The national intermediary and network for voluntary health organisations in Scotland

Consultation Response

Cancer strategy: draft vision, aims and priority areas

June 2022

Voluntary Health Scotland (VHS) is the national intermediary and network for voluntary health organisations in Scotland. We work with our members and others to address health inequalities and to help people and communities live healthier and fairer lives. Our members and network include a range of medium and large condition specific organisations, smaller community organisations, as well as social enterprises.

Many of our members have a specific focus on cancer support and research alongside other members with a more general interest in preventing poor health outcomes and inequalities. There are significant inequalities in cancer prevention, diagnosis, treatment and support which vary across different cancers and communities. The Scottish Government's long-term monitoring of health inequalities provides good data on the gap between the most and least deprived areas in terms of cancer. What is less well documented is how different ethnic minority groups, people experiencing homelessness, people with alcohol and drug dependency issues, gypsy traveller communities and other marginalised communities experience cancer support services. This is something we hope will be explored further to fully understand the health inequalities that exist in cancer care and outcomes.

1a. What are the most important aspects of the cancer journey you would like to see included in a long-term strategy?

Access to screening and prevention: The gap in screening uptake between the least and most deprived areas of Scotland is stark and addressing it needs to be made a priority. Areas and communities with the lowest uptake should receive additional support to encourage uptake of screening alongside making the location of services more convenient. The review of breast cancer screening carried out by the Scottish Government found the design, location and delivery of breast screening was a barrier to accessing the service. We welcome the calls to address the stark inequalities in screening uptake in the Central Belt by establishing statistic satellite screening centres. To reduce inequalities public transport provision needs to be a key consideration in the location of screening services.[1] As a matter of urgency the remaining self-referrals paused during the pandemic must now be fully restarted, as has been seen in England and Northern Ireland. The pause in services for women over the age of 71 until the autumn causes a significant inequality in access to services based on age.

1c . What do you think we should prioritise over the short-term?

Restarting Services: As mentioned in 1a, we urgently need to restart self-referral routes and cancer services that remain paused. There needs to be a concerted effort to raise awareness and help patients regain the confidence to return to health services following the pandemic.

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[1] https://www.gov.scot/binaries/content/documents/govscot/publications/independent-report/2022/05/major-review-scottish-breast-screening-programme/documents/major-review-scottish-breast-screening-programme-march-2021/major-review-scottish-breast-screening-programme-march-2021/govscot%3Adocument/major-review-scottish-breast-screening-programme-march-2021.pdf

Workforce Strategy: There have recently been worrying reports on the high cancer diagnoses rate via emergency care.[2] Cancer Research UK (CRUK) has attributed this to staff shortages and the lack of available kit to test and diagnose cancer through the usual routes. While staff shortages are not a quick fix and will require a long-term commitment, CRUK has called urgently for more information on the Workforce Strategy.

Community Outreach: Community and voluntary organisations in areas where awareness of cancer symptoms and screening uptake are low should be resourced to empower communities and provide trusted information about risk factors. Community organisations are well placed to improve awareness of screening opportunities and symptoms as a trusted voice in the community. We have seen the third sector plugging the gaps in service provision during the pandemic and establishing ourselves as a trusted partner for health services. People were able to rely on the third sector to adapt while other services were paused. This relationship and trust with communities needs to be harnessed and properly resourced to reach those currently underserved in health.

2a. Do you agree with the proposal for a 10-year strategy?

The options considered for this new strategy are: i. Extending or renewing the current recovery plan taking into account the ongoing impacts of the COVID-19 pandemic. ii. A 5-year strategic plan to indicate that the short-term recovery plan was interim and that we are shifting back to a more normal approach. iii. A longer-term strategy with short-term action plans which will evolve with changing landscape but remain consistent with the overarching ambitions.

We agree a long-term ambition with flexibility built in would be the best approach. This will allow for the longer-term challenges in services such as staff shortages to be addressed beyond parliamentary cycles, while also allowing for agility as services recover from the pandemic.

Public Health Scotland has highlighted the impact of under-diagnoses during the pandemic. It notes some cancers saw greater inequalities in under-diagnoses than others. For example, lung cancer diagnoses fell by 12% in people from the most deprived areas and by 5% in the least deprived areas.[3] This highlights the need for a significant campaign to address under-diagnoses, highlight symptoms and enable people to reengage with health services.

3a. Do you agree with this vision?

"*A compassionate and consistent cancer service, that provides improved support, outcomes and survival for people at risk of, and affected by, cancer in Scotland*"

Yes, however we would suggest rephrasing slightly to "*A compassionate and consistent cancer service, that provides improved support, outcomes and survival for* ***all*** *people at risk of, and affected by, cancer in Scotland."*

This would incorporate the strategy's ambitions to tackle health inequalities by recognising the need to make a determined effort to reach everyone. We believe this slight change in wording communicates the need for a more ambitious approach and recognises the inequalities which are currently experienced across services and in outcomes. This would set the tone and ambition to reach those marginalised communities sometimes described as

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[2] https://healthandcare.scot/default.asp?page=story&story=3062

[3] https://publichealthscotland.scot/media/12645/2022-04-12-cancer-incidence-report.pdf

"missing in health".[4] Equitable access to cancer services should be at the heart of the strategy and we welcome the prominence that compassion is given in this vision.

Do you agree with these goals?
The Aims of the strategy set out more-specific goals that we will prioritise and that we can measure. Our proposed aims are:

1. **Slowing down the increasing incidence of cancer**
2. **Earlier stage at diagnosis**
3. **Shorter time to treatment**
4. **Lower recurrence rates**
5. **Higher survival rates**
6. **High quality, consistent experience of the health service for people affected by cancer**
7. **An enabling environment for research and innovation in diagnosis and treatment**
8. **Reduced inequalities in all these areas**

Yes, and we would especially stress the importance of reducing inequalities in all these areas. Taking a human rights approach to health and supporting people to realise their right to health would also help reduce inequalities by breaking down stigma and discrimination and improving access and trust. The inequalities in cancer incidence, diagnosis, treatment, survival and services have been well documented by Public Health Scotland (PHS), the Scottish Government and third sector experts. Of people in the 45-74 year age group, those living in Scotland's most deprived areas were more than twice as likely to die of cancer than those in the least deprived areas (573.7 deaths per 100,000 population compared to 220.0 per 100,000 population, in 2020).[5] There is a slight time lag in the data we have available on cancer incidence, but the inequalities between the most and least deprived populations are clear.

The research and innovation environment sometimes receives less attention in terms of reducing inequalities. Inequality in access to research grants and funding must also be tackled. It is important that diversity data on grant funding is collected so that systemic issues of underrepresentation in research can be addressed. Without a diverse scientific and research community we cannot expect to tackle inequalities. CRUK published an examination of equality in its grant giving which provided an insight into the importance of data collection and the gaps in the research environment.[6] More recently CRUK highlighted the importance of diversity in STEM and its approach to Equality, Diversity and Inclusion.[7]

5a. Do you agree with these principles?
It is important to agree Principles that will underpin a future cancer strategy and guide our planning for and conducting future cancer services. These should reflect the values that we think are important in ensuring the best outcomes. Our proposed principles are:

- **putting patients at the centre of our approach**
- **actively involve communities and users of services**
- **be inclusive**
- **provide high quality, compassionate care**
- **ensure services are sustainable**
- **collaborate across all sectors**

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[4] https://elearning.rcgp.org.uk/pluginfile.php/149461/mod_page/content/46/Missingness%20in%20health%20care-%20a%20%E2%80%98new%20normal%E2%80%99%20is%20not%20a%20level%20playing%20field.pdf

[5] https://www.gov.scot/publications/long-term-monitoring-health-inequalities-march-2022-report/pages/12/

[6] https://news.cancerresearchuk.org/2021/02/25/examining-equality-in-our-grant-giving/

[7] https://news.cancerresearchuk.org/2022/03/03/why-diversity-in-stem-is-vital-to-cancer-research/

- **use an evidence-based approach and make the best use of emerging data/research/technology**
- **strive for consistency through a ‘Once for Scotland’ approach**

Yes, especially actively involving communities and service users in future planning. Communities, be that geographical or patient communities, are not a homogenous group and for that reason services and support must be as person-centred as possible. Involving service users is important, as no one person can speak for a community.

Collaboration across all sectors is also vital, at Voluntary Health Scotland we argue that tackling health inequalities should be “everybody’s business”. However, collaboration with the third sector must be met with sustainable long-term funding as organisations are routinely already operating at capacity following the pandemic. Third sector and community organisations have a vital role to play in prevention, supporting patients and in the delivery of palliative care, we are trusted in our communities and should be resourced to tailor support for communities.

We are proposing that the following themes are used consistently in the overarching strategy and 3 year action plans:

- **Person-centred care**
- **Prevention**
- **Timely access to care**
- **High quality care**
- **Safe, effective treatments**
- **Improving quality of life and wellbeing**
- **Data, technology and measurement**
- **Outcomes**

We believe “reducing inequalities” should also be a theme to embed this consistently across the overarching strategy and subsequent action plans. Inequalities are mentioned in other aspects of the strategy; however, this is a notable omission in the overarching themes. Tackling health inequalities should be a golden thread throughout the strategy. Taking an approach of proportionate universalism and active outreach in service design would make services universally available while also increasing the intensity proportionate to the degree of need in communities.[8] This would go some way to reaching those often “missing in health”, who are less likely to take up the screening offer or engage with NHS services for a multitude of reasons. The inverse care law is the perverse relationship between the need for health care and its actual utilisation. In other words, those who most need medical care are least likely to receive it. Conversely, those with least need of health care tend to use health services more and more effectively. Taking an approach of proportionate universalism would go some way to reaching the people at the sharp end of the inverse care who are less likely to be engaging with services despite their needs.

8a. In your experience, what actions do you think would be most effective for helping to stop people getting cancer, and reducing inequalities in cancer incidence?
We propose to look at Prevention in relation to risk factors for cancer that can be modified at the population level and at the individual level. We are considering, for example:

- **alcohol minimum unit pricing,**
- **smoke-free zones,**
- **restricting promotion and advertising of foods high in fats, sugar and salt,**

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[8] http://www.healthscotland.com/documents/24296.aspx#:~:text=Proportionate%20universalism%20is%20the%20resourcing,the%20level%20of%20presenting%20need.

- **mandatory calorie labelling,**
- **raising awareness of weight management services,**
- **healthy eating advice,**
- **smoke cessation services.**

Many of the current suggestions for prevention put the onus on the individual as opposed to bringing down barriers to good health. We believe there is a role for encouraging people to make healthier choices. However, this must be coupled with removing barriers to good health. The role of obesogenic environments and the availability of healthy food options need to be considered as a major barrier to effective prevention. We need to be thinking about the availability of affordable and healthy food for families in their local communities. The built environment has a significant role to play in this as evidenced in Voluntary Health Scotland's response to the National Planning Framework 4 consultation.[9] Prevention in health policy needs to be far more ambitious and all encompassing. It should consider access to good food, opportunities for exercise and active travel alongside accessible services to aid prevention.

There needs to be a significant shift in the narrative from blaming individuals for poor life-style choices, which is stigmatising, and instead enabling people to live healthier lives regardless of income, race, gender or background. The NCD Prevention Coalition Scotland report highlighted that while "interventions focused on individual action can work in certain circumstances, it has been shown that they are less effective amongst those with low health literacy and within more deprived groups, sometimes exacerbating inequalities in the health of Scotland's communities."[10] The poorest fifth of UK households would need to spend 40% of their disposable income on food in comparison to 7% for those in the least deprived quintile, to meet the Eatwell Guide.[11] Tackling obesity must be central to prevention and access to healthy food is key to this. Implement the remaining recommendations from the NCD Coalition should also prioritised.

Currently the actions in this section of the strategy do not hit the right tone and are in danger of stigmatising individuals and exacerbating inequalities. At present they largely ignore the barriers some people face in making healthier choices such as poverty, accessibility of services and the obesogenic environment. An effective prevention strategy that seeks to tackle inequalities needs to enable people to access good food, services and housing. We believe producing healthy eating advice is not the problem, the problem is families on low incomes can't afford good food.

10a. Do you agree with these areas of focus for high quality care?

Under High quality care, we want to think about actions outside of direct treatment that affect the care given to those affected by cancer. We are considering:

- **Workforce (thinking, for example, about requirements and modelling for oncology and other workforce, including specialist nurses; leadership)**
- **Service delivery (thinking about national, regional and local services; flexible use of workforce; role of cancer network; strategic alliances and working across health boards, for example)**
- **Inequalities (thinking about how to make sure everyone is included, and targeting those who may be at a disadvantage)**
- **Accessibility (breaking down barriers such as geographical, cultural or language)**

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[9] https://vhscotland.org.uk/consultation-response-draft-national-planning-framework-4/

[10] https://diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/public/2020-09/NCD%20Prevention%20Scotland%20Report.pdf

[11] https://foodfoundation.org.uk/sites/default/files/2021-10/FF-Broken-Plate-2021.pdf

- **Integrated support services between NHS and Third Sector**

We welcome the focus on integrated support services between NHS and third sector. We hope this will include addressing barriers in data sharing and patient referrals. The third sector must also receive long-term funding to enable sustainable service delivery. Third sector and voluntary organisations play an important role in providing emotional, informative and practical support for people who receive a cancer diagnosis. Another key recommendation from the Scottish Government review of breast cancer screening services was the need to improve patient support networks, which the third sector is well placed to do. Organisations such as Cancer Support Scotland play a crucial role in holistically supporting the wellbeing of those affected by cancer.

Accessibility as a key area of focus is also welcome. We hope that the inclusion of language also covers alternative accessible communication. RNIB highlighted in their response to the Health, Social Care & Sport Committee Health Inequalities Inquiry that requests for accessible formats are not being correctly managed or not logged centrally to enable consistency. Information online, by phone and through the post all need to be accessible to the recipient. RNIB notes the “effects of not receiving information in a preferred and accessible reading format should not be underestimated. This is leading to people with sight loss feeling unable to take control of their own health needs whilst their patient confidentiality can be compromised.”[12]

With regards to inequalities, we agree that targeting those who may be at a disadvantage is key. This is where the role of assertive outreach and proportionate universalism are vital in reaching out to communities currently underserved or missing in health.

12a. Do you agree with these areas of focus for quality of life and wellbeing?
Under Improving quality of life and wellbeing, we are considering:
- **Prehabilitation and rehabilitation**
- **Psychological support**
- **Patient pathways (including quality of care, waiting times, less survivable cancers)**
- **Palliative medicine, Best Supportive Care and End of Life care**
- **Support to family/carers**

Yes.

13a. Do you agree with these areas of focus for data, technology and measurement?

Yes. Our only reservation is we would want to avoid e-health ever being the only option for patients. Digital poverty and literacy are significant concerns for us in terms of access to services such as NHS Near Me. Additionally, some people do not have privacy at home to participate in Near Me video consulting, this risks people disengaging with services if they are not offered the option of “in-person” consultations. We would support a flexible patient-centred approach which offers both “in-person” and online appointments when appropriate.

15a. What would you like to see an Earlier Diagnosis Vision achieve?
Think ahead to the next 10 years, think big picture – what change(s) should we be aiming to influence when it comes to earlier cancer diagnosis? Consider access to care/cancer screening/primary care/diagnostics and awareness of cancer signs and symptoms.

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[12] https://yourviews.parliament.scot/health/health_inequalities/consultation/view_respondent?_b_index=0&uuId=1056161353

We would like to see assertive outreach coupled with proportionate universalism in bringing screening programmes to communities currently underserved in health. In terms of increasing awareness of signs and symptoms a collaborative approach should be taken with community organisations and leaders as trusted voices in the areas they support. Micro-grants could be provided for community organisations to host pop-up information events, signposting to screening services, providing individuals with travel support or accompanying them to screening appointments. This would also help in reducing the stigma associated with accessing services for some communities.

16a. In your experience, are there aspects of cancer diagnosis, treatment or care that affect people from marginalised groups differently? If there are negative effects, what could be done to prevent this happening?

Our response to this consultation is focused on the inequalities in cancer services and outcomes, including for marginalised communities. Please refer to the previous answers to questions for further details on this. Voluntary Health Scotland is part of the Inclusion Health Partnership which published a report on understanding the lived experience of COVID-19 for marginalised communities. This report found the pandemic had a significant impact on access to statutory services for marginalised communities. It made multiple recommendations on how service design and delivery could enable marginalised groups to access services. The lived experience of people from marginalised communities should be proactively sought to inform the design and development of services. To ensure that services meet their needs and that barriers to access are identified and addressed for those who experience stigma and exclusion.[13]

The NHS Race & Health Observatory's Ethnic Inequalities in Healthcare rapid evidence review also documents some of the stigma and discrimination people face in accessing services.[14] For example, the report highlights a systematic review of what affects ethnic minority (Black African, White Irish, and South Asian) people's access to genetic cancer services, it found that there was low awareness of these services amongst these groups. Additionally, White patients were more likely to be referred to genetic services and this may have been due to variation in the use of family history screening questionnaires in primary care. In the review, it was found that South Asian people who did not speak English felt interpreters were making decisions on their behalf, or selectively choosing what information to translate for them.

There is a significant need for greater workforce training, better health literacy and education (including education for communities) in understanding of the needs of specific minority ethnic communities, including their risk of particular cancers. There also needs to be recognition that ethnic minorities are not a homogenous group. This goes beyond ensuring literature is in different languages, we need a much deeper understanding of the different health care experiences of all minority groups and how needs differ from each other. We also need better data on cancer and ethnicity to better monitor progress to tackle health inequalities over time.

People with disabilities face a particular challenge in accessing services in terms of physically being able to access venues and with regards to accessible communication. Moreover, screening can be a very distressing experience for people with learning disabilities. There must be support available for people with learning disabilities in accessing information and services in a way that best suits their needs. Services need to be co-

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[13] https://vhscotland.org.uk/wp-content/uploads/2022/02/Summary-Report_-Lived-experience-of-COVID-19-for-marginalised-communities.pdf

[14] https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf

designed with service-users for this reason, as they are best placed to identify barriers to access.

Intersectionality also needs be factored in, as most people have intersecting identities which impact their engagement, access and experience of services in different ways. This should encompass issues such as disability, age, ethnicity, gender identity, mental health, sexuality and immigration status. For example, a female refugee who is gay faces multiple barriers in accessing screening services due to these intersecting identities. She may have experienced stigma in health services and may not fully realise her right to health due to fear of services communicating with the Home Office. This is why implementing a human rights-based approach to health is crucial and why training for health care professionals on these issues is needed.

Language is noted as a key consideration in terms of accessibility in this strategy. This needs to include translated materials, interpreter support, alternative formats, easy read formats and non-stigmatising language. Moreover, these formats must be made available at the same time as standard texts, as otherwise people can be left to source information from other sources which leads to misinformation and disengaging with services.

16b. Similarly, is how we manage cancer different for people from higher or lower income households? What could be done to do this better?

A cancer diagnosis comes with a significant financial burden. More support and targeted interventions are needed for people from lower income households. The financial hit as a result of a cancer diagnosis can come from an array of extra and often unexpected needs, as well as a drop in earnings if people are less able to work. Macmillan Cancer Support highlights that around one in two people with cancer in Scotland see an increase in day-to-day living costs (47%), with one in four experiencing extra costs of travelling to and from their appointments (26%) and one in five (19%) seeing their household fuel bills rise.[15] Macmillan Cancer Support provides a support line and welfare benefits service teams which help people access the support they are entitled to. Clinical teams should be signposting to this kind of support, so no one is left trying to navigate the social security system alone while dealing with a cancer diagnosis. This support must also be sustainably resourced to cope with increased referrals.

Macmillan Cancer Support also highlights the importance of personalised care, based as close to the patients' neighbourhood as possible as a key approach to tackling health inequalities. The Macmillan/Scottish Government partnership involves a link worker meeting people in their community to do an "holistic needs assessment" of their financial and wider social needs during and after treatment. This involves assessments for welfare support as well as adapted housing needs, carers assessments, mobility needs and a whole range of issues. This helps tackle the whole other range of non-medical issues thrown up by a diagnosis of cancer that need to be dealt with closer to the ground to reduce health inequalities. Macmillan link workers are at the heart of linking NHS patients into local support services.[16]

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[15] https://yourviews.parliament.scot/health/health_inequalities/consultation/view_respondent?_b_index=0&uuId=719886107

[16] https://yourviews.parliament.scot/health/health_inequalities/consultation/view_respondent?_b_index=0&uuId=719886107

16c. Is the experience of cancer different for people living in rural or island communities? What could be done to prevent any negative impacts?

Travelling to services is a significant barrier for rural and island communities. This is in terms of both cost and time. There was a recent call for NHS Dumfries & Galloway services to be reviewed as patients from Stranraer can face a 135-mile road trip one way for radiotherapy and scans in Edinburgh.[17] This creates a significant inequality in the care provided to patients. A review of services is needed alongside a specific focus on the current barriers to delivering care in more remote and rural communities.

Access to services is another issue highlighted in the Scottish Government's review of breast cancer screening. In semi-urban and rural areas, the limited availability of appointments in a local venue served to increase the inconvenience of attendance, with travel to other towns adding to the time and cost involved in accessing the screening.

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[17] https://www.bbc.co.uk/news/uk-scotland-south-scotland-60233679