

# MACMILLAN Torbay Community Engagement Project Report

November 2024



*Funded by:*

**MACMILLAN.**  
CANCER SUPPORT

*In partnership with:*

**Torbay Communities**  
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# Executive Summary

The Macmillan Torbay community engagement project took a place-based and integrated approach to engaging with Torbay residents. Delivered by Engaging Communities Southwest in partnership with Torbay Communities and funded by Macmillan Cancer Support. The project ran for two years between November 2022 – November 2024. The project's main aims were to:

- Understand more about health inequalities in the local area by carrying out engagement with Torbay residents and local community groups.
- Develop a better understanding of barriers to diagnosis and local needs and issues in relation to cancer by carrying out engagement with Torbay residents.
- Co-produce interventions with local communities to improve access to information for Torbay communities and support for those living with cancer in Torbay.
- Collaborate with organisations and individuals involved in community engagement and development locally.

In order to meet these aims the project had two key engagement workstreams:

1. To engage with communities more likely to experience barriers to diagnosis in relation to cancer. This workstream focused on engaging with target communities known to experience health inequalities rather than individuals affected by cancer to gather information on barriers to accessing healthcare information and services. The target communities were identified as adults with a learning disability, LGBTQ+, ethnic minority groups, and those living in a socio-economically deprived area.
2. To engage with Torbay residents living with, or affected by, cancer. This stream focused on engaging with individuals who had been either directly or indirectly (through a friend, family member, loved ones' diagnosis) impacted by cancer to gather information on local needs and issues in relation to cancer.

Due to being a test-and-learn project, a wide range of different methods were used for engagement. Insights on local needs and issues in relation to cancer were largely gathered through cancer café listening events, an online survey, and informal interviews. Insights on health inequalities and barriers to diagnosis were largely gathered through focus groups, drop-ins at community events and hubs, meetings with leaders of local community groups, and co-design sessions.

## The project's key findings were:

1. Access to primary healthcare services is an overarching issue affecting all Torbay communities. When engaging with both the target groups and wider public around how they would deal with a concerning sign and/or symptom, most conversations centred around issues with accessing primary healthcare services in Torbay.
2. Engagement fatigue around health is very prevalent in Torbay. Individuals and groups expressed concerns around the worth of sharing their healthcare experiences. This overall feeling of apathy made engagement difficult across all communities in Torbay.

3. There is a lack of community-based cancer support services in Torbay. Both individuals and groups told us they struggle to find cancer support for themselves and family members.
4. For those who had experienced a cancer diagnosis there is a clear want for peer-based in-person cancer support.
5. Accessible information and healthcare are issues for learning disabled communities and communities for whom English is not a first language.

### The project's key recommendations were:

1. A more sustainable model of engagement is needed to avoid exasperating local engagement fatigue. Any future engagement work needs to consider sustainable relationships. A two-year project unable to commit to future work risks compromising the relationships built and heightening barriers to engagement for future work.
2. All communities in Torbay would benefit from cancer-focused community-based support. There was a clear want for in-person peer-based support. The local VCSE sector would be capable of facilitating a peer network if resources were made available.
3. Raise awareness of the impact primary care issues are having on Torbay residents, particularly on those more likely to experience health inequalities. This report needs to be shared amongst local health networks and key stakeholders to raise awareness.
4. Material which raises awareness of cancer signs and symptoms needs to be accessible in multiple ways. Accessing localised information and advice on health was a common issue for adults with a learning disability and for those whom English is not a first language in Torbay.

One of the key aims of this project was for Torbay Communities to co-design and co-produce some solutions to the issues raised through engagement with local communities. Selected results of the co-design work can be found in the appendix of this report with a full report section on co-design from page 43, written by Torbay Communities. The co-designed resources are available to local community groups and organisations. Key summarised overall suggested next steps, taken from the co-design element of this project, are:

**Gauge Impact:** return to the co-design groups in a year and find out if there had been any changes in their experience or situation.

**Build Relationships:** develop ways for Macmillan to continue to develop those co-design relationships with users in the community. There could be potential for staff training.

**Continue with engagement and co-design process:** this will ensure users have a voice, allows them to contribute and offers a potential solution to survey / engagement fatigue.

**Monitor the ripple effects of this work:** there may be ripple effects from this work due to other members of the public seeing the co-designed pieces of work and reacting positively.

**Reprint calendars yearly:** identify resources and how this will be managed.

**Dissemination of learning:** share the learning from this process with key stakeholders.

**Minority groups:** engage with a broader range of the community to then identify people facing minority barriers to information or treatment.

# Introduction

The Macmillan Torbay community engagement project took a place-based and integrated approach to engaging with Torbay residents. The project worked to understand more about health inequalities experienced in the local area, barriers to accessing the current support offer around cancer, issues with community-based support, and to co-produce some solutions with the community.

Funded by Macmillan Cancer Support and working in partnership with Engaging Communities South West and Torbay Communities, the project ran for two years between November 2022 and November 2024.

The project took a phased implementation approach; year one focused on engagement with local communities to develop understanding on the barriers to diagnosis, issues with support through treatment, and managing the impacts of cancer. Year two focused on asset-based community development work with Torbay Communities, to co-produce some solutions to the issues identified in year one.

To achieve this the project had two key engagement workstreams:

1. To develop understanding on barriers to diagnosis, engagement took place with communities more likely to experience health inequalities in relation to cancer. This first engagement workstream engaged with key target communities rather than individuals affected by cancer. The target communities were identified as adults with a learning disability, LGBTQ+, ethnic minority, and those living in a socio-economically deprived area.
2. To identify local needs and issues in relation to cancer support and advice, the second engagement workstream focused on gathering information from Torbay residents living with, or affected by, cancer. This workstream focused on engaging with individuals who had been either directly or indirectly (through a friend, family member, loved ones' diagnosis) impacted by cancer. This workstream captured the experiences of both those in the afore mentioned target groups and the wider Torbay community.

# The Partnership

**Engaging Communities South West (ECSW)** is a not-for-profit organisation offering a range of services, including community voice, facilitation of engagement events, data capture and analysis, report writing, communications support, training and service/project evaluation and review. We provide these services to advance three key areas: Community Voice, Access & Empowerment, and Strategic Support. We also manage the contract for local independent health and social care champion Healthwatch Torbay.

**Torbay Communities** develops opportunities with the Voluntary, Community and Social Enterprise sectors across Torbay. We empower communities by building on strengths and skills through Asset-Based Community Development. Our overall aim is to create stronger and more resilient communities, actively encouraging local involvement and decision-making in improving the region, as well as developing and supporting volunteering opportunities of the highest standards.

**Macmillan Cancer Support** is a large UK based charity dedicated to providing practical, emotional and financial support to people affected by cancer. They offer a range of services, including a helpline, local support initiatives, and financial assistance to help individuals and their families navigate the challenges of cancer diagnosis and treatment. Their mission is to ensure that no one faces cancer alone.

**Note: the term *we* is used throughout this report - *we* refers to the project team.**

## Aims of the Project

The project's main aims were to:

- Understand more about health inequalities in the local area by carrying out engagement with Torbay residents and local community groups. Particular emphasis was placed on engaging with communities known to experience health inequalities in relation to cancer. These communities were identified as adults with a learning disability, LGBTQ+, ethnic minority groups, and those living in a socio-economically deprived area. The identification of these target communities is explained in further detail in the next section of this report.
- Develop a better understanding of barriers to diagnosis and local needs and issues in relation to cancer by carrying out engagement with Torbay residents.
- Co-produce interventions with local communities to improve access to information for Torbay communities and support for those living with cancer in Torbay.
- Collaborate with organisations and individuals involved in community engagement and development locally.

# Background Research

## Torbay

At project inception Torbay had a population of 134,500, a large proportion of whom were over 65 years old (35,600 – 26.5% - over 65 compared to 18.1% across England).

Cancer waiting times data provided by NHS England indicated that 2032 cancer patients were treated by Torbay and South Devon NHS Foundation Trust, with Fingertips Public Health data indicating that an average of 2,745 people per year received a cancer diagnosis following a 2-week wait referral from Torbay based GPs.

The number of people diagnosed with cancer in Torbay and South Devon had increased 11% in the last 3 years (2017-2020) and numbers were expected to continue to increase.

*All statistics from 2022 at the beginning of the project.*

## Four Target Communities

Engagement in workstream one placed emphasis on four target communities who were more likely to experience health inequalities in relation to cancer. Reasons for this are:

**Areas of deprivation:** It is well established that people from more deprived areas are not only more likely to get cancer, they're also more likely to be diagnosed at a late stage for certain cancer types and have trouble accessing cancer services. They are also more likely to die from the disease. 27% of people in Torbay (over 36,000) live in an area classified as amongst the 20% most deprived areas in England. Targeted work in Torbay's most deprived wards will raise awareness and facilitate co-produced solutions to improve early diagnosis and community-based support.

**Ethnic minority communities:** patients from an ethnic minority background nationwide consistently report poorer patient experiences through the annual CPES. However, the respondent ethnic profile of the NCPES since 2017 has been exclusively white, meaning that we know and understand little about the experiences of ethnic minority experiences in Torbay. Census figures highlight 3,260 people of black and minority ethnic origin living in Torbay. The recent Torbay Racism Review Panel Report also highlighted issues with lack of representative voice and data from ethnic minority groups in Torbay.

**Learning disabled adults:** it is known that cancer incidence among people with learning disabilities is rising – and that there is a higher risk of gastro-intestinal cancers in this group. Several numbers of studies have also found evidence of late diagnosis, possible discrimination around treatment options, and lack of patient involvement and assessment of capacity in decision making. The Torbay JSNA estimates that there are 5,000 local residents with a learning disability, and targeted, appropriate engagement is required to understand their needs and issues in relation to early diagnosis, access to treatment and information/support.

**LGBTQ+:** research indicates that LGBTQ+ people experience health inequalities and have a cluster of risk factors that could lead to greater cancer incidence and later stage diagnosis. Torbay JSNA indicates that there are approximately 3,064 LGB people living in the area, and engagement is required to understand how sexual orientation and gender identity can affect the cancer experience so that everyone can access the appropriate support specific to their needs.

# Project Advisory Group

At the start of the project an advisory group was established. This advisory group met quarterly and were responsible for identifying local priorities and working with the project staff team to agree the work plan. The terms of reference for this advisory group can be found in the appendix.

## The members of the advisory group were as follows:

<b>Pat Teague</b>	<b>Lay Chair – Engaging Communities South West Trustee</b>
<b>Abi Gascoyne</b>	Project Coordinator – Torbay Macmillan Community Project
<b>Di Charlton</b>	Macmillan Engagement Lead - Devon, Cornwall and Isles of Scilly
<b>Amanda Nadin</b>	Macmillan Partnership Manager – Devon, Cornwall & Isles of Scilly
<b>Annette Gillett</b>	Macmillan Partnership Quality Lead - Devon, Cornwall and Isles of Scilly
<b>John Arcus</b>	Operations Manager - Torbay Communities
<b>Jess Slade</b>	Participation Development Lead - Torbay Communities
<b>Amanda Lynn</b>	Community Builder Lead Coordinator - Torbay Communities
<b>Ian Nightingale</b>	Chair of Torbay Prostate Support Association
<b>Janet Helmore</b>	Lay rep
<b>Kevin Helmore</b>	Lay rep & Mencap Torbay committee member
<b>Fahida Rehman</b>	Cancer Clinical Nurse Specialist - Torbay Hospital



# Methodology

Due to being a test-and-learn project, a wide range of different methods were used to engage with different audiences/communities in Torbay. Year one focused on raising awareness of the project and listening to local stories. Year two focused on some more targeted engagement and developing co-design workshops to address some of the issues raised in year one.

Individual cancer stories and experiences were gathered through an online survey, cancer café listening events, face-to-face drop-ins and events, and one-to-one interviews. Information on barriers to diagnosis amongst communities known to experience health inequalities was largely gathered through focus group sessions, drop-ins at community events and hubs, and co-design sessions. We also gathered feedback about these communities through meetings with leaders of local community groups and organisations. These meetings gave us valuable insight into barriers to engagement, issues with accessing healthcare and support, and have helped guide any ensuing engagement.

**Over the two years the project directly engaged with 385 local people.** This number relates to the direct conversations we had with people. During the engagement process we also gathered additional anecdotal feedback from community organisations. These findings have been incorporated throughout this report.

## Detailed list of engagement methods

Method	Details
<b>Desk research</b>	Mapping activity - desk research which aimed to explore the nature and availability of cancer support services already available in Torbay. This was an ongoing exercise. As the project developed and engaged with more people, we returned to this mapping exercise and added new knowledge. More details can be found on <b>page 14</b> .
<b>Meetings</b>	Meetings with organisations working locally to support those affected by cancer in Torbay. We gathered their opinions on issues with support in Torbay. These organisations included: Torbay Prostate Support Association, Shine Cancer Charity, Breast Cancer Now, The Lodge Cancer Support & Information Centre, and The Swallows Head & Neck Cancer Charity.
	Meetings with organisations working to support local communities. We gathered their opinions on key issues affecting their service users around accessing health services, support, and information. These organisations included: Torbay Community Helpline, Torbay Carers Service, Age UK Torbay, Dimensions for Autism, the Community Builder for local asylum-seeking communities, the Chinese Community Wellbeing Society, The Eddystone Trust, Torbay Pride, Torbay Mencap, Intercom Trust, Imagine Multicultural Group, Turning Heads, and local churches.
	Meetings with local health and social care networks/leads. These meetings helped us to build understanding on how healthcare systems work in Torbay, as well as spread the word about the project. We attended a One Devon (ICS) Involvement Network meeting, met with the Personalised Care Improvement Programme Manager and the Head of Personalised Care at TSDFT, Torbay Council and the Torbay Public Health team.

<b>Event stands</b>	To raise awareness and gather feedback we attended the following events: Paignton Community Hub's launch event, Paignton Library's Fun Family Festival & Torbay Carers Rights day celebration, Goodrington Lion's Family Fun Day, Healthwatch Torbay's Winter Wellbeing Fair, The Big Plan Event run by Torbay's LD Ambassadors, Torbay Health and Wellbeing VCSE annual network event, and Torbay Pride.
<b>Drop-ins</b>	To ensure we offered a regular face-to-face service to gather feedback we launched a Monday drop-in service at Paignton Community Hub.
<b>Networking</b>	To raise awareness of the project and gather feedback from other organisations working locally we joined the Torbay Wellbeing Network Group and the Healthwatch Torbay Assist Network.
<b>Online</b>	To gather feedback online we launched a webpage and Facebook page with chat function.
<b>Surveys</b>	We launched a survey aimed at all Torbay residents affected by cancer We also launched a targeted survey for LGBTQ+ communities.
<b>Interviews</b>	Conducted one-to-one informal interviews at various community locations to gather local cancer experiences and stories
<b>Focus Groups</b>	Ran co-hosted focus groups with the following: <ul style="list-style-type: none"> <li>• Torbay Multicultural Network</li> <li>• Torbay's LD Ambassadors</li> <li>• Melville &amp; Torquay Town Centre Area group for community living supported by Torquay Community Builder</li> <li>• Torbay Mencap family carers group</li> <li>• Dimensions for Autism</li> <li>• Turning Heads CIC</li> <li>• In collaboration with Healthwatch Torbay and NHS Devon, ran a focus group with the local Ukrainian community.</li> </ul>
<b>Co-hosted drop-ins</b>	Working in collaboration with Torbay Community Builder team, we attended various local community coffee mornings to gather feedback. In collaboration with Ellacombe Community Partnership youth workers and the Community Builder for Ellacombe & Plainmoor we ran a drop-in session at Ellacombe Primary School to gather feedback. Alongside staff from Torbay Communities we attended three of the local Live Longer Better meet-ups to gather feedback.
<b>Co-design workshops</b>	Series of co-design workshops with Torbay's LD ambassadors, Turning Heads CIC, and the local Ukrainian refugee community. Whilst the focus of these was on co-producing some solutions to issues raised by the community, the creative discussions these workshops elicited were able to provide further valuable insight into both personal cancer experiences and barriers to information and advice. Further information about these workshops can be found in the co-design section of this report on page 43.
<b>Cancer Cafes</b>	Two cancer café listening events; one in Torquay and one in Paignton. These were run in collaboration with Torquay PCN and were advertised through the PCN's networks.

## Key Engagement Questions

Our engagement questions all aimed to understand how cancer outcomes could be improved in Torbay. To achieve this, we needed to explore the following questions:

1. What do people do and where do they go for information and/or support when they have a sign and/or symptom that is causing concern?
2. How do different communities within Torbay understand and deal with concerning symptoms? How do they define concerning?
3. What would improve early diagnosis within: areas of socio-economic deprivation, black and ethnic minority communities, LGBTQ+ communities, and adults with a learning disability?
4. And for those who had experienced or been impacted by cancer, what sort of support did they receive, what was missing, and what would have helped?

**Focus Groups & Meetings** - we used two different templates of questions for focus groups, interviews and meetings. The template used was dependent upon whether we were gathering information on somebody's cancer experience or gathering feedback on barriers to information and advice. *A copy of this template can be found in the appendix.*

**Survey** - the survey consisted of 6 multiple choice questions focusing on the type of support accessed, 2 open-ended questions requesting further details on the usefulness of this support and what alternative support may have helped, and 9 multiple choice demographic questions. The survey was largely shared online through social media platforms, our webpage, and email dissemination. The printed leaflets/posters for the project also had a QR code which linked to the survey. *A copy of the survey can be found in the appendix.*

## How we raised awareness of the project

We utilised several different methods to engage with as many people as possible and maximise exposure of this project, including:

- Targeted meetings with organisations (as detailed previously).
- Targeted leaflet drops in Torquay.
- Paid-for social media advertising.
- Sharing information and advertisements across local Facebook groups.
- Suite of printed leaflets and posters dispersed across various local community locations.
- Advertisements in local magazines: Brixham Signal & Ellacombe Community Magazine.
- Information disseminated through the Community Builder Team and their networks.
- Information distributed via Healthwatch Torbay community networks including via their website, social media and email newsletter.
- Torquay PCN disseminated information about the cancer café events through their networks.

## Selection of related marketing material

- Screenshot of the project Facebook page (upper right)
- Project Lead Abi Gascoyne at an event with project marketing materials on display (bottom left)
- Examples of social media posts (bottom right).



# Co-Design and Co-Production

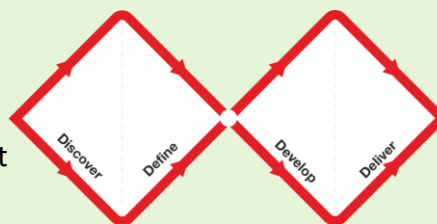
One of the main aims of this project was to develop co-produced and co-designed solutions with communities in Torbay known to experience health inequalities in relation to cancer. Partner organisation, Torbay Communities, led on this co-design aspect of the project and have therefore contributed some content to this report. A detailed section on the co-production/co-design work carried out through this project can be found on page 43 of this report.

Where you see this green box within the report it will focus on the co-design/co-production element of the project relevant to that report section and is written by Torbay Communities.

## Codesign Methodology

As year two focused more on developing and running co-design workshops aiming to address some of the issues raised in year one a different methodology was required, this is detailed below by Torbay Communities.

The co-design methodology used was based on the 'double diamond' approach, which works with people of lived experience. The process unfolds through a series of workshops and puts individual's experience at the forefront of decision-making, with the intention of improving service delivery and user-experience of services. The 'double' aspect then develops the learning from the design process into meaningful outcomes or actions. Jess Slade, Community Participation Lead for Torbay Communities, led the co-design with support from our Community Builder Team who work across 30 neighbourhoods in Torbay. The work is informed by asset-based/strength-based approaches that enable people to lead their own lives based on their experience, passions and ambitions.



**DISCOVER:** The first diamond helps people understand, rather than simply assume, what the problem is. It involves speaking to and spending time with people who are affected by the issues.

**DEFINE:** The insight gathered from the discovery phase can help you to define the challenge in a different way.

**DEVELOP:** The second diamond encourages people to give different answers to the clearly defined problem, seeking inspiration from elsewhere and co-designing with a range of different people.

**DELIVER:** Delivery involves testing out different solutions at small-scale, rejecting those that will not work and improving the ones that will.

# Existing Support

During the first couple of months of the project we conducted a service mapping exercise. This mapping explored the nature and availability of cancer support services currently operating in Torbay. This was an ongoing exercise - as the project developed and engaged with more people, we returned to this mapping exercise to add new knowledge. The final version of this map is included below.

**Note** – this map only includes services who told with us that they offer cancer-specific services for Torbay residents – there are lots of other charities and organisations operating locally that provide advice and support, but do not have cancer-specific offer.

## Support Groups

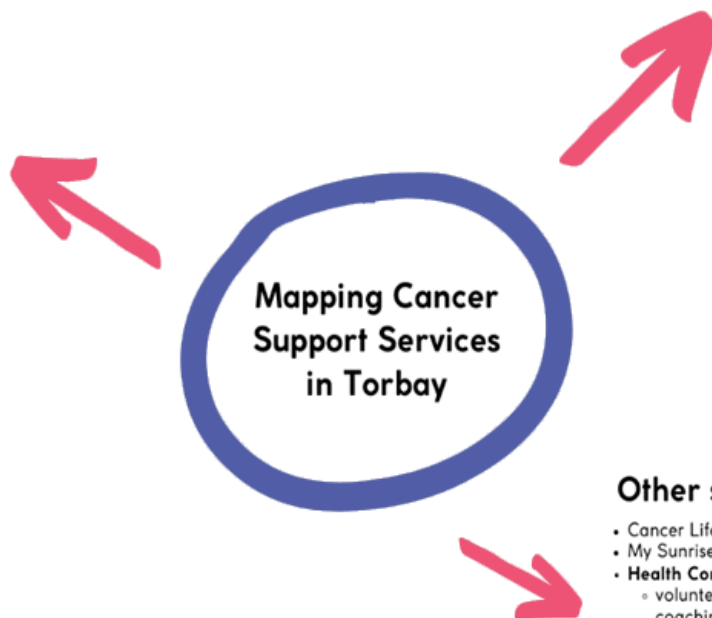
- **The Swallows**
  - nationwide head and neck cancer charity
  - Torbay/South Devon group meet on second Wednesday of each month at Kingskerswell Community Centre
  - support both patients and family/care givers
- **Torbay Prostate Support Association**
  - supports men of all ages (and their partners)
  - aims to raise awareness + fundraise for specialist equipment
  - regular social events + information events with speakers
  - host large PSA testing events
  - buddy scheme (under review)
- **Breast Cancer Now**
  - nationwide charity with in-person peer support group in Torbay for those living with secondary breast cancer
  - group meets first Tuesday of every month at the Livermead Hotel
  - the group is facilitated by a Macmillan staff member from Plymouth
  - when possible clinical professionals attend sessions to speak with the group
- **Shine Cancer Support**
  - Nationwide cancer charity for younger people
  - Have a *Devon-wide network* which hosts peer support Zoom meet-ups on the first Wednesday of every month.
  - Have multiple attendees from the Torbay area

## The Lodge

- Macmillan cancer support and information centre in Torquay
- telephone and/or face to face support
- no professional referral needed
- Support offered includes:
  - cancer information materials
  - emotional support
  - financial & benefits advice
  - advice about Macmillan grants
  - wig fitting service
  - genetic counselling referrals
  - host Look Good Feel Better workshops
  - complementary therapies
  - signposting to local services
  - peer support groups (under review)

## Other support services

- Cancer Lifeline Southwest
- My Sunrise App
- **Health Connect Coaching Programme**
  - volunteer-led, health and wellbeing, 6-month coaching programme. Individuals get matched with volunteer coaches who have/had the same or similar health conditions.
  - recently created a cancer-specific pathway for the programme
- **Citizens Advice Devon-Wide Macmillan Welfare Benefits Advice Service**
  - provide welfare benefits advice, help clients access blue badges and Macmillan grants
  - Also offer emergency advice and referrals to other CA advice services - e.g. debt, house, employment, relationships



To view a larger version of this map online please visit <https://shorturl.at/rQURz>

# Summary of Key Engagement Findings from Target Groups and Wider Engagement

The key engagement findings summarised below incorporate the findings from both engagement stream one (discussions with target communities) and stream two (discussions with individuals affected by cancer from the wider Torbay community). Therefore, some of these findings (such as access to primary healthcare services) are reflective of barriers to diagnosis, whilst others refer directly to cancer support structures in Torbay.

- 1. Access to primary healthcare services is an overarching issue affecting all Torbay communities.** When engaging with the target groups and wider public around potential barriers to diagnosis and how they'd deal with a concerning sign and/or symptom, almost all conversations turned to issues with accessing GP services in Torbay. Across all communities GPs were seen as the first point of call for healthcare concerns and questions, but we were told patients are having issues with contacting their surgery, making appointments, accessing online systems, and communicating with health professionals. Many said this has or would result in them leaving a sign and/or symptom until it really concerned them or was deemed an emergency. Issues around primary healthcare was the overarching theme of engagement, and often dominated discussions with the public.
- 2. Engagement fatigue around healthcare is very prevalent in Torbay.** Individuals and groups (particularly those that we were targeting) expressed concerns around the worth of sharing their experiences given they'd done so before and hadn't seen much change. This overall feeling of apathy made engagement difficult across all groups and the wider community in Torbay. Many explained they weren't willing to share unless we could prove the tangible impact it would make to the area.
- 3. There is a lack of cancer-specific support services in Torbay.** Communities and individuals told us they struggle to find cancer-specific support for themselves and family members. The nature of support wanted included support for families and children, bereavement support, and informal support groups.
- 4. For those who have experienced a cancer diagnosis there is a clear want for peer-based in-person support.** People told us they wanted to be able to speak to someone in an informal environment who has had similar experiences to themselves. At present there are only two support groups in Torbay, and another just outside. These only cater for three specific cancer types.
- 5. Accessible information and health care is an issue for learning disabled communities and for those whom English is not a first language.** Refugee and asylum-seeking communities in Torbay told us about the recurring issues they're having with accessing translation services in medical settings. Learning disabled communities highlighted barriers they have locally with accessing GP services and finding appropriate health information.

# Detailed Findings By Target Group

The feedback in this section has been filtered by the four target group areas:

- LGBTQ+
- ethnic minority
- socio-economically deprived
- learning disabled

The findings in this section have come from both stream one (developing understanding on barriers to diagnosis and health inequalities in the local area) and stream two of engagement (developing understanding on local cancer needs around support). Because of this, each section has both cancer-specific feedback from those who have been impacted by cancer, as well as feedback from the wider community around issues with accessing healthcare information and services.

Quotes from participants have been written in *italic* and are verbatim.

Some specific community groups spoken with are mentioned in the introductory paragraph of each section but not within the main body of the section, to avoid potential identification of participants.

## How we analysed data

The data from this engagement was initially segmented by demographic detail and target group, then collated and themed. After an initial read-through of all responses, it was clear that five key themes were prevalent throughout:

- 1. Cancer-specific feedback**
- 2. Access to services**
- 3. Care – from health or social care professionals**
- 4. Information & knowledge around health**
- 5. Potential suggestions for improvement**

All data was examined using these themes as tags to identify trends, ideas or patterns from what Torbay residents had told us. These themes are presented by target group in greater detail on the following pages.



## LGBTQ+ Findings

We engaged with members of this community through two surveys (the overarching survey for this project and another more targeted survey specifically aimed at local LGBTQ+ communities in Torbay), community events (such as Torbay Pride), and guided conversations. We also spoke with several charities and organisations working with local LGBTQ+ communities to gather their feedback. We gathered information from both those who had been impacted by cancer and more generally from the wider LGBTQ+ community about barriers to accessing health information and care. Key issues around access to services, waiting times, trust, and awareness of LGBTQ+ healthcare issues were raised as possible barriers to early diagnosis. Feedback from those who had been impacted by cancer highlighted the want for more cancer-specific support in Torbay. These issues are discussed in more detail below.

### LGBTQ+ - Cancer-Specific Feedback

- **Charity-based support.** We received no feedback on community-based support. One person commented on the help they received from a local charity, and another on the usefulness of printed literature produced by charities.
- **Accessing support.** During engagement we encountered several people looking for signposting to cancer-specific support. For example, at the Torbay Pride event, ten people asked for signposting advice to local cancer support groups after being unable to find any for themselves. In the survey two people also mentioned problems with accessing cancer support and advice post-diagnosis through their GP:
  - ‘Said they would contact me to support me but didn’t’*
  - ‘My GP surgery told me ‘it was none of their business’’*
- **Suggestions for support.** We received lots of feedback about the support people felt was missing in their cancer journey. Suggestions for support varied. For example:
  - **Peer-based support:** *‘speaking to someone else who had fought and come out the other side well would have given me more hope and something to aim for.’*
  - **Support groups:** One had instigated their own informal support network of 5 men who had cancer experience (after initially meeting in the Hope course).
  - **Advice Lines:** One suggested some sort of local advice helpline. It was explained that both through the treatment process, and afterwards, they had lots of questions – *‘the ambiguity caused considerable stress’*. They suggested it would have been helpful to have a support line/centre with qualified medical professionals on hand to answer questions. A Q&A phonenumber was also suggested by someone at Torbay Pride 2023.
  - **Wellbeing check-ins:** One person shared that during their recent cancer experience they had been attending 6-weekly check-ups at the hospital but *‘felt that something was missing from them...they were all very medical...no soft approach’*. They suggested that there be some sort of general wellbeing check for patients at these regular check-ups, this *‘would catch multiple issues’*.
  - **Post-treatment support:** Two people expressed their feeling of being *‘dropped’* after their treatment had ended. One explained that you *‘very much feel that you’re on a*

*conveyor belt’ during treatment but it all suddenly comes to a stop. ‘You attend hospital daily and sometimes more than once a day for 6 weeks, then just as the effects of treatment are at their worst you stop going.’ Both explained they would have valued some sort of post-treatment support.*

- **Young person support:** We spoke to two family groups at Torbay Pride who expressed concerns around the lack of services available to support young people who are dealing with cancer in the family. Both families spoken to had had to rely on pastoral support at school due to no mental health nor grievance support being available to under 18s locally.

**The following section details the feedback received from the LGBTQ+ community around wider issues with accessing healthcare information and services. The feedback encompasses the experiences of both those who have been impacted by cancer and those who haven’t.**

### LGBTQ+ - Access

- **GP access.** GP accessibility was identified as a key access issue. The majority of those spoken to explained that their GP would be their first contact if they had a worrying sign or symptom, but accessing this service is causing an issue. For example:  
*‘I don’t feel taken seriously by a GP until it’s urgent’*  
*‘GPs are ‘not accessible’ in Torbay’*
- **Other healthcare services.** Three individuals told us they had concerns with accessing health services in general because of their sexual orientation or gender identity. Two had experienced delays and/or refusal of access to services (e.g. CAHMS). When asked how these experiences affected their use of healthcare services, we were told they approached services with increased wariness.
- **Waiting times.** Waiting times and trust was another access theme. We were advised by a local charity working with this community that, both locally and nationwide, there are prevailing issues around gender identity and accessing healthcare. There is currently an 8 year – and growing - wait list to access gender identity clinics. The recent closure of the NHS Tavistock Clinic in 2024 has exasperated this issue further. This accessibility issue was cited as a key contributor to lowering levels of trust in healthcare systems amongst the community.
- **Suggestions.** Survey participants were asked for suggestions on how we could improve these issues with trust and healthcare access, the following suggestions were made:  
*‘Designated [LGBTQ+] liaison person at Torbay hospital and covering GP practices’*  
*[services should] ‘advertise that they are LGBTQ friendly with posters’*  
*‘GP with specialist understanding/interest in LGBT+ health needs’*  
*‘Increased awareness of LGBTQ in general so we don’t have to keep explaining things’.*

### LGBTQ+ - Care

- **Stigma.** Members of this community reported they encounter issues with stigma when using local healthcare services. One community group explained that when you combine the stigma issue with others, such as hate crime reporting inadequacies in policing, this

led to extremely low levels of trust in public services overall amongst this community. The group felt like this, in combination with the higher prevalence of poor lifestyle choices in the community (e.g. alcohol and drug use), is what is leading to health inequality issues within LGBTQ+ communities in Torbay. Another LGBTQ+ organisation working locally explained that members of the community can often feel uneasy accessing primary healthcare services due to a lack of trust in how the service will treat them. It was explained that experiences of stereotyping are common.

- **Awareness.** One survey participant explained that lack of awareness around LGBTQ+ issues had led to them approaching healthcare services with wariness for their child. The example given: they find themselves having to repeat and stress their child's story and preferred name continually to healthcare professionals. This was echoed in a discussion with an organisation working to support LGBTQ+ individuals locally. It was explained that issues with lack of receptiveness around language (e.g. pronouns), and misunderstandings around common LGBTQ+ healthcare issues, has eroded trust in primary healthcare provision for many they work with.

### LGBTQ+ - Key Observations

- **Engagement difficulties.** Three LGBTQ+ focused organisations explained the difficulty of engaging with this community locally. Torbay's LGBTQ+ scene largely focuses on nightlife, and as such there is a lack of appropriate venues and/or organisations through which to run focus groups. This echoes our experience in engaging with Torbay's LGBTQ+ community for this project. We made multiple attempts to run focus groups but could not find a local group willing to collaborate with us.
- **Focused survey.** Due to not initially picking up LGBTQ+ voices through community drop-ins nor the overall project survey, we chose to launch a targeted survey specifically for LGBTQ+ individuals. This allowed us to tailor social media posts and share with organisations working in this area. This targeted survey elicited much more detailed feedback than the overall project survey.

### LGBTQ+ - Co-Design Findings

The way we work across our social inclusion programmes is person-centred and holistic. From that perspective identifying someone as part of a group based on one characteristic, such as sexual orientation, is not always the best way to identify user needs. The groups that meet in Torbay linked to the LGBT+ community tend to meet for social and celebratory reasons (organising and running the annual pride Festival), not for health and wellbeing. We have gained insights from individual interviews but also felt there was not a strong enough group to work on a co-design project.

**Recommendation:** To gain insights from LGBT+ service users (and the other target groups for this study) we recommended a wider engagement across Torbay public related to their experiences of cancer services that would then include people in the target groups.

# Ethnic Minority Groups Findings

We engaged with ethnic minority groups living in Torbay primarily through focus group events and meetings with community leaders. We did also pick up a handful of voices through community events and guided conversations. Of the 104 survey respondents only 61 were willing to provide demographic data on ethnicity, so whilst we may have picked up survey responses from those in ethnic minority groups, we have been unable to identify them as such for the purposes of this section. We heard from one person who had been directly impacted by cancer, but mostly gathered information around barriers to accessing healthcare and information. It is also important to note that due to the use of translators for focus group sessions a lot of the quoted feedback below is the words of a professional translator rather than directly from the individuals giving feedback. The feedback in this section has largely emerged from focus groups, meetings, and conversations with the following:

- Chinese Community Wellbeing Society
- Torbay Multicultural Network
- Community Builders working with refugee and asylum seekers
- Imagine Torbay
- Ukrainian communities living in Torbay.

## Ethnic Minority Groups - Cancer-Specific Feedback

**Post-treatment support.** One gentleman with a recent cancer experience gave an in-depth account of the issues he's having with cancer support post-treatment. His symptoms had been picked up on arrival in the UK by a GP (at a 60+ health check). Whilst the patient believes the cancer treatment and care he received at Exeter Hospital '*had been brilliant*', he is now suffering from lasting effects of the treatment, which at time means he is unable to look after himself (do food shopping, clean, etc.). He can't seem to access any support through his GP or adult social care. He thinks this may be a translation issue, due to having low levels of English.

The gentleman also explained that he has recently been having issues with recurring infections but has had to '*battle for tests and answers from the GP*'. He explained that it's been very hard to get any communication, tests, or follow-up advice now hospital treatment is over. At the time of speaking the gentleman had decided to return to Ukraine the following month to get tests and care he believes he needs.

**The following section details the feedback received from ethnic minority communities around wider issues with accessing healthcare information and services. The feedback encompasses the experiences of both those who have been impacted by cancer and those who haven't.**

## Ethnic Minority Groups – Access

- **GP access** - GP accessibility was identified as a key access issue, for example:
  - **Translation issues.** In one focus group session, all 17 participants recounted issues with translation services at their GP practices in Torbay. Participants explained that

translation doesn't seem to be available online, via telephone, or in person. Example given: close to the time of booked appointments participants will often receive a message from their surgery informing them that translation will not be available for their upcoming appointment. Participants explained that they are given 2 options: to rebook for another time or to attend the appointment without translation. Five participants explained to us that they'd previously '*made the mistake*' of going for the first option only to have the same issue again of no translation service at their rebooked time.

- **Registering.** One organisation raised concerns around accessibility and the '*signing up*' process for practices in Torbay. Their members have found that many Torbay practices don't offer registration forms in alternative formats or languages.
- **Appointments.** When speaking with one community leader we were informed that asylum-seeking individuals and families are finding accessing GP appointments '*an uphill battle*'. It was explained that there are currently several individuals living in hotels with serious health conditions which need medication and/or monitoring, but they're struggling to be seen by a GP. This has resulted in a couple of potentially avoidable A&E visits.
- **Accessing other healthcare services**
  - **Transport.** Several focus group participants explained they found '*it stressful*' accessing medical services locally for themselves and their children, due to not having transport nor local support systems to help them (i.e. friends & family). Most had their GP within walking distance but stressed that knowing they're unable to access other services easily in an emergency is of particular concern.
  - **Support structures.** Childcare was also raised by several women in a focus group. Lack of support structures makes it difficult to attend medical appointments if they have children (i.e. school timings, childcare). One woman explained that this has previously led to them '*leaving it until their child is really sick and last minute*'.
  - **Medical records.** 10 people in a focus group raised concerns about issues with medical records and accessing support/treatment. Participants recounted recent experiences of their GP asking to see their medical records before referring on for specialist treatment and/or advice. Due to their refugee status none of the participants were able to bring their medical records with them and are very unlikely to be able to access them now. Participants explained that '*the GPs seem to find this answer hard to accept*'. Examples given:

One participant has had a '*very stressful time*' trying to access care for her daughter since arriving in Torbay. Her child has '*heart and brain issues*', but she feels she cannot get the GP to '*take her seriously*'. She continues to return to the doctor to stress the seriousness of the issue but reports the GP explains that without medical records they have '*to start at the beginning*'.

Another participant explained that she is anaemic with thyroid issues. Due to not having access to her medical records, she is struggling to get the GP or hospital to understand she needs regular checks. She has also requested an ECG through the GP, but the practice will not allow this without seeing her medical records.

## Ethnic Minority Groups – Care

- **Translation.** Some more focus group participants explained they have issues translation issues at Torbay Hospital. It was explained that there is one in-person translator available for hospital appointments, but they are not always available and cultural tensions between Ukraine and Russia (participants were Ukrainian, Torbay Hospital translator is Russian) are leading to some patients refusing this service.
- **NHS App.** We had positive feedback around the NHS App. Several focus group members reported they use it regularly. Despite this app not being available in their language, they reported finding it easier to use written English than conversing with healthcare professionals in person (the app gives them the time and space needed to translate and understand the information for themselves).
- **GP care & cultural clashes.** There was a general feeling amongst several that we spoke to that they *'don't feel taken seriously by the GP'*. Participants explained that they seemed to be having lots of *'cultural clashes'* with GPs in Torbay, which is in turn creating *'stress and trust'* issues. During one of the focus group sessions we discussed how in some cultures it is the norm to take a proactive interest in your own and your children's health. But this seems to be the root of some cultural clashes with Torbay GPs. Three participants in a focus group recalled recent instances when a local GP had asked them *'are you the doctor?'* during an appointment. Another focus group participant recounted an experience when she took her child to the GP for recurrent headaches and the GP suggested it was caused by *'stress of the war'* in their home country. She tried to request a CT after this but was refused on account of the *'stress'* diagnosis.

## Ethnic Minority Groups – Information

- **Understanding healthcare systems.** During focus group sessions, we were told that there's a lack of information regarding UK healthcare systems when refugees arrive here. Participants explained that there is no touchpoint available locally where they can get this information verbally, nor had they come across any online or printed information in a language that they can understand. The groups explained that they were learning the NHS system through trial-and-error. Most in the group understood that GPs are usually the *'first point for help'*, but there was very little understanding amongst all focus group participants about other frontline services (i.e. minor injuries, urgent care, pharmacies etc.).

We had very similar feedback from a local organisation working to support ethnic minority communities in Torbay. They raised concerns around how *'confusing'* UK healthcare systems can be on arrival. Example given: in other countries the GP isn't the first point of contact, and understanding this can be a *'stumbling block'*. It was explained that *'go and see your doctor'* is a common saying but *'doesn't translate well. Where is this doctor? At the hospital? The pharmacy?'* The organisation also highlighted that working out *'what is free versus what isn't'* can be a barrier to some of their members. It was explained that whilst they're used to private healthcare systems, the mix of private and NHS in the UK can be confusing, and the group have observed this being a reason for some communities they work with delaying treatment.

- **Pharmacy information.** Several participants in focus group sessions explained that they found the relationship between pharmacy and GP services in the UK confusing. They gave examples of when they'd tried to access the GP for their children and felt '*brushed off*' to the pharmacy. The pharmacy subsequently directed them back to the GP due to the age of the patients. Participants were unsure whether this was a language barrier issue, or a problem experienced by all.
- **Managing Expectations.** During two focus group sessions it became clear that some of the frustrations participants were experiencing with local NHS services were to do with managing expectations. We discussed differences in healthcare systems, and differing protocols around things like women's health and screening. Participants explained they are unclear around criteria for screening (e.g. mammograms). Cultural differences around managing health were also discussed. Some in the group explained that self-checking for lumps and bumps '*is not really a thing*' in their country as they have regular screening and check-ups with health professionals. It was suggested that information about self-checking and screening needs to be made more accessible.

### Ethnic Minority Groups - Key Observations

- **Engagement fatigue.** Several groups we approached explained that they are subject to multiple engagement requests like this every month, which has led to engagement fatigue and apathy issues. We were also told that asylum-seeking and refugee communities felt '*let down*' by NHS services and the local council, and so wouldn't be willing to engage unless urgent health or living concerns were addressed first.
- **Accessing communities.** Many individuals residing in Torbay, from an ethnic minority background, don't have a formalised support group or organisation representing their needs locally. Accessing individuals through a community-based approach without these organisational structures in place was very difficult.
- **The subject of cancer.** The subject of cancer was seen as a cultural taboo amongst some of the groups we spoke to, which either resulted in not being able to engage at all or having to adapt the engagement questions to focus on wider health information and access issues. Religious groups we spoke with also felt the topic of cancer was not one their congregations would be comfortable addressing and that a wider health approach wouldn't be relevant to them.
- **Language barriers.** Language barriers also presented an issue throughout engagement. We had a couple of requests to translate the projects' materials into different languages (e.g. Arabic, Swahili, Mandarin, Cantonese). Whilst this was possible, this project did not have the time and resource needed to translate the entire survey linguistically and culturally, hire translators to analyse the ensuing answers, and hire translators again to conduct follow-on guided conversations.

## Ukrainian Refugee Community - Co-design findings

As part of the project engagement, we ran two focus group sessions with Ukrainian refugees and in this process developed the first stages of co-design. As with the other target groups access to the health care system in the UK for refugees showed as the main issue. We discussed the value of co-design around cancer support with this group when the major issues they described are system wide – capacity, complexity, how services link-up etc. The people in the Ukrainian group described themselves as coming from a society that has good access to health care and healthy prevention measures. They had an up-to-date awareness of the signs and symptoms of cancer for themselves and their family but found it difficult to understand the UK NHS system and find ways to navigate it. Two of the group had had cancer, but our co-design focused on participant's awareness and access to information and services. In the co-design session, the issues they described were:

**Basic information:** None of the participants were aware of the 2-page NHS information sheet 'How the NHS works: a guide for migrants'. It is in English and translated into 10 other languages including Ukrainian. When we showed them the information sheet, they thought the translation was poor and lacked clarity. Local NHS staff were not aware of the form either. The information sheet also lacks localised information that is also translated. People need to know what services are available, where it is and the process for accessing it – in one package. They also need to know what regular screening is available and how to access those locally.

**Recommendation:** create localised information sheets and web / app pages, in easy read format in relevant languages for communities.

**Local situation versus NHS delivery model:** The inconsistencies between the ideal ways to access medical services and the reality also showed as a barrier. This included availability of GP appointments, non-availability of dental services, changes to appointments for GP and consultants, extensive waiting lists.

**Recommendation:** not only does information need to be clear and localised – it needs to be up to date so it can reflect current local delivery.

**Understanding the system:** They described it as complex. What is the role of a GP, a pharmacist, practise nurse etc. What is the role of Macmillan? One person was given the wrong information, that a pharmacist could refer people to other services or specialists for treatment. Another described paying for pharmaceuticals from a chemist for their child when they should have been covered by a prescription. They described the Ukrainian medical system as comprehensive and there was regular screening programmes provided – so participants were well aware of treatment needs but found it difficult to understand or access NHS systems.

**Navigating the system:** It was difficult to find out about the touchpoints - access a GP or a dentist, how to get to a specialist, inoculations, who could refer, the role of pharmacists, the prescription system, A&E, small injury units, community hospitals, etc.

**Recommendation:** translation is not enough; some people may need a guide / advocate to help navigate the system. Example: it is not just the language barrier that stops people getting a GP appointment.



**GP Procedures:** Parents were mostly well aware of the diagnosis for themselves or family but couldn't produce recent medical notes / history, so GPs were discounting their accounts and delaying treatment until a full assessment was carried out in the UK. They believed this was putting their families at risk by delaying treatment. This was compounded by delays in getting a suitable assessment in the UK.

**Understanding how to benefit from the NHS system:** One of the refugees managed to get an emergency dental appointment, but didn't receive treatment because pain wasn't considered bad enough.

**Translation Services:** Changes to translation services which have been going through a new procurement process seems to have added confusion for staff and patients. Issues were - How do you know you are entitled to a translator and the steps to engage one. The lack of availability of a suitable translator (Example: one individual described having been assigned a Russian interpreter which seemed insensitive to the refugee's situation). Children were put in a situation of translating for their parents in a medical assessment which was difficult / awkward for the parent.

**Recommendation:** A need for translation and interpretation not just for understanding NHS services but also local knowledge for accessing local services. This would have been very beneficial soon after arrival. Translation services could be made available for a booked session with a GP or consultant. Healthwatch are in a position to escalate this discussion to improve access to health services.

**Testing systems:** Six of the group offered to act as 'secret shoppers' to demonstrate the process and how difficult it is to get into and use health systems. Example: phone 111 and try to access a translator; or get an appointment with an emergency dentist; or the experience of a GP appointment; or ringing the Lodge to find out what they can offer.

**Recommendation:** this would highlight how many steps people have to take to get appropriate treatment. This idea has been raised with Healthwatch Torbay.

**Cancer treatment:** one person returned to Ukraine as he said he couldn't access cancer treatment in Torbay. Other people have not received the treatment they believe they require.

**NHS App:** NHS app was considered a useful resource – but could be improved with a translation facility. Even without translation – Ukraine refugee feedback was that they could take it with them and have a go at translating themselves using other apps.

## Socio-economically deprived areas of Torbay Findings

We engaged with individuals and families living in more socio-economically deprived areas of Torbay through the project survey, community events, cancer cafes, coffee morning drop-ins, and guided conversations. We also spoke with several charities and organisations working with economically deprived communities in Torbay (e.g. Age UK Torbay) to gather their insight and the experiences of their service users. We gathered stories from those who had been impacted by cancer, and from the wider community around barriers to accessing healthcare information, support and services.

Socio-economically deprived areas of Torbay were identified and defined using Torbay's JSNA. However, it is important to note, that this often had to be combined with local knowledge as the disparity in poverty within postcodes and wards in Torbay is vast. Therefore, we cannot guarantee 100% of feedback in this section has exclusively come from an economically challenged or deprived resident of Torbay.

### Economically Deprived Communities - Cancer-Specific Feedback

- **Financial issues**

- At one community group meeting two members felt that *'there's not a go-to place for trusted information on financial support and allowances'* and that *'there's a lot of conflicting information online'*. They said many people *'fall through the net because they're simply not told about financial hardship schemes when they are diagnosed'*.
- A large community support team said they *'keep coming across huge issues with support for Torbay people who are end of life with cancer'*, and that these usually relate to housing issues. In particular a lack of financial support for those renting in the private sector. The team said they have had to deal with several evictions in the last year with those on end of life treatment and that this number is increasing. The team said they feel that the council needs to step in immediately at diagnosis when the patient is terminal – to ensure the patient has suitable accommodation and will be provided for. They also stated that the housing banding system was *'a big issue'* with many difficulties *'getting those with end of life up into the top banding quickly'*. As an example, they referenced someone under end of life who was living in a tent on the beach as no private landlord would take them. They were often unable to attend hospital appointments due to having to *'wait until the tide went out to get off the beach'*. The same team said they had used Macmillan grants before but these grants *'only supply up to white goods – which is not useful when the service user can't even get a roof over their head'*.
- A local resident expressed a similar concern that benefits do not accommodate for end-of-life support and leads to those with a terminal diagnosis without sufficient homes/food/etc. They stated that *'unless we get this basic benefits issue sorted other community support in Torbay would be irrelevant'*.
- One individual said their breast cancer diagnosis felt like a *'money pit'* as everything cost money, including transport to hospital, pharmacy, food shop, etc.

- **Hospital care**

- At a drop-in event multiple individuals with a similar diagnosis stressed how communication between different hospital departments is continually difficult. They find themselves *'having to repeat their story regularly or highlight to medical staff how they're working with outdated notes'*. The group did, however, unanimously agree that the breast care unit nurses are *'brilliant'* and *'seem to be able to communicate within their team very well.'*
- One individual with a breast cancer diagnosis explained that throughout their treatment all NHS staff defaulted to *'ask a family member'* when they questioned how they look after themselves during and post-treatment. When she went in for day surgery, she said she was told she couldn't leave without a family member accompanying and staying the night. Hospital staff didn't have a solution when it was explained they didn't have any friends or family. She commented having to *'explain [this] again and again to NHS staff'* and that this *'reinforces how on your own you are'*.
- At a community drop-in we had feedback regarding oncology care from a patient who felt *'looked after'* but did feel *'bounced around with lots of appointments at different locations'*. They stated this had financial impacts and they felt the amount of appointments was *'excessive, as many tests/issues could have been dealt with all at one appointment'*.
- At a drop-in several individuals reported issues with hospital pharmacy services. They stated the hospital pharmacy is *'more often than not unable to deliver on designated days'* and that this *'leads to patients waiting in when they don't need to or missing the delivery all together'*. They also reported experiences with missing items when collecting prescriptions, having to wait *'a considerable time at the pharmacy for their medications to be dispensed'*.

- **GP access & support**

- One person told us they had *'to pursue the doctors relentlessly for appointments'* about her husband's cancer symptoms and subsequent care. She emphasized the *'strain'* this puts on carers of those with cancer and how she couldn't find *'support locally for families affected by this'*.
- An individual explained that his diagnosis had been picked up was because upon moving here he told his GP he'd been having regular PSA tests previously. He expressed concern that *'there must be lots of missed cases in Torbay as they don't do regular testing at GPs'*.

- **Charity-based support**

- One member of a community group had positive feedback about the Macmillan community nurse that visited their home, explaining how important it was for the nurse to come to their home for this in a comfortable environment. She *'offered lots of practical advice around benefits and finances'*.
- We had positive responses about nurses that cared for loved ones; *'Macmillan and Rowcroft nurses made all the difference.'*

- One person said they did try the Macmillan emotional support helpline for counselling support but had *'a bad experience with this as the Helpline is only as useful as the individual you get on the end of the phone'*. The individual was trying to access information on pets and cancer treatment.
- An individual with a lymphoma some years ago explained that Macmillan had supported her with a small grant for travel and she *'was very grateful at the time'*.
- Several individuals fed back that the Macmillan Lodge at Torbay Hospital *'was useful for one-off and practical issues, [but] unfortunately isn't able to offer long-term substantial support.'*
- **Suggestions for support.** We received lots of feedback about the support individuals would have valued during their cancer journey. Suggestions varied, for example:
  - **Support groups:** One individual felt it would have been helpful to have some community-based cancer support groups saying *'it would have been nice to speak to those with similar issues, but I couldn't find anything'*.
  - **Advice Lines:** One individual with experience of ovarian cancer suggested that having access to a 24-hour help/support phone line would have better supported her. She explained that you *'often don't want to pester the consultant'* with small signs, symptoms, worries or questions, so having someone available at the end of the phone that could advise if a wait time, symptom or appointment was something they should be chasing or not would have been a real help

Another individual explained it would have been really helpful to have access to a local phonenumber staffed by a clinician - that it could be used *'if you're slightly worried about a sign or symptom and need some [localised] advice on where to go next'*.

The following section details the feedback received from economically deprived communities around wider issues with accessing healthcare information and services. The feedback encompasses the experiences of both those who have been impacted by cancer and those who haven't.

### Economically Deprived Communities – Access Issues

- **GP access.** There was a strong consensus amongst those we spoke to that GPs were seen as the most reputable and trusted source of help when concerned about signs/symptoms of cancer. However, the majority of people spoken to were also having issues accessing their GP. We had lots of feedback from communities around the frustrations of trying to get GP appointments or contacting their GP. For example:
  - In Torbay GPs are *'incredibly difficult to see'*
  - GPs are *'almost completely inaccessible'*
  - [we] have to wait in *'hour-long'* phone queues with *'no guarantee'* of an appointment.
  - Some Torquay town centre residents mentioned *'trying to get hold of the GP but then giving up, sometimes leading to unnecessary hospital admissions'*

- One individual told us they had used the online triage system five weeks ago for a concerning mole but still had no response.
- several participants in a focus group explained they believed cancer signs and symptoms would be *'picked up much earlier if we could access a GP easily'*.
- The above was reiterated by other groups who discussed how the *'old route'* to help and support when worried about signs/symptoms of cancer is *'no longer available due to local GP surgeries being inundated and inaccessible'*.
- One group unanimously agreed that they know they should go to their GP, but getting hold of a local GP is *'very difficult'* and that *'this often means they leave things until they become urgent/more serious'*.
- We also received feedback around issues with accessing GP services online. Some residents reported not having Wi-Fi at home – which leads to complications with accessing information and help from the GP. For example:
  - 'It's difficult when most surgeries in Torbay are requesting you contact them through an online triage system'*
  - 'We are forced to fill out online forms to access an appointment'*
- **Hospital services.** Members of one focus group expressed concern over waiting times at Torbay Hospital - *'waiting times for everything up at the hospital are diabolical'*. Another commented *'the situation at Torbay A&E puts you off reaching out for help, even when the situation starts to become urgent'*. Others mentioned that this situation *'causes stress when considering issues like cancer'* that needs more urgent help.

### Economically Deprived Communities – Key Observations

- It was challenging to bring up the conversation of poverty in groups or to find the right way of asking people whether they deemed themselves as socio-economically deprived. It was also difficult to base this on postcode or ward, as the disparity in poverty within these is vast in Torbay. Therefore, we cannot guarantee 100% of feedback in this section has exclusively come from an economically challenged or deprived resident of Torbay.
- Due to funding issues many of the venues or support organisations that were located in more economically deprived areas of Torbay have closed or are running with a much-reduced service. For example – the ward of Ellacombe in Torquay currently has no community centre nor community-based venue for residents to gather. A lack of community hubs or meeting places made engagement with these communities difficult at times.
- Many of the people in this community directly (themselves) or indirectly (family) impacted by cancer also felt unable to share their stories as they were *'too raw'*.

## Economically Deprived Communities – Co-Design Comments

The engagement work allowed us to record insightful personal experiences and stories that informed the study but there were not sufficient joint issues to form a group around co-design. Generally, people had good knowledge of signs and symptoms of cancer. They had seen ads and leaflets from Macmillan and other health providers, but consistent with other groups the main issues that concerned them were getting appointments, and access to health services. Specific concerns related to cost of living - price of parking, transport to medical appointments, use of phone minutes to call the surgery, changes to scheduled appointments, pharmacy services, non-availability of some drugs, etc. These were seen as barriers that meant they would wait for a sign / symptom to be extreme before going to see their GP surgery (Example: mole on the skin). Some people noted they had been advised to go private to get treatment, but thought the costs were prohibitive.

## Learning Disabled Findings

We engaged with adults living with a learning disability in Torbay through the project survey, focus groups, community events, drop-ins, and guided conversations. We also met with local community groups working within LD in Torbay to gather their insight and the experiences of their service users. These included Torbay Mencap, Torbay Mencap Carers, Turning Heads, and Torbay's LD Ambassadors. We largely gathered information from the wider community around barriers to accessing healthcare information, support and services, but did speak to a handful of LD adults and their carers who had been impacted by cancer.

### Adults With LD - Cancer-Specific Feedback

**Cancer support.** We had mixed feedback about support services for those who had been impacted by cancer in Torbay. At a group meeting we received feedback that Macmillan nurses in the community offered '*incredible*' support, and the cancer nurses encountered were '*absolutely fantastic*'. However, at an event we heard from two individuals who struggled to access support. One individual explained they '*couldn't find any support for them or their family, and no one could signpost them to support when they asked at the hospital.*' One individual, whose husband had experienced testicular cancer, stated she '*ended up with mental health issues because of the lack of support.*' One carer at the event explained that they felt supported when their cared for was going through treatment, but now they've been '*signed off*' by the hospital and told to monitor closely themselves they '*feel like they've been left on a cliff edge*'. They explained that relying on family members to monitor and check LD adults once in remission puts a lot of pressure and stress on family as '*they feel unqualified and worried they are going to make mistakes*'.

The following section details the feedback received from learning disabled communities around wider issues with accessing healthcare information and services. The feedback encompasses the experiences of both those who have been impacted by cancer and those who haven't.

### Adults With LD – Access

- **GP access**
  - **Phone queues.** Several carers for adults with LD reported that their GP Surgery had *'very long phone queues'*, leading to carers *'giving up'* or *'not bothering unless it's an emergency'*. In a focus group session participants all agreed that it's very hard to get hold of the doctor on the phone at the moment, saying they *'spend hours waiting in queues'*. One participant believed that this issue with GP access is the primary issue of cancer signs and symptoms not being caught early enough in the community – *'people wait until it's an emergency... so it's too late'*.
  - **Online issues.** There was a suggestion that Torbay GPs *'reliance of technology'* (e.g. online booking systems) is leading to those with LD becoming *'isolated from primary care'*.
  - **Reasonable Adjustments.** It was highlighted in one focus group session that GP receptionists seem to have a lack of understanding around reasonable adjustments. One participant gave an example of being *'called obtuse for reiterating [that they] need to use the phone rather than an online system due to sight impairment issues'*.
  - **Environment.** At an LD group committee meeting, several attendees commented on the *'challenging behavior's'* notices displayed in GP surgeries around Torbay. Many with LD do present with these challenging behaviors and these posters up at the entrance could infer that they're not welcome or don't have a right to treatment.

### Adults With LD – Care

- **Annual health checks.** We received lots of feedback from those in this community about the availability and quality annual health checks for those with a learning disability. One group we spoke to understood that most GP surgeries in Torbay are *'running about 3 months behind'* with annual health checks. Three in the group had had their last annual health check 15 months ago. It was suggested that *'lots of people are having to chase to get an annual health check'*. At two separate group meetings the issue of consistency was raised. Collectively the groups believed annual health checks are not consistent, as *'different staff members and different surgeries seem to ask different questions and have different levels of care'* and that the quality of health checks seems to be *'sporadic'* or *'very basic'*. One carer said that the *'only check they do now on these annual health checks is blood pressure. This isn't enough.'* Others highlighted this also, with several LD adults reporting only verbal check-ins and not physical (no bloods, blood pressure, physical monitoring, weight/height check, etc.). It was highlighted that LD patients cannot always explain themselves, their symptoms, or how they're feeling verbally. Some attendees at this meeting also said they felt there was *'a lack of continuity in care and this can be worrying at times – particularly with LD'*.

- **Medical notes.** Three carers discussed issues with *'flags'* on medical notes/systems – *'for some reason the computer systems still don't always flag that someone has a learning disability'*. It was suggested that this is a real problem in achieving equitable medical access and care. At an LD group committee meeting it was also raised that many LD adults in Torbay aren't registered as having LD at their GP surgery – so aren't being called forward for relevant health checks.
- **Communication issues.** One LD Group felt that family/carers/support workers may often overlook comments about feeling ill or symptoms which may indicate something which needs checking. This is because pain can be a difficult concept to explain and communicate with LD adults and is very individualized. The group also felt that professionals will often assume that ill health is due to the LD and not other issues. It was raised that professionals often put family/carer views before that of the person. Their experience of medical intervention is that it was often not well explained or communicated by professionals. Another group explained that for communication *'hospital Passports can be very useful but only really help if you're more profound'*. Hospital passports were also mentioned positively at a focus group session.
- **Specialist care.** At another LD group committee meeting, concern was expressed around there currently only two LD specialist nurses in Torbay – suggesting that *'lots of issues are being missed at primary care level as there's not the understanding there.'*
- **Support living.** We received multiple comments from carers about the poor food and diet available in supported living accommodation in Torbay, with a general consensus and that this *'must be a contributor to poor cancer outcomes amongst LD communities'*.

### Adults With LD – Information

- **Representation.** At a meeting with one LD Group, it was highlighted that there is a *'lack of LD representation'* in any advertisements around self-checking – or cancer awareness in general – and there *'seems to be a focus on physical disability sometimes, but never on LD'*.
- **Cancer signs and/or symptoms.** When a group of adults with LD were directly asked about where they would go for cancer information, they all said they would ask their doctor, pharmacist, or check the internet – *'they always say you have to look online but it sometimes isn't easy'*. Some members of the group said the hospital sometimes has leaflets but *'there's not much information around'*. Participants believed information about cancer should be incorporated into education much earlier.
- **Accessible information.** One group reported that clear communication at GP surgeries can be an issue. Participants explained that sometimes their GPs draw pictures – which helps – but this isn't consistent. The group stated that accessible information is a problem amongst adults with LD. Some members reported finding just one hospital department (in Plymouth) that had made reasonable adjustments around information, whereas others (e.g. Torbay) seemed to have not. Example given - there was no easy-read offer for patients. The group also felt like things are *'very confusing'* when you go into hospital – *'You get told to sign things and 'you don't really know what you're signing for'*.



- **Terminology.** At another LD group meeting an End of Life care planning book was highlighted by Plymouth Hospice – the group explained that the terminology around health and cancer is complicated – for example, *‘screening generally means watching a film’*.

### Adults With LD – Suggestions

- **Accessible information.** During a focus group session, it was suggested that it would be useful to have an easy read version of the Macmillan fold-out signs & symptoms card as all in the group said they *‘would never pick up one of the big [Macmillan] easy read books unless ...already worried about something’*, but they would pick up one of the fold-out pocket-sized cards. There were further suggestions on how to improve this by card - making statements clearer, with a larger more legible font and also including a QR Code which links to video/audio versions of the information. The group felt that this leaflet should then be put on clear display at all healthcare settings and not *‘just hidden in a leaflet stand’*. Another group explained that all cancer information needs to be presented in a larger and much clearer way with no jargon or long words and accompanied with pictures – particularly any of *‘equipment that may be used’*. The group stated that cancer information needs to include *‘what they’re going to do, how they’re going to do it, where you’ll have to travel to, if there could be problems/complications, and what’s next/afterwards.’*
- **Carers.** It was noted by one LD group that it is a difficult balance knowing how, where and when to educate LD adults on cancer, as some will be receptive to any teaching on signs/symptoms, but for others it can do more damage than good (e.g. they will fixate on the problem and will stress themselves out thinking they may have cancer). It was suggested that this later group need to be reached through their carers – who need to be better educated about how to spot signs and symptoms in those they care for.
- **Training.** At an LD Group Committee meeting, the group believed that *‘each GP surgery needs an LD champion to help with training, as some surgeries have little to no understanding of LD needs and issues’*.
- **Specialist care.** Another suggestion was that it would be very useful to have a specialist clinic once a month in the community for those with LD – where they could come for checks and to answer queries/worries with trusted staff that they grow to know and trust.
- **Health checks.** Several individuals suggested that for those that have had a cancer diagnosis – checks should be included as part of their annual health check – just a simple lump and bump check. Or teaching the patient (if possible) to look for lumps and bumps themselves. At present this isn’t included in the annual health check.
- **Reasonable adjustments.** When one group were asked to suggest what key things they thought would make services and care more accessible for those with LD, the following was listed:
  - Working with people they trust.
  - Having information in formats they understand.
  - Being given extra time for any appointments.

- Having time to ask questions or have information repeated.
- Knowing who to speak to about any worries or concerns.
- Explanations in ways they understand.
- Being listened to and having staff who are knowledgeable about the individual, their communication and their behaviour.

### Adults With LD - Key Observations

- Not all LD groups in Torbay were happy to engage on serious health issues like cancer. One organisation working closely with local LD networks explained that sometimes discussions like this are actively discouraged. Cancer in particular is associated with death and is therefore not talked about, so to avoid stress and upset.
- Engaging with adults with a LD required a tailored approach to engagement. For instance, focus groups usually had to be done as part of a series. We couldn't launch in with questions about support and information. In two instances we had to instead begin with a session explaining what cancer was.

### Detailed Themed Feedback from the Autism Community

During engagement we also had the opportunity to speak with individuals with an autism diagnosis. Whilst this was not one of our initial project target groups, we felt it was important to note the findings here, given the feedback highlighted that this community experience multiple access, care and support issues. The feedback below relates to adults with an autism diagnosis who are therefore not Learning Disabled.

#### Adults With Autism – Access

- **Primary healthcare.** At a group meeting, all discussions focused on the inaccessibility of primary healthcare and issues with trust in the system. Some members who wished to be tested for autism felt *'fobbed off'* at not being able to, stating that GPs discouraged them to get tested due to various reasons such as *'long waiting times'* or because they *'were too old'*. In addition, the group reported instances where they'd approached their GP for help and felt as though they *'were a nuisance or being patronised'*.
- **Social care.** Several individuals expressed concern about the long waiting times for social care reviews – we're currently *'three years behind in Torbay'*. Another individual highlighted that there was *'only one social worker in Torbay with a specialism in autism and that this causes long delays and frustration in community.'*
- **Annual health checks.** An Autism support group highlighted that the new National Strategy for People with Autism details that all those with autism should also get access to an annual health check, but the group reported that this isn't currently happening locally.
- **Mental health.** At a group meeting concerns were expressed around the long waits for mental health support in Torbay – *'currently at 4 years'*, with some members reporting being actively discouraged by GPs to seek mental health support because of these wait times. The group felt as though *'nothing has changed'* in health or social care locally

since the release of the children, young people, and adult autism strategy in 2021 and *'if anything, mental health support has gotten worse'*. Some members also said that they had only ever been offered CBT – but this is well known to not be very effective for those with autism.

### Adults With Autism – Care

- **Misdiagnosis.** Several individuals highlighted issues with misdiagnosis in the autism community. At a focus group session, half of the participants had previously been diagnosed with unstable personality disorder before being diagnosed with autism. They explained it's then *'a battle to get the previous misdiagnosis removed from your medical notes'*.
- **Early diagnosis – cancer.** When discussing issues with early cancer diagnosis at a focus group session, it was highlighted that due to processing issues those with an autism diagnosis tend to put things off/put up with symptoms for much longer before accessing help. Many are also not aware of their own body/changes. The group felt that this made it easier for GPs and medical professionals to *'fob them off'*.
- **Medical notes.** One group reported recurring issues with medical notes – they find themselves having to repeat their story and argue repetitively for reasonable adjustments in medical/health settings as their autism diagnosis and needs are not recorded.
- **Awareness of autistic needs -** We had several reports of those with an autism diagnosis being given healthcare information in an easy read format. This is not appropriate and is off-putting to those with autism.
- **Reasonable adjustments.** An organisation working locally with the autistic community also highlighted that people with autism often have issues with touch - which can cause big issues with screening. Cervical screening was given as an example. The group stated that *'there doesn't seem to be any extra help or support to ensure those with autism still attend these screenings'*. The organisation also highlighted issues with hyper and hypo sensitivity to pain and pain threshold differences in people with autism. They don't feel as though these issues are understood by GPs or other health professionals, which causes problems with vaccines and administering medication.

### Adults With Autism – Suggestions

We received several suggestions for how to improve access and support from individuals and organisations within this community.

- **Reasonable adjustments in primary healthcare.** It was suggested that GP surgeries need several routes of contact, as well as several times when patients can get in touch with them, as those with autism can find it difficult to contact the GP at 8am for an appointment.
- **Alternative pain scale.** One group explained that many people with autism find it difficult to describe their pain and where it is coming from – they suggested that an alternative pain scale model should be developed for those with autism to use in all care settings.

# Detailed Wider Engagement Findings

Given the mixed method nature of the project, we received lots of feedback from Torbay residents who had been impacted by cancer, but did not fall into one of our target groups. It was decided that this feedback elicited some important themes and was particularly useful when presented in comparison to the target group feedback. Therefore, the data in this next section represents the views of the wider public in Torbay around cancer care and support, and not the project target groups. Those with a cancer experience who could be identified as belonging to one of the afore mentioned target groups are highlighted in the previous report section.

The feedback in this section has come from a mix of sources, including the online survey (in which **104** local people shared their experiences of being impacted by cancer), informal interviews, cancer café events, and community event drop-ins. It is important to note that not all of those spoken to had experienced a cancer diagnosis themselves. Whilst the majority had, this section also encompasses the experiences of those who have been impacted the diagnosis of a friend, family member, loved one, or someone they care for.

## How we analysed data

The data from this wider engagement was initially segmented by demographic detail (to look for differences in age, area, gender etc.) and then collated and themed. After an initial read-through of all responses, it was clear that five key themes were prevalent throughout the wider engagement:

**Theme 1 – issues with finding appropriate support locally**

**Theme 2 – mixed experiences for those who have managed to access support**

**Theme 3 – lack of cancer-specific community-based support in Torbay**

**Theme 4 – strong preference for in-person cancer support**

**Theme 5 – positive experiences whilst undergoing treatment locally**

All wider engagement data was examined using these themes as tags to identify trends, ideas or patterns from what Torbay residents had told us. These themes are presented in greater detail on the following pages.

**Please Note:** Any commentary is included as verbatim in *italic* to illustrate the themes identified from the data analysis. Not all comments are included, and some relate to more than one theme.

## Theme 1 – issues with finding appropriate support locally

Results across all engagement methods indicated that local people have had difficulty with identifying or accessing cancer support services in general Torbay. In some instances, this was because of a lack of signposting, in others there was no relevant support offer available locally.

We were able to filter the survey data by age, ethnicity, disability, and residential area. Disability and residential postcode were the only two that observably affected these results. Of those who defined themselves as having some type of disability, 35% stated they are not able to access support needed, compared with 23% of people who defined themselves as non-disabled. The results of the survey also suggested that those who live in a more socio-economically deprived postcode in Torbay<sup>1</sup> are less likely to be able to access the support they need; 47% of responses from postcodes in more deprived areas felt as though they were adequately able to access support compared with 68% of people not in a deprived postcode area.

### We had several people tell us they couldn't find any support in Torbay:

*'It was difficult to find any support'*

*'[a] Facebook group is all I have found [for support]'*

*'Something for my daughter. There was no support for her as a child'*

*'Most of the time I just needed someone to come to the home and see my sister. I knew there was problems, and I kept telling various people but no help'*

*'There was no support when we needed it, at the weekend and late at night'*

*'[As a family we] very much felt on our own'.*

*'[when treatment had ended it was] like walking out of the door and nothing was there'.*

### Some told us they turned to hospital staff for support:

*'I haven't had any support apart from my wife and [the] care of oncology clinic in London which we pay for'*

*'[only support available was] the urology cancer nurses for some advice over the phone.'*

### Some told us they struggled to access the right type of support:

*'I have tried multiple times, in multiple ways to access pre-bereavement support'*

*'Pre-bereavement support. It has been, so far, impossible to access any support.'*

Two separate families told us that finding support *'at the right time' in their journey was difficult. Straight after diagnosis is not always the best time.*

One lady explained she had used the Macmillan Lodge for support but was signposted here straight after diagnosis. She felt it wasn't the right time; the last thing you want at that point is to *'be sitting in a room full of upset people'.*

*'It would have been helpful to have a navigator as sometimes you don't know where to start and you don't know whether the service is right for you'.*

One individual felt *'the level of support in Torbay depends on what type of cancer you have'.* She explained that she had a cervical cancer diagnosis and felt *'very alone'* in her journey. Despite searching for support in person and online, she has been unable to find anything.

<sup>1</sup> As defined by the Torbay 2023-2024 JSNA

## Theme 2 – mixed experiences for those who have managed to access support

Of those who had managed to access support services mixed experiences were reported. Whilst some found services very useful, others felt the current offer did not meet their needs. This seemed to apply to both local support structures and national ones (accessed online or via phone).

For example, we had a selection of positive feedback:

*'I've been using Macmillan and I'm still using them, they're amazing, I don't know where I'd be without them. I have my own lady peer who I go to see to talk to about what I've been through and going through and she's brilliant.'*

*'Cancer Lifeline South West were life changing. [The] hospital saved my life physically. This charity saved the rest of me and put me and my young family back together.'*

*'Force Cancer in Exeter has been amazing. I have accessed their services, and they couldn't be more supportive.'*

*'Lymphoma Action's information was incredibly helpful'*

*'I used the support in Newton Road [the Macmillan Lodge] for getting financial advice. They were very helpful and practical - this was my biggest worry while I was off work for 13 months'*

*'I received support from Macmillan and from myeloma.org. Both were informative and easy to access'*

*'Macmillan nurses absolutely fabulous I could discuss anything'*

*'The Rowcroft staff were fantastic...we felt secure once they were there...if it weren't for the experienced Rowcroft staff we wouldn't have known when that vital time to say goodbye was'*

One gentleman explained that Rowcroft counselling support for bereaved family members had been useful due to *'not having a time limit'*. Different family members had accessed it months and years apart.

We also had a selection of negative feedback in this area:

*'I did call Macmillan a couple of times in desperation, but they weren't really helpful'*

*'My husband was supposed to be supported by Macmillan and Rowcroft but it was woefully inadequate'*

*'I tried to access cancer support from Rowcroft Hospice for some palliative care, but all they offered was foot massage for her'*

*'Counselling post treatment was required but took too long to start - I had sorted my own feelings by then so felt I was wasting my time and theirs'*

*'The [Macmillan] Lodge was only able to help on a one-off basis. I always thought Macmillan would be more engaged and signpost/help with contact and appointments that would be useful'*

### Theme 3 – lack of cancer-specific community-based support in Torbay

Out of all wider engagement responses only a couple of people mentioned accessing community-based cancer support in Torbay.

This does not seem to be a signposting issue. The results of the mapping exercise (see page 14) corroborate that there are only two community-based cancer-specific support groups in Torbay; the Breast Cancer Now support group and Torbay Prostate Support Association. There is a Swallows Head & Neck Cancer Support Group in Newton Abbot, but this falls just outside of Torbay.

When asking people what sort of support would be or would have been helpful, many spoke about the relevance of the community-based support on offer locally. A consensus emerged that if community-based support was available it would need to be tailored specifically to those who had experienced cancer (e.g. not other health issues). Those who had been impacted by cancer told us that they had struggled to find cancer-specific support in the community for themselves, children, and loved ones impacted by the diagnosis. An example of this; at a cancer café listening event we were told by several people that they would value community support specifically for cancer. There was a consensus that it would be difficult to have one for every cancer but felt that even a *'general cancer'* support group in Torbay would be useful. Unfortunately there were no detailed quotes to include in this section.

### Theme 4 – a strong preference for in-person support

Across all wider engagement methods there was consensus that in-person support was or would be most welcome. The results of the survey clearly indicated that there was a strong preference towards in-person support across all demographics. There were no discernible differences between age, location and disability. 75% of those who answered the question asking them to rank support preference ranked 'in-person' as their preferred way to access support. In later free text questions where participants were invited to share more information about which type of support would be most useful, in-person support was the most frequently mentioned.

Examples of this:

*'In person, someone to contact me to offer me emotional support, even 4 years later'*

*'In-person support would have been so helpful for my mum'*

*'In-person cancer support group support [was missing]'.*

In conversations about types of in-person support, peer support came out as a strong theme. Many mentioned that they would value being able to speak to someone locally who had gone through/was going through a similar journey.

Examples of this:

*'Speaking to someone else who had fought and come out the other side well would have given me more hope and something to aim for'*

*'Coffee morning support groups for people with cancer or recovering. Somewhere to go with people facing the same journey as you'*

*'Face to face peer support groups [would be useful]'*

*'Meeting people same as you with cancer'*

*'Peer support and/or buddy system would still be good ...I'd value someone to talk to with a similar story'*

*'I was in my 30's and [there was] nothing for us youngsters with young families. People were lovely but I was at a different life stage and had different support needs. I would have liked to have met other mums with cancer. Though obviously also wouldn't!'*

Opinions varied on what would be important to consider with peer-support models. One individual explained they'd reached out to Force in Exeter to see if they could 'pair' them with someone who had received a similar diagnosis for peer support. Whilst at cancer café event it was suggested by several that being 'paired' with a person a similar age was more important than similar cancer-type. It was explained that they'd met a lot of older people with a similar cancer diagnosis, but *'they are thinking very differently...[whereas] we need to think about getting back to and on with work, life, childcare'*.

We also had several people saying they'd be very keen to volunteer to be a peer supporter themselves.

## Theme 5 – positive experiences whilst undergoing treatment locally

Although the focus of our engagement here was around support structures, we inevitably also had lots of feedback relating to medical treatment and support received at hospital. This feedback was largely positive and encompassed a wide range of services delivered by Torbay and South Devon NHS Foundation Trust.

For example:

*[I was] 'well supported from operation to end of radiotherapy, thanks everybody'*

*'All the care from my surgery - Corner Place - right through to the Gastroenterology unit, Allerton ward and now Oncology have been brilliant'*

*'I accessed Breast Care and all tests completed on time. I cannot fault the timely treatment I had. I live in Torquay and was able to access all treatment at Torbay hospital and Mount Stuart Hospital'*

*'Oncology dept/Ricky Grant unit, all information given to me at diagnosis. No problems at all, 24/7 helpline, I live 4 miles away from hospital. Parking is free. Macmillan support and information and The Lodge, all the care from my surgery Corner Place, right through to the Gastroenterology unit, Allerton ward and now Oncology have been brilliant'*

*'The district nurses who came out to care for my wife were incredible'*

One gentleman was treated for mouth cancer at Torbay. He recounted the hospital treatment and support *'were excellent'*; *'the medical teams around me offered all the support I needed'*.



# Learning from Project Engagement

The following section summarises the project team's main learning points across the two engagement workstreams, as well as across both target group and wider Torbay community engagement.

## Engagement fatigue

Engagement fatigue was a recurring issue throughout this project. Individuals and community groups frequently expressed feelings to apathy and exasperation; a general feeling of *nothing changes so what's the point*. Many told us they'd shared their experiences multiple times already and seen little to no change. This was particularly prevalent with the target groups. Early on in engagement we were told by multiple organisations working with target groups that they are subject to engagement requests like ours every couple of months. For this reason, many would not engage as they felt like these repetitive requests not only disrupted their ability to offer regular support to their service users, but also risked reputational damage for themselves. We had frequent challenges to proving how and where the project would make tangible impact and improvement in Torbay.

## Issues with local healthcare landscape

The most prevalent theme across both the wider public and target group engagement was issues with primary care access. We heard hundreds of stories about Torbay residents feeling as though their GP wasn't accessible or wasn't able to help. Across all groups GPs were seen as the go-to trusted destination for help with cancer signs and/or symptoms. However, during engagement we came across multiple people who presented with a concerning sign and/or symptom (i.e. an angry looking mole or lump), but were either struggling to get hold of their GP or were unwilling to try until they deemed the situation an emergency. Because of the widespread prevalence of this issue in Torbay, the issues with accessing primary care tended to dominate conversations during engagement, and it was often difficult to try exploring other topics (e.g. support structures) with participants.

For those with a cancer experience, many were hesitant to give their experience on support, explaining they were more concerned with their diagnosis and treatment staying on time, without cancelled appointments or delayed interventions. There was an acute understanding of the pressure the NHS is under, and a deep concern that this was or is affecting their treatment. Many didn't feel they had the time or capacity to think about support, only their treatment.

## Target group approach

Early in the project it became clear that solely focusing on capturing the experiences of those in the target groups could be problematic. Firstly, by taking this prescriptive approach and focusing engagement only on organisations/venues working with these target groups,

we in fact risked missing some target group voices that may be isolated, or even imbedded in community structures or organisations not demographically focused. Secondly, this approach risked ignoring the opportunity to draw important comparisons with the experiences of the wider Torbay public affected by cancer. For instance, we would not be able to understand if issues such as primary healthcare access or lack of community support were felt by just one target community or were more widespread across all Torbay communities. For this reason, the decision was made that some methods would capture Torbay-wide experiences (e.g. the survey and community events) whilst others would target particular groups (e.g. community drop-ins and focus groups).

### **Collaboration and capacity**

On inception it was envisioned that this project would work collaboratively with local organisations and community groups to co-host focus groups and guided conversations. After several months of conversations with said community groups and community leaders it became clear that such an approach in Torbay is untenable for many. Whilst this project had the capacity to fund the co-hosted work, many leaders explained that time and capacity would not allow. Many (particularly those working with the target groups) have been overwhelmed with engagement requests like ours in recent years, and the combination of reduced staff and increased workloads have left little time or capacity to engage.

When this project was devised it was also envisaged that Torbay's Community Builder team would play a large role in engaging with the project's target communities, running co-hosted focus groups and interviews. However, feedback from the team highlighted issues with both capacity and subject matter. Several Community Builders fed back that the groups they worked with were not comfortable engaging around the subject of cancer.

### **Relationships and sustainability**

Cancer is a delicate subject and finding individuals and groups willing to recount emotional stories and share very personal experiences with us took a considerable amount of time. Whilst the survey was able to quickly collate some stories, gathering detailed qualitative experiences from individuals often took a couple of engagement attempts. Once this trust and relationship had been established individuals tended to express a want to keep the relationship going (i.e. be kept in the loop as to what this project was doing and how their contribution had made an impact). The report will be shared with all those involved, however given the two-year time restraint of the project it was difficult to promise any other tangible outcome and sustained relationship with individuals. It similarly took time to build rapport and trust with organisations. Dissolving the project after two years, with no tangible way of ensuring legacy for those involved, risks eroding trust and enhancing the feeling of engagement fatigue mentioned earlier.

# Co-Design and Co-Production

One of the main aims of this project was to initiate co-designed solutions to some of the key issues raised by the target groups we engaged with in Torbay. Partner organisation, Torbay Communities, led on this co-design aspect and wrote this next section of the report detailing the co-production/co-design activities carried.

## Introduction

The work we were able to undertake with the LD community provided the best platform for embarking on a co-design process. Specific sessions with Ukrainian refugees and people from an area of deprivation provided insights which highlighted the complexity of navigating the UK Health system. Although these barriers do impact on a person's cancer journey, we felt the main issues for people related to systematic NHS and healthcare problems, which wouldn't be adequately addressed at a community or co-design level to take people through a full co-design process. Engagement with LGBT+ groups didn't identify a suitable user group to start the co-design process. The process, findings and recommendations for each group are described below.

## Learning Disabilities

We worked with two groups - the LD Ambassadors and an LD group supported by Turning Heads CIC – to co-design ways to improve identifying and communicating signs and symptoms of cancer for the LD community.

### 1. LD Ambassadors

Learning Disability Partnership Board Ambassadors (LD Ambassadors) are people of experience who meet regularly to share things which people with learning disabilities are talking about and may need help with. They also check that work is being done as agreed by relevant organisations. The Ambassadors give people with learning disabilities a voice in Torbay. For the co-design process we met with 8 of the Ambassadors over a 4-month period in 2023/24. This included four co-design workshops with 5-8 people attending each session. Dr Rachel Gaywood the LD lead 'champion' for Torbay Surgeries has been involved in guiding this codesign process.

### 2. Turning Heads CIC

Turning Heads is a community interest company helping to build a community that values and empowers togetherness. They work with people and organisations across Torbay including families, children, people with learning disabilities, those who are furthest from employment and education and those who might be isolated or vulnerable. Turning Heads runs day activities from The Windmill Centre in Hele (Torquay), a Community Kitchen and

Social Supermarket from Victoria Park Methodist Church in Plainmoor (Torquay) and a Skills Centre at Windsor House in Lime Avenue (Torquay). We held four initial meetings with staff and the directors of Turning Heads where we decided how we would work with LD people who attended day services at the Windmill Day Centre and the Skills Centre. We benefited from insights from some of the staff who are people of experience. We held four sessions covering how we might raise awareness of cancer in the LD community and an open session at the Centre. On average 60 people attend the Day Centre.

## Double-diamond Co-design Process

### DISCOVER:

The themes that emerged related to how people might be aware of and identify generic signs and symptoms of cancer; and how they could communicate this to a health professional, advocate or family and friends. In between the co-design sessions participants took their ideas to the wider LD groups / people, family and friends to further explore the themes. Each session started with a review of feedback and led to suggestions and solutions that that could become part of a design process. Jess Slade led the sessions with support from Turning Heads Manager Alan Tilley and Jo Morgan - who facilitates the LD Ambassador meetings. Jo was key to the process as she is trusted by the Ambassadors and was able to interpret questions for participants.

DEFINE & DEVELOP: The solutions were defined and developed as:

#### 1. Developed with Turning Heads

**Calendar showing signs and symptoms for the top 12 most commonly diagnosed cancers in our locality:** The idea for the calendar came from a comment – ‘why is it not on the calendar?’ It is common practice for people of experience to have a wall calendar showing what is happening today for them – it helps them plan and organise their day. The co-design process refined the concept to – an A3 format calendar, large enough to write on, with easy-read descriptions, appropriate fonts, clear diagrams covering one form of cancer each month; and the look and feel of the calendar, including a QR code directing people to the Macmillan website for more detailed information. Macmillan branding and logos feature.

**Posters of the 12 most commonly diagnosed cancers in our locality:** These have been designed to use in Doctor’s Surgeries and other community Venues which support people with LD locally here in Torbay. We have designed them to mirror the advice and design of the calendar and will be distributing these with the hope that someone at each venue will change each month i.e. January, February, March etc. They have also been printed in a durable material so they can be reused year on year to help raise awareness on an ongoing basis.

## 2. LD Ambassadors

**Common Symptoms of Cancer:** Signs and symptoms sheet / guide that can be taken to a consultation, or shared with family and friends where an individual can see highlighted what the common signs and symptoms are and where that might be hurting clearly indicated on the body. These were designed to be durable so it could be used long term and not thrown out.

**How are you feeling:** Participants wanted to have a simple clear sheet showing a human body that someone can mark-up, write on or point to, a place where you add your own notes, with basic emojis as well to clarify communication, be in easy read, with a clear and appropriate sized font. They wanted it on paper so they, or a representative, could write on it and take it to appointments. They asked that there would be multiple copies of this to go with the Common Symptoms Sheet Example: A 'how are you feeling?' sheet for each Doctor's appointment they attend. During the co-design process we identified that LD people need a way to record symptoms as they are happening that is easy and available.

A double sided A3 to A7 folded version of the Common Symptoms of Cancer and the How are you feeling sheets has also been designed to be available in doctor's surgeries and LD community settings for people to pick up and take home.

**Simplified health check guide for GPs / consultants / practice nurses:** that has key questions to ask for signs and symptoms of cancer suitable for communicating with an LD person.

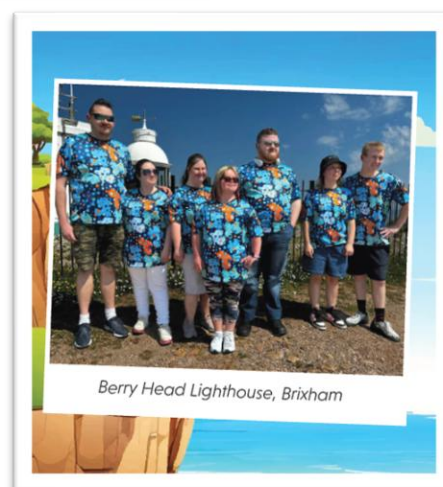
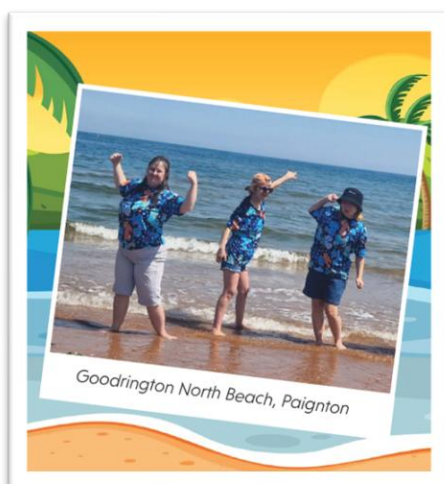
Both groups felt it was important that each person needs to also get the sheets with the calendar and the printed material would prompt conversations among the LD community as well as carers, family and friends.

### DELIVER:

#### Turning Heads:

Over two one-hour sessions the group participants agreed on who would be models for photos in the calendar, what would be the theme of each photo, suitable locations, appropriate backdrops, and a diagram of the body to show the location of the cancer. Example: People on the beach for the month highlighting skin cancer.

**The shoot:** Photography sites chosen covered Brixham, Paignton and Torbay and models wore matching T-shirts. The group chose the style of matching T-shirts. We completed two full days of photo sessions and models chose how they wanted to demonstrate symptoms. Example: 'How would I show that I had a headache.' Selected pictures from this shoot are on the next page.



**Wording:** We did three full days with the group to establish suitable wording for the twelve cancer themes. Sessions had 8 -10 people, and they were asked to ‘state clearly what they thought.’ To hold people’s attention, we did half-hour sessions, with a good break in between for them to do some fun activities (crafts, baking etc.).

**Final design:** We did two days reviewing draft designs to hear feedback, make changes and finalise details. The group have signed off on the final designs. Matt Saunders prepared all the artwork ready for printing.

**Communication and distribution:** Suggestions of 500 to be printed for the groups and a set of posters for all Doctor’s Surgeries and identified Community Hubs for LD. We are discussing with stakeholders how to get the calendars to LD who need them. They will be given out to people who attend Turning Heads, the Ambassadors group, and to carers of people with LD. We can also make them downloadable from relevant websites.

## 2. LD Ambassadors

**Font:** FS Me font (similar to Mangal Pro) for easy read and print developed by Mencap.

**Other Groups:** During conversations with the LD group, participants felt it was important to design the document to be disability friendly for other groups and wanted to encourage anyone to use the sheets if it was useful for them for wider distribution. Example: sight impairment and looking at particular fonts which were easier for all to read. Black lettering on yellow background was chosen to assist visually impaired people.

## Codesign Insights

Jess Slade led the co-design process linking in with the engagement work delivered by Abi Gascoyne and the ECSW team. The process was reviewed on a regular basis with the advisory group.

**Relationship building:** It takes time to build trusted relationships with people of experience that will enable to fully enter into the co-design process. This means that the engagement work has to reach a certain momentum before we could start the co-design process. People have to be ready to share for this project to work. Working with existing LD groups and Ukrainian Refugees enabled the process to start.

**Common barriers:** it was difficult to identify common barriers to accessing cancer information and care from the first case studies. This required a deeper conversation and gathering of in-depth personal stories to establish what the common barriers might be so that a group co-design process could be developed.

**Partner working:** it was important to understand each delivery partners' role and were engagement work and co-design cross over.

**Meaningful change:** for people to enter into a co-design process they need to feel that their contribution will be valued and will lead to change. Some of the larger systematic issues faced by the medical system consistently appeared as barriers for people to access information or cancer care but couldn't be addressed meaningfully as part of a co-design process – because we were unable to enable change in those areas. Example: finding a temporary solution as a work around for a fundamental resourcing and capacity issue, will generally not lead to a meaningful or sustainable solution.

**Energy:** It is important to go with the energy. The LD Ambassadors and Turning Heads Charity were keen to make a difference, so it allowed us to focus that energy on things we could improve.

**Recommendation for further exploration - what would be useful to cover in a call back from a cancer professional straight after diagnosis. There would be potential for co-designing a check list to include certain prompts.**

## Co-design Considerations & Findings

**Working alongside ECSW:** although we conceived the project as working from engagement, building relationships, running focus groups, recording individual stories and then establish groups that wanted to work on co-design – the project wasn't linear and co-design came about through existing relationships as well as through the engagement strand of the project.

**Working from a place of trusted relationships:** we run training for Healthy Ageing Live Longer Better. Because we have built up trusted relationships over a number of months, participants who have had cancer felt more open to discuss their illness, treatment, access and experience of cancer services.

**Collaboration:** One of the big advantages of working with Healthwatch is they can make wider recommendations on health system related issues. Torbay Communities have experience with double diamond co-design and also have a good reach into the community through our Community Builder team, Community Connectors, and with ECSW, the Torbay Community Helpline.

**Reflective conversations:** For the engagement work it is important to have skills in holding personalised / holistic conversations rather than opening up with direct questions on cancer or people's experience of cancer.

**Engagement:** The engagement work focused more on people with cancer. For these people accessing the basic health care they felt they needed, getting appointments with GPs, consultants and specialists, getting treatments and surgery was more of a priority for them than being able to identify a need for peer support or taking part in co-design to improve system delivery.

**Co-design:** The co-design work primarily worked with people to improve ways to communicate signs and symptoms. Most of these people did not have cancer.

**Targeting minority groups:** The demographics in Torbay mean that some of the target groups don't have regular support or group representation on health and wellbeing issues. This meant we ended up interviewing people who came forward who had important insights to share, but were not in the target groups. It was hard to interview people knowing their information may not make a difference.

**Support for the project:** There seemed a lack of referrals from GP's, the Lodge and other medical staff, who have the information of those in the target groups who are currently accessing Cancer Services and Support.

The process has already made all the participants more aware of the signs and symptoms of cancer and also demonstrated that it is OK to talk about illness. The people that have engaged in the process also share their knowledge and awareness with others and know why it is important to check. When they hand out calendars to people, they can explain why the calendars are useful.



## Co-design Recommendations

**What will happen in subsequent years?** To stay relevant for people a new calendar would need to be created annually, the guide and form updated if required, and distribution to relevant groups coordinated.

**Recommendation:** There would need to be future resourcing to coordinate the development, continuation and distribution of calendars and forms. We see the potential to develop an even easier form with stickers / stamps / magnets showing smiley faces and unhappy faces that would indicate what hurt or was uncomfortable.

**Availability:** Some LD will not have a carer or family or friends to help interpret signs and symptoms, so having these resources available to GPs, consultants and practice nurses is also important.

**Recommendation:** ensure distribution to relevant professionals. It would be easy for GP surgeries to display a calendar in reception / waiting rooms and show the forms on a video monitor in waiting rooms.

**Participants:** The people involved in this co-design tended toward high functioning and were relatively independent, so the outcomes may not be truly representative for people with more complex disabilities or people who require a carer, etc.

**Recommendation:** this could be assessed in a further co-design process with a different group.

**Reflective conversations:** Cancer is a sensitive subject for people, so it is crucial the people undertaking similar studies are aware of the best way to engage people in those conversations.

**Recommendation:** ensure appropriate training is in place for people carrying out similar studies.

**Guides:** The Macmillan Easy Read Guide What is 'Cancer' is 18 pages and daunting for some people to consider looking through.

**Recommendation:** Macmillan create a 2-page simplified version as a supplement to the longer version that is easy to read, with clear diagrams showing what to do locally if certain symptoms are affecting you. It was clear in our co-design process that local information needs to be added to guides on signs and symptoms. If this is connected it will help people to navigate to the right health professional / service.

**Macmillan QR codes:** You can scan the codes for more detailed information on types of cancer, but these versions are not all in an easy read format.

**Recommendation:** create easy read versions accessible by QR codes.

**Health System:** Many of the issues, challenges and barriers faced by the people we engaged with are also identified by the general public. Example: We are not in a position to influence the process for someone with LD getting a GP appointment, or an annual check – yet improving this process may have a marked impact on health outcomes for that person.

**Recommendation:** The recommendations that have come from this work would apply to other parts of the Health System, not just cancer services or the work of Macmillan – as a way to help identify symptoms. Equally, simplified versions developed by the LD community in Torbay may be of value to the general public and health professionals.

**Macmillan Cancer Support information line:** The answer phone message lists signs and symptoms, but doesn't provide you information for who to contact, or where to go.

**Recommendation:** develop a communications plan that delivers localised information to each area.

**Online information:** navigating online services remains a barrier for a range of people.

**Recommendation:** ensure communications strategies have more than one media option for delivering information, guidance and directions.

**Community Engagement:** When carrying out engagement, consultations and co-design processes with user groups it is important to identify what can be influenced, and explain that to participants, because both ECSW and TC's are aware of engagement fatigue from people in the community who do get asked for their feedback / opinions, often as a tick box exercise when decisions on services and resourcing have already been made; and they often don't get to feel or see improvements to service provision – leading to – 'why should I bother – it won't change things'.

**Recommendation:** It has been important in this project to make things fun and creative for participants to hold their attention, knowing that they can help make improvements and to have tangible results to show people (in this case printed resources). This helps to energise their desire for change, acknowledges their voice has been heard and shows that action has been taken.

**Co-design:** seeing it as a tool to initiate change in the culture of an organisation.

**Recommendation:** Rather than seeing co-design as a one-off project to solve a specific issue, we feel it is better to see co-design as an ongoing opportunity to build relationships with clients and shift the culture of an organisation. In our experience the best co-design outcomes come from a process that is integrated into an organisation's delivery plan. This allows organisations to maintain a dialogue with their client base and develop meaningful relationships with users that allows them to contribute to improvements, it builds trust and creates a culture (staff, management, volunteers, clients and partner organisations) of dynamic responsiveness to meet changing needs. This takes time and resourcing. Usually, 3-5 years to start to see the impacts, respond to the impacts and improve procedures. Having design products like the calendar, guide and form are something tangible that can act as a prompt between project participants and other people in the community.

**Form:** Feedback from participants were that annual checks were not as consistent or detailed as would be expected.

**Recommendation:** the simplified form / guide could be used by GPs as part of an annual check.

**GP appointments:** Feedback was that you are only allowed to talk about one thing / issue / symptom – or what hurts in a GP consultation. Feedback from some of the group also showed they were unsure what questions to ask of a GP.

**Recommendation:** it would help some people if GPs were aware they are about to consult with a LD person and then for them to be clear on what the consultation may involve.

**Form:** The form and guide can be the beginning of a conversation – 'let's fill one in together'.

**Recommendation:** GPs can print a spare and give it to the client – the person can then fill-in at home next to the calendar.

**GP Surgeries:** How do we enable surgeries to use these resources both now and in the future?

**Recommendation:** Advocation from the LD community, the GP lead for LD, Macmillan Cancer Services, The Lodge and other stakeholders.

**Awareness of time periods:** Recalling how much time has passed or the time of key events was not strong for some of the LD participants. ‘I can’t remember the last time I was here.’

**Recommendation:** the form offers a GP a record they can start a conversation and then review. It is something they can have available at home and make a record at a time when they notice how their body feels.

**Making resources available through Apps:**

**Recommendation:** Resources created could be shared through the NHS app or Connect Plus. (Not all GP surgeries access the NHS app).

**Evaluation:** So far everyone is giving positive feedback for the designs. But they are only just designed – so we are half way through a Double Diamond Co-design process. Ideally it would be good to talk to GPs, clients, staff, carers, volunteers, families over the coming year.

**Recommendation:** Impact report carried out by Turning Heads and the LD Ambassadors after 6 months and then a year – resources from this allocation held over to cover costs (c£1000)

## Overall recommendations from co-design work

**Impact:** it would make sense to go back to the co-design groups in a year and find out if there had been any changes in their experience or situation. Example: had the GP used the co-designed How are you feeling sheet / Common Signs and Symptoms sheet in their annual check-up, did the person find the information clearer from the GP, did the GP find it useful, etc.?

**Relationships:** the process of co-design builds relationships with users in the community – can we find ways for Macmillan to continue to develop those relationships – if so who and how? There would be potential for Jess to train Macmillan staff who work locally in some of the relationship building / co-design techniques.

**Continue with engagement and co-design process when wanting to ensure users have a voice:** We see a lot of survey / engagement fatigue from communities where they are asked to contribute but then the relationship ends, and they can be unaware then of the impacts or benefits of their contribution. Further, everyone seems to be working at capacity, so taking time out to feedback or enter a co-design process, especially for someone with cancer trying to ensure they can access basic treatments, is not a high priority for people.

**Ripple effects:** even if not recorded or identified we perceive that there will likely be ripple effects from this work. Example: an LD Ambassador has a signs and symptoms calendar on their wall, it is viewed by a plumber and they decide to go to the GP to have a check.

**Reprint calendars yearly:** we would need to identify who would resource and manage this.

**Dissemination of learning:** the learning from this process could be invaluable across the UK and also relate to identifying signs and symptoms for a range of health conditions. How would we make these resources available? Healthwatch / ECSW have a range of health-related projects and Torbay Communities run a Healthy Ageing programme.

**Minority groups:** on the theme of cancer, not all minorities in Torbay have groups focusing on health and wellbeing. So, to identify and work with some individuals it may have been better to have had engaged with a broader range of the community as a way to then identify people facing minority barriers to information or treatment. This was recommended at the start of the project but we were told to only focus specifically on the four specified minority groups. Referrals to the project from places like The Lodge, GP Cancer Nurse, GO Surgeries etc. would also have helped us identify and work with more individuals.

## Co Design Queries

If you have any questions on codesign or queries for Torbay Communities please contact:

**Organisation: Torbay Communities**

**Phone number: 01803 212638**

**Email: [info@torbaycdt.org.uk](mailto:info@torbaycdt.org.uk)**

**Website URL: [www.torbaycommunities.com](http://www.torbaycommunities.com)**

**Registered Charity Number: 1140896**



Jess Slade (left) leading one of the co-design sessions with Turning Heads to produce the calendar.

# Key Recommendations & Next Steps

This section considers the overall learning and findings from both the engagement and co-design stages of this project and puts forward our key recommendations.

## 1. A more sustainable model of engagement is needed

Future engagement work needs to consider sustainable relationships. A two-year project which is unable to commit to future work risks heightening engagement fatigue in Torbay.

Given how prevalent this fatigue was felt across all Torbay communities, we quickly adapted the co-design element of this project to ensure the process delivered some tangible outcomes (e.g. the calendar, posters, and fold-out leaflets). However, the limited two-year length of the project has resulted in issues with ensuring these tangible outcomes will be implemented and have impact. It may also compromise the community relationships that have slowly been built over the duration of the project.

Further, the co-design approach does not lend itself well to time-limited work. Instead, it should be seen as a way of working that builds relationships slowly over time, creates trust, and allows meaningful change. For example, the calendar, leaflets and posters designed as part of this project should not be seen as an endpoint, but rather as the beginning of another phase of work that could be used to prompt more conversations between project participants and people in the community.

One possible way to alleviate exasperating engagement fatigue with this project would be to commit to working with the groups that carried out the co-design work in a years' time and measure the impact their work has had in Torbay. A commitment to ensuring the materials produced through co-design work are also available online once this project ceases would also help ensure some legacy for those involved.

## 2. All communities in Torbay would benefit from community-based cancer support

The findings from this project demonstrate there is a clear want for in-person cancer support in Torbay. There was particularly strong support for peer-support. A considerable legacy for this project would be to encourage resources be made available for the setting up and facilitation of in-person cancer support groups, and in-person cancer peer-support networks in Torbay. The VCSE sector in Torbay would be able to help facilitate this with additional resource.

## 3. A greater awareness of the impact primary healthcare access is having on residents

When so many in Torbay are struggling to access key primary care services it is difficult to have insightful conversations about cancer support or information. This report needs to be disseminated widely amongst health networks and key stakeholders in Torbay, including but not limited to Torbay and South Devon NHS Foundation Trust, NHS Devon, Torbay Council

and Healthwatch Torbay. We recommend that Healthwatch Torbay investigate some of the important issues raised here around accessing primary care services, particularly the issues raised by those more likely to experience health inequalities.

#### 4. Material which raises awareness of cancer signs and symptoms needs to be accessible in more ways than one.

We received lots of feedback in both the engagement and co-design stages from the LD community about the accessibility of awareness-raising material. Accessible information and advice were also raised as common issues for those whom English is not a first language in Torbay. We would strongly recommend Macmillan revisits their Easy Read documents and consider producing a simple leaflet that aims to raise awareness of cancer signs and/or symptoms within learning disability communities. This project has produced a version of this that could be adapted to disseminate across the UK. It would also be beneficial to have sections of the Macmillan website in an Easy Read format. Participants in this project requested QR codes be added to their co-designed work. Unfortunately, there were no Easy Read webpages on the Macmillan website that we could direct these QR codes to.

Similar work with cancer signs and/or symptom awareness material needs to be done at touchpoints and venues used by those for whom English is not a first language. This project has found that these touchpoints are not always easy to identify in Torbay, with some communities not having one at all. In these instances, we'd recommend that something akin to a cancer champion scheme be used.

## Recognition

Engaging Communities South West would like to thank everyone involved in the production of this report, particularly our partners Torbay Communities and Macmillan, and all the people in Torbay who shared their valuable feedback in this report.


### Special thanks to:


- Torbay LD Ambassadors
- Turning Heads CIC
- Torbay Prostate Support Association
- Dimensions for Autism
- Chinese Wellbeing Society
- Coffee Morning group at Devon Dumpling
- Imagine Torbay
- Ellacombe School
- Torquay Salvation Army
- Torbay Multicultural Group
- Mencap Torbay
- Coffee Morning group at Paignton Library
- Torbay Pride
- Intercom
- Ukrainian communities living in Torbay
- Knit & Natter at Churston Library
- Live Longer Better – Torquay, Paignton & Brixham groups
- Breast Cancer Now – Torbay support group
- Age UK Torbay


# Appendix

## 1. Example copy of the Survey

Macmillan Torbay Community Engagement Project - survey







**This survey is designed to collect information on the support services in Torbay people have accessed, or would have liked to have had access to. It is aimed at any Torbay resident who has been impacted by cancer. This includes, but is not limited to, anyone who has had a cancer diagnosis, anyone who has cared for someone with cancer, or anyone who has had a close friend or relative affected by cancer. The information you share with us will help us to spot trends and identify areas which need improvement in Torbay.**

**At the end we ask you to volunteer some personal information. This helps us to understand how different groups experience services and supports our focus on equality, diversity and inclusion. This information will not be used to identify you. All data will be held by Engaging Communities South West. To find out more about how we handle your information please email: [macmillan@engagingcommunitiessouthwest.org.uk](mailto:macmillan@engagingcommunitiessouthwest.org.uk).**

\* 1. Please tick which of the below applies to you:

- I have/have had a cancer diagnosis
- a close friend or family member has/has had a cancer diagnosis
- I have cared/am caring for someone with cancer
- Other (please specify)

Macmillan Torbay Community Engagement Project - survey

\* 2. Are you currently...

- receiving treatment
- post-treatment
- Other (please specify)



\* 3. Have you been able to access the support you need/needed?

- Yes  
 No  
 not sure

\* 4. Have you accessed support from any of the following? (tick all that apply)

- |   |   |
|---|---|
| <input type="checkbox"/> GP surgery                             | <input type="checkbox"/> social media cancer support groups                                 |
| <input type="checkbox"/> another medical professional           | <input type="checkbox"/> another support group (not cancer specific)                        |
| <input type="checkbox"/> community groups (not cancer specific) | <input type="checkbox"/> speaking to someone who has had a similar diagnosis (peer-support) |
| <input type="checkbox"/> online cancer support groups           | <input type="checkbox"/> cancer charities   |
| <input type="checkbox"/> in-person cancer support groups        | <input type="checkbox"/> I didn't/couldn't access any support                               |
| <input type="checkbox"/> Other (please specify)                 |   |

### Macmillan Torbay Community Engagement Project - survey

\* 5. Please could you tell us a bit about the support services you have used.

*e.g. Were they useful? Were they easy to find out about? Did you have any problems accessing them? Did you have to travel far?*

\* 6. What sort of support would you prefer or find most useful? Or what support was missing that would have been helpful?

*e.g. In-person instead of online support; cancer-specific support or non-cancer specific support; support closer to home*

\* 7. How would you prefer to access support? (please rank the options below, with 1 being most preferred and 3 the least)

- in-person  
 online  
 telephone

**\* 8. How did you find out the support available? (please tick all that apply)**

- |   |  |
|---|--|
| <input type="checkbox"/> my GP  | <input type="checkbox"/> TV adverts                                    |
| <input type="checkbox"/> hospital staff                                 | <input type="checkbox"/> friends/family                                |
| <input type="checkbox"/> another medical professional                   | <input type="checkbox"/> word of mouth                                 |
| <input type="checkbox"/> internet (e.g. social media or online adverts) | <input type="checkbox"/> I didn't find out about any available support |
| <input type="checkbox"/> printed adverts                                |  |
| <input type="checkbox"/> Other (please specify)                         |  |

9. We'd love to keep you updated about our work in Torbay. Over the next couple of months we'll be running activities and workshops looking at how we design better cancer support services in Torbay. We're always looking for Torbay residents who have been affected by cancer to get involved.

If you're happy for us to keep in touch about this work please leave your email address and/or phone number below:

**\* 10. What is your postcode?****\* 11. How old are you?**

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85+
- prefer not to say

16. if yes, what type of disability do you have (please tick all that apply)

- physical disability
- long-term health condition
- mental illness
- learning disability
- cognitive impairment
- visual impairment
- hearing impairment
- speech impairment
- Other (please specify)

\* 17. Do you have a religion or belief?

- Christian
- Muslim
- Hindu
- Sikh
- Jewish
- Buddhist
- no religion
- prefer not to say
- Other (please specify)

18. do you have a disability:

- Yes
- No
- prefer not to say

## 2. Example copy of the Focus Group Template

*Please use this form to record what has been discussed and the information you have gathered. This form is intended for collating information on how communities in Torbay access cancer information and advice. Those spoken to do not need to have experience with cancer.*

*Please add pages or expand the boxes where more space is required.*

<p><b>Time, date &amp; place of feedback</b></p>
<p><b>Demographic information</b> <i>(e.g. individual or group feedback, age/gender/postcode, does the person/people fall into one of four target communities?)</i></p>
<p><b>Where would you go to seek information about your health?</b> Prompts: <i>Who would you speak to first? Friend/family/clinician? Why would you seek help here first?</i></p>
<p><b>Where would you look to find information on the signs and symptoms of cancer?</b> Prompts: <i>Have you looked for information? How easy was it to find and follow? Who would you speak to first? Friend/family/clinician? Why would you seek this help first?</i></p>
<p><b>What would help you be better informed on cancer signs and symptoms?</b> Prompts: <i>Leaflets/posters (printed information)? Websites (online information)?</i></p>
<p><b>Anything else discussed</b> <i>(if any other issues are raised in the session please record them here. We're keen to hear about any issues with access to information or services, or any ideas the group may have)</i></p>

*If anyone would like to hear more about the project, or get involved, we'd love to hear from them. Similarly, if anyone in the session has been impacted by cancer and are willing to share a bit more about their experience or get involved in our upcoming co-design workshops please take their contact details.*

### 3. Copy of Advisory Group Terms of Reference

#### 1. Project Background

The Macmillan Torbay Equity Project is a place-based and integrated approach to engaging with people affected by and living with cancer in the Torbay area. The project aims to understand more about health inequalities experienced in the local area and to co-produce solutions with the community. The project will run for two years, funded by Macmillan Cancer Support, and working in partnership with Engaging Communities South West and Torbay Community Development Trust. ECSW is a not-for profit organisation offering a range of services, including community voice, facilitation of engagement events, data capture and analysis, report writing, communication support, training and service/project evaluation and review. ECSW will be leading on phase one of the project, with support from TCDT. TCDT is the VCSE support agency for Torbay and leads on a number of partnership programmes using the asset-based principles of collaboration. TCDT will be leading on the co-design and intervention stages of the project in phase two, with the support of ECSW.

#### Core objectives:

- To carry out engagement with Torbay residents affected by cancer. Engagement will be broad, but emphasis will be placed on engaging with communities which are known to experience health inequalities in relation to cancer. For example; learning disabled, BAME, LGBTQ+, and socio-economically disadvantaged communities.
- To develop a better understanding of local needs and issues in relation to cancer, with a key focus on understanding how the groups outlined above experience health inequalities.
- To co-produce interventions with local communities to improve access to information and support for those affected by and living with cancer in Torbay.
- To collaborate with other organisations and individuals involved in community engagement and development locally, and raise awareness of the Macmillan project.

#### Implementation:

The project will take a phased implementation approach over two years:

1. Year one will focus on engagement, in order to develop understanding on the barriers to diagnosis, issues with support through treatment, and managing the impacts of cancer.
2. Year two will focus on asset-based community development work, to co-produce solutions with the community to the issues identified in year one.

#### Engagement:

The number of people diagnosed with cancer in Torbay and South Devon has increased 11% in the last 3 years (2017-2020) and numbers are expected to continue to increase. For this reason engagement will be broad. However, research also tells us that some groups in particular experience health inequalities in relation to cancer in Torbay. Therefore, the following groups, with protected characteristics around health inequalities, will be the focus of targeted engagement:

- BAME communities
- Learning disabled communities
- LGBTQ+ communities
- Socio-economically disadvantaged communities

Targeted engagement work in Torbay with these communities will raise awareness of the issues faced, and later in stage two of the project, help facilitate co-produced solutions to improve early diagnosis and community-based support.

**Engagement will focus on three key areas:**

1. Early diagnosis; e.g. where do people from different communities in Torbay go for information and/or support when they have symptoms? What are the barriers to accessing information?
2. Support through treatment; e.g. where do people go for support and what gaps are there? Are patients accessing support? If not why not?
3. Living with the consequences of cancer/treatment; what support is there for those living with cancer long-term or the long-term effects of cancer treatment?

The engagement workstream will lay out how each of these key areas and communities will be targeted. The workstream will include:

- Focus groups targeting the four key communities identified above.
- A survey aimed at Torbay residents, with a particular focus on targeting communities who may experience health inequalities in relation to cancer.
- Attending community events to raise awareness of the project.
- Collaborating with other organisations and individuals involved in community engagement locally.

**2. Role of advisory group**

The advisory group has responsibility for identifying local priorities and working with the project staff team to agree a work plan to help deliver the project's aims and outcomes. They will provide a system oversight of the project. **Key responsibilities of the advisory group:**

- To bring service knowledge and/or local expertise to the project
- To bring local accountability and transparency to the project
- To agree the work plan, and ensure it closely reflects issues and priorities local to Torbay, and the needs of Torbay communities
- To review the quarterly activity reports and ensure the content is reflective of the workplan goals
- To help develop the structures needed to engage target communities
- To help identify engagement avenues and opportunities and/or potential collaborations with organisations and services
- To promote the project and help ensure it has local influence
- To highlight any issues or problems the project may encounter and hold to account and/or challenge any potential risks. To look at best practice and draw attention to opportunities for improvement.

**3. Membership**

The advisory group will endeavour to comprise of 7-8 members. Members will be people with expertise and/or local knowledge. This will include the project staff team, staff from the partnership organisations, staff from voluntary sector groups, and those with lived experience.

**4. Meetings**

The advisory group meetings will be a collaborative forum that aim to address the group's responsibilities as laid out in point 2. The group will meet quarterly. Meetings will be arranged by the project coordinator and will take place in person. If the group would prefer another meeting mechanism this will be agreed upon at the first meeting. A week prior to each meeting the project coordinator will ensure that a sufficient number of members can attend (75% of the group). If this percentage cannot be met, the chair will be contacted, and the meeting shall be rearranged for the nearest available date. The chair will be appointed by the project team and agreement will be sought from the advisory group at the first meeting. The chair will work alongside the project staff team to lead meetings and ensure the group is meeting their responsibilities as laid out in point 2. Meetings and advisory group membership will be for the duration of the project's two-year existence.

#### 4. Example copy of LD Ambassador A4 Cancer Posters

## Common symptoms of Cancer



**Head:**

- A headache which won't go away
- Feel tired for no reason, it lasts a long time

**Throat/Mouth:**

- Sore throat, won't go away
- Croaky voice
- Difficulty with swallowing/chewing

**Chest:**

- Hard to breathe
- A cough that won't go away
- Have a fever/infection for a long time
- Changes to nipple, breast/chest or armpit

**Belly:**

- Tummy ache
- Feel bloated
- Changes to eating habits
- Losing weight without trying
- Sickness

**Anywhere:**

- Lumps
- Bumps
- Rashes
- Mole changes (size, shape, colour, bleeding, itchy)
- Sores
- Ulcers
- Swellings/inflammation
- Easy or unexplained bruising

**Privates/Bum:**

- Passing blood (when you pee, poo or have sex)
- Changes to your periods
- Struggling or hurts to wee/poo
- Needing to wee/poo more or less than usual
- Changes to your poo or wee (colour, runny, hard)

**If in doubt, check it out!**

**Speak to your doctor if you're worried about anything mentioned above**




Torbay Learning Disability  
Partnership Board

Together we fill in the missing pieces



**MACMILLAN**  
CANCER SUPPORT



Engaging  
Communities  
South West




Torbay **Communities**  
Stronger together


5. Example copy of LD Ambassador Symptoms Checklist

## How are you feeling?


Feel unwell or like something's not right? Draw arrows to what feels okay and what feels not okay, add notes to the boxes and then take it to your doctor.



**Okay**

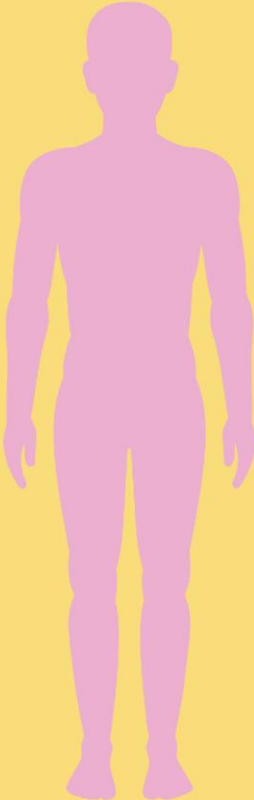


**Not Sure**



**Not Okay**

**If in doubt,  
check it out!**



**Tick one (or more) of these boxes if you have any:**

Pain		Bleeding	
Rashes		Lumps	
Changes		Sickness	



6. Example copies of Turning Heads Calendar Posters



**April**  
Shoalstone Pool, Brixham






## Bowel Cancer

**What to watch out for:**




- » Losing weight without trying
- » Tummy ache
- » The runs, squits AKA diarrhoea
- » Struggling to poo (constipated)
- » Blood in your poo
- » Bleeding from your bum





Parents and Carers can scan the QR code with their phone's camera for more information on this type of cancer



**REMEMBER:** just because you might have one of these symptoms, it doesn't mean you have cancer...but ***If in doubt, check it out!***








**June**  
Goodrington North Beach, Paignton

## Melanoma


(A form of Skin Cancer)

**What to watch out for:**

Uneven shape	
Jagged edges	
Multiple colours	
Size over 6mm	
Notice changes	

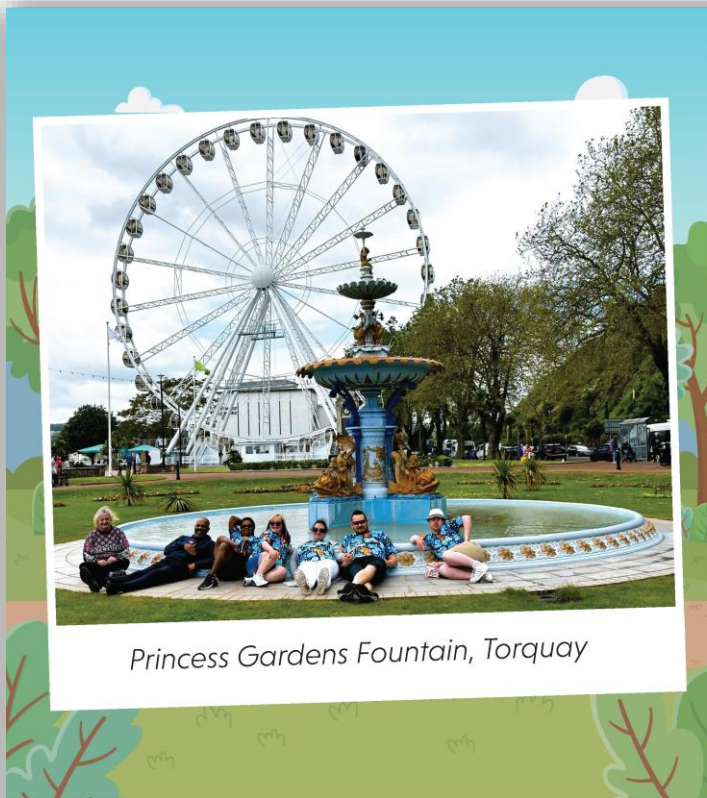
- » New moles that may look weird or different from the rest
- » Moles, freckles or dark spots that change size, shape or colour
- » Inflamed and/or "angry" moles
- » Bleeding/itchy skin
- » Moles that turn crusty or bleed
- » A new growth or dark stripe on a nail

Parents and Carers can scan the QR code with their phone's camera for more information on this type of cancer



**REMEMBER:** just because you might have one of these symptoms, it doesn't mean you have cancer...but ***If in doubt, check it out!***

7. Example copy of Turning Heads Calendar Page

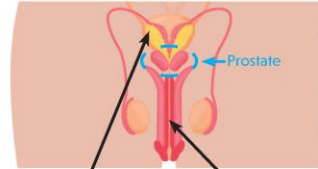


Princess Gardens Fountain, Torquay

### Prostate Cancer

The prostate is between a man's bladder and penis. Women don't have one.

**What to watch out for:**



- » Need to pee more often
- » Harder to start/stop peeing
- » May not make it to the toilet in time
- » Feel like you can't empty your bladder completely
- » Pain when peeing
- » Blood in pee
- » Pain when ejaculating
- » Pain in back/hips/pelvis

REMEMBER: just because you might have one of these symptoms, it doesn't mean you have cancer...but

**If in doubt, check it out!**

## March

- » Brain Tumour Awareness Month
- » Prostate Cancer Awareness Month
- » Ovarian Cancer Awareness Month

- » Women's History Month
- » World Autism Acceptance Week (31st March-6th April)

Mon	Tues	Wed	Thurs	Fri	Sat	Sun	Notes and Goals
					1st <i>St. David's Day (Wales)</i>	2nd	<p>Parents and Carers can scan the QR code with their phone's camera for more information on this type of cancer</p> 
3rd	4th <i>Pancake Day</i>	5th	6th	7th	8th <i>International Women's Day</i>	9th	
10th	11th	12th	13th	14th	15th	16th <i>Young Carers' Action Day</i>	
17th <i>St. Patrick's Day (Ireland)</i>	18th	19th	20th <i>Spring begins</i>	21st <i>Red Nose Day and World Down Syndrome Day</i>	22nd	23rd	
24th	25th	26th	27th	28th	29th	30th <i>Mother's Day, clocks go forward</i>	
31st							

# Engaging Communities South West

*“An inclusive, innovative and independent champion for the aspirations of local people.”*

## Contact us

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In Partnership with **healthwatch**  
Torbay