into their population health planning. This has meant combining public health and prevention elements with measures to tackle the wider determinants of health as well as health inequalities after the point of diagnosis.

In Greater Manchester, a proportion of transformation funding, as part of the devolution agreement, has been allocated to the Prehab4cancer programme. The programme launched in April 2019 and helps those newly diagnosed with cancer who are awaiting the start of treatment or those in the recovery period after surgery, with a tailored programme of exercise and nutrition. Early evaluation shows successful results with participants improving their fitness and maintaining weight.

The recent announcement of devolved powers to West Yorkshire has the potential to bring the NHS and local government organisations much closer together to improve support for people with cancer. Models like the pan-Leeds Cancer strategy, which has resulted in citywide integration of health and care organisations, has demonstrated increased patient satisfaction and meeting patient need, and could be enhanced and rolled out more widely.

In Scotland, Macmillan's Improving the Cancer Journey (ICJ) programme has shown how integration can improve care for everyone, particularly the most socioeconomically deprived people in society. The programme, piloted in Glasgow, uses a multi-partnership model to

bring together existing providers from the health and wider welfare sectors – including employment, welfare and housing support.

After diagnosis people with cancer are sent a letter of invitation for a holistic needs assessment (HNA) which consists of a visit with a link officer from the Council to establish any physical, emotional, social, financial, family, spiritual or practical concerns the person may have. Once these needs are identified the link officer either signposts or refers on to relevant agencies to support the person and their individual needs. The top three concerns identified are money and housing, fatigue and getting around.

Under evaluation (Improving the Cancer Journey Programme), the level of concern identified through the HNA reduced significantly between the first assessment and last review. Scores went down from average 7.15/10 to 3.85. The majority rated the outcome of their referral as 'very helpful', giving it 9/10 on average. Most who were supported by the ICJ were worried about money and either did not know about help available or felt it was inappropriate to raise these concerns in a health setting. Consequently, having an accessible expert to guide someone through the system provided security, reassurance and the confidence to self-manage. For example, the ICJ has a dedicated housing professional in the team to ensure people are supported to stay in their homes and has so far prevented 26 people becoming homeless due to their cancer diagnosis.

Following the success of the programme in Glasgow, the Scottish Government and Macmillan are jointly investing £18 million to roll out the Transforming Cancer Care (TCC) based on the ICJ model.

See below for more information on TCC and here for more detail on the ICJ programme.

To what extent does health devolution accelerate integration within the NHS and between health and social care services, and help make the NHS Long Term Plan a reality?

The Long Term Plan was an NHS plan and downplayed the role of local authorities and Health and Wellbeing Boards. There are signs that local authorities have had mixed engagement with ICSs. However, a 'system by default' approach is seeing more power and financial control moving to ICSs which are having an increasingly autonomous role in setting local priorities including for workforce, cancer (via cancer alliances) and end of life care. The draft plans looked promising for personalised care – though Macmillan has concerns around workforce and the ability of the system to prioritise Living With and Beyond Cancer work, when cancer alliances face pressure over the 62-day wait.

How does health devolution affect policies to empower individuals to have more control over their health and social care services and outcomes?

In the North West, Macmillan works with Greater Manchester Cancer to ensure the voices of people affected by cancer are at the heart of service improvements. Experiences can be shared by people with cancer, their family members, carers and friends. Greater Manchester has signed a User Involvement Charter to show their commitment to putting people affected by cancer at the heart of improving cancer services.

To create the Northern Ireland Cancer Strategy 2020 the Department of Health have included people living with or who have lived with cancer and their carers. Training has been provided to these people about the Health and Social Care systems and structures, as well as the priorities and plans for the future, so they can better input into discussions on the proposed strategy. The coproduction of the strategy with professional cancer services staff, patients, cancer charities, commissioners, care providers and other key stakeholder groups will allow for the strategy to deliver the best standard of services and improvements of outcomes for people in Northern Ireland.

What impact does health devolution have on the charity sector, social enterprises and the independent sector as providers and partners in health and social care structures?

Macmillan have worked closely with the Scottish Government to create the Transforming Cancer Care (TCC) programme. The £18m partnership makes Scotland the first country in the UK where cancer patients will be guaranteed wraparound support. Both the Scottish Government and Macmillan have invested £9m into the TCC Programme to ensure everyone with cancer is offered emotional, practical and financial help from a dedicated support worker.

The TCC allows health, social care and third sector partners to accelerate the transformation of support available to people during and after their treatment from diagnosis onwards. This means cancer care teams in hospitals no longer need to help with non-medical issues, freeing them up to provide personalised care to those with complex medical problems. This could mean there is more time to support new patients – which will potentially help ease waiting times pressures.

By 2023 all people in Scotland with a new cancer diagnosis will have the opportunity to access services to support and meet their needs and ensure people with cancer can have the best quality of life. Inequalities will be addressed by ensuring support is targeted to those who need it most and that is accessible to those who live in the most socially deprived areas of Scotland. There will be integration across health, social care and third sector, and an increase in the ability of partners to meet the needs of people with cancer. Co-production with users of cancer services will maximise impact.

In Greater Manchester, the Health and Social Care Partnership signed a MoU with the voluntary, community and social enterprise sector (VCSE). This sets out shared priorities between the two sectors, outlining work that is underpinned by £1.1m in funding to the sector until 2021. However, the GM VCSE Leadership Group has been contributing to health and social care activity since budgets were devolved. The MoU aims to get communities involved in co-designing health and social care to create a better system. The relationship between the VCSE and the Health and Social Care Partnership has been vital and have included working closely together to co-design, co-deliver and provide solutions, services and support so people can manage conditions at home and in the community.

[i] *Health Inequalities - Time to Talk*

[ii] *Mind the Gap: Cancer Inequalities in London*

[iii] *Health Inequalities - Time to Talk*

[iv] National Audit Office, 2019

[v] *Social Care Wales Workforce Development Programme*

[vi] https://humbercoastandvale.org.uk/how/workforce/