Minutes
All Party Parliamentary Group on Cancer (APPGC)
'Making cancer care inclusive for all'

Monday 13 November 2023, 14.30-16.00, Committee Room 17
Chaired by Baroness Morgan (Vice Chair, APPGC)

This meeting brought together Parliamentarians and stakeholders from the cancer sector to discuss some of the current inequalities that exist across the cancer pathway among those with protected characteristics, specifically those in the LGBTIQ+ community and disabled and neurodivergent people.

Welcome and introductions

Baroness Morgan opened the meeting by noting that Elliot Colburn MP, chair of the APPGC, was unable to join in person to Chair, but would attend the meeting virtually.

Baroness Morgan spoke to highlight some of the challenges associated with inequalities in cancer care, including the fact that people with certain protected characteristics have a poorer experience of cancer services, later diagnosis, poorer survival rates and experiences of discrimination. She highlighted the need for more data and evidence on these issues to help build our understanding.

Elliott Colburn MP spoke via video link to welcome people to the meeting on what he said was an important topic for the APPGC.

Baroness Morgan said that people who experience inequalities are not a homogenous group and that efforts to address these issues must be person-centred and intersectional.

Baroness Morgan introduced the first speaker.

Speaker: Steward O'Callaghan (SO), CEO, OUTpatients

SO noted that their organisation, a UK LGBTIQ+ cancer charity, has recently rebranded after previously being known as Live Through This.

SO presented data from the GP patient survey showing the increasing numbers of people are disclosing their Trans identity, particularly in younger age groups. They noted that the system needs to be ready to meet the needs of these people.

SO spoke to the current challenges with data for this community, with sexuality and trans status not being monitored as standard. They noted repeated engagement with NHS bodies in England to address this issue, but a lack of prioritisation

SO highlighted data that showed very small numbers of oncologists reporting that they ask patients about sexuality or gender.

SO noted the specific barriers people from LGBTIQ+ communities can face as part of their cancer journey. This includes invites for cervical screening and breast screening only being sent to those with a female patient marker, excluding trans men. They noted the extra burden for patients in having to advocate for appropriate screening.

SO noted particular issues related to conversations about psychosexual wellness and concerns about dignity in end-of-life care for this community.

In summary, SO highlighted the need for person-centred care, the need to get ahead of a growing problem of LGBTQI+ people requiring cancer care and the need for separate markers on health records for sex assigned at birth and gender identity.

Baroness Morgan introduced the second set of speakers.

Speakers: Katie Munday (KM) and Rosie Tansley (RS), Community Researchers

KM and RS discussed their recent research project to understand the experiences of cancer services for disabled and neurodivergent people. In partnership with community groups, they spoke with 30 disabled and/or neurodivergent people.

The research identified a number of themes participants, including inappropriate assumptions being made, feeling unsafe, issues with physical access, issues with inaccessible information, isolation and loneliness, the need to advocate for oneself and a resistance to change and adaptation.

They discussed their research outputs, including a report, events, journal articles, accessible outputs, sharing findings through partners and a short film sharing the experiences of attendees.

They summarised the report's recommendations, including:

- taking a person-centred approach where specialists work together to ensure the right course of action that considers all aspects of patients' needs,
- finding ways to identify patients support needs and help staff recognise potential adaptations,
- providing patients with clear directions and information in advance to allow time for planning,
- providing clear information for patients of what to expect during the process, with information shared in a way that can be accessed and understood to help patients make informed choices,
  providing patients with options to meet their needs
  prioritising supporting patient attendance in a way that works best for the patient
  staff training on communication needs.

They summarised their findings as: compassion and reassurance matter; effective communication is key; make accessibility a priority.

Baroness Morgan introduced the final speaker.

Speaker: Hayley Snowden (HS), Health Inequalities Programme Manager at West Yorkshire & Harrogate Cancer Alliance

HS spoke through the aims of the alliance to reduce inequalities in access care and outcomes for those affected by cancer.

Local priorities include taking action to reduce avoidable cancers, such as through smoking cessation for the most deprived populations, maximising uptake of screening for the most deprived populations, encouraging early presentation in line with CORE-20 PLUS 5 objectives, focusing on communities including those from ethnic minorities, deprived communities, those with learning disabilities and the homeless, and exploring gaps in access to two-week wait pathways for some groups on particular pathways e.g. black men and prostate cancer.

HS noted that the alliances work must be data and research driven. Projects have included work to improve screening uptake for people with learning disabilities, South Asian women, LGBT people and Black men and women.

There is a focus on patient engagement and co-creation, with effort to involve communities at an early stage, and collaboration with the VCSE sector.

HS noted issues with record keeping, noting that in one area 50% of patients' ethnicity were recorded as 'unknown'.

HS described cancer alliances as collaborators who come together regularly to share learning.

Baroness Morgan facilitated questions from attendees:

Representative from Prostate Cancer UK asked SO for more detail on their organisation's professional training offer, including who took up the training and what impact it has had.

SO noted that the lack of baseline data on populations makes it difficult to evidence whether professional training impacts things like screening attendance. They also noted that the professionals attending this training are a self-selecting group with an interest. They have noted increases in confidence and awareness as a result of the training. They would like to attract more consultants to take up the training offer.

Representative from the British Liver Trust spoke about stigma as a barrier for health seeking behaviour and asked for any examples of innovative approaches to stigma

SO spoke about the importance of person-centred care to tackle stigma and noted that cultural change will not impact systemic barriers. They also spoke of the importance of cultural specificity when trying to reach communities who experience stigma.

HS spoke about a liver surveillance scheme in Manchester that goes out to communities who may be unwilling to seek care in hospital settings, such as asylum seekers and refugees.

Representative from Breast Cancer Now asked whether mechanisms of accountability are strong and clear enough to impact standard practice.

KM described systemic issues in the whole of society not just the NHS and the need for investment in the short-term to address these issues.

SO spoke about the perception that minority communities are not the priority and the need to use data to make the case at a national level for the great work happening locally.

HS noted that alliances can't hold people to account but can make change at a local level and report on this.

A representative from Young Lives Vs Cancer asked about whether there are any particular issues for young people with cancer at intersections with these communities.

SO stated that this was particularly an issue for larger numbers of young people identifying as trans, they are more likely to disclose and advocate for their needs. Peer support is also important for them.

HS spoke about poorer uptake of cervical screening amongst younger women, particularly those who have received an HPV vaccine

SO spoke about information sources like TikTok, where misinformation can be an issue and the need to spread good information through those channels

A representative from Macmillan Cancer Support asked what more central government could be doing to prioritise and address these inequalities.

SO raised international comparisons, noting that US state-funded health services are mandated to record sexual orientation and gender identity. They spoke of the need to educate decision makers on these issues. They noted that some communities have been politicised.

HS recommended influencing upwards through the National Cancer Board

Baroness Morgan closed the meeting by summarising key themes including data as a bedrock, the need for granular data on small communities, and the need for an inclusive cancer plan and inclusive framework for cancer care.