Creative Cancer Awareness

A Creative Health approach to support increased uptake for bowel screening by adults with a learning disability



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Executive Summary

This report presents early findings from a quality improvement pilot delivered by partners Artlift and NHS Gloucestershire Integrated Care Board (ICB), in collaboration with Steering Group members from Inclusion Gloucestershire and Gloucestershire Health & Care NHS Foundation Trust.

The Creative Cancer Awareness project aimed to increase uptake of bowel cancer screening among people with a learning disability, a population experiencing significant health inequalities and lower engagement with preventative services.

The pilot tested whether creative, arts-based approaches could support more accessible and effective conversations about bowel health and screening. A co-produced steering group session with Experts by Experience informed the design and refinement of workshop content.

The pilot model, whereby workshops were delivered in partnership with organisations already working with people with a learning disability, was successful in engaging 35 adults with a learning disability who had never previously encountered information about bowel cancer prevention in any accessible form.

Findings evidence that creative activities can enhance engagement with sensitive health topics. Collage-based activities were particularly effective in facilitating participation and discussion, while clay-based approaches required adaptation for some participants to ensure accessibility and comfort. A key recommendation from evaluation is that exercise and enhancing understanding around unhealthy foods are given more focus in future workshops.

The Creative Cancer Awareness project was also successful in creating the conditions for earlier presentations, referral and diagnosis; 91% of participants left knowing more about bowel health and warning signs. 90% found it easier to discuss the topic. Nobody across any workshop said they would tell no one about symptoms. Participants also demonstrated understanding of appropriate escalation, e.g. more would tell a doctor or nurse about blood in the stool (68%) than about constipation (54%).

Evaluation evidenced that trust between participants, carers and healthcare professionals was strengthened and that carers were a critical part of the intervention so engaging them as active participants in the project strengthened outcomes.

Learning regarding evaluation highlighted the importance of clear and accessible feedback methods, as more complex approaches affected the reliability of responses.

Overall, the pilot demonstrates that a creative, mixed-method approach has strong potential to improve engagement with bowel health messaging within the adult population with a learning disability. Further sustained investment is required to enable refinement of approach and evaluation methods to maximise accessibility, impact and scalability.

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Project Background

Health context

Reducing health inequities and supporting the population to have improved health is a priority for NHS England, and a key focus of the NHS 10 Year Health Plan, which includes this stated aim:

'Life outcomes will be improved for groups who are currently disadvantaged including those with a learning disability, through more holistic, on-going support'.

The focus of the 10-Year Health Plan is on prevention, rather than sickness, with a pledge to deliver prevention via an increase in screening access and uptake for all those eligible through personalised, patient-centred care.

The National Cancer Plan for England states that Cancer Alliances and neighbourhood health services will work with local communities, screening commissioners and providers, to develop targeted local campaigns to reduce the gap in screening uptake between the most and least deprived areas and to increase uptake in ethnic minority and underserved communities. (pg 31)

Statistics and findings of recent studies highlight a clear and urgent need to develop more effective and accessible approaches to engagement of people with a learning disability:

- A 2024 study led by the Scottish Learning Disabilities Observatory and published in the BMJ Open, concluded: 'adults with learning disabilities are more likely to die from cancer compared to the general population'. In some cases, such as bowel cancer, the percentage of deaths is nearly double the rate of people without a learning disability.[1]

  Lead researcher Dr Laura Ward, said:

  'These findings are deeply concerning. Adults with learning disabilities are missing out on lifesaving cancer treatment due to their cancer being found too late and we urgently need to find out why this is case'
- A 2024 Nuffield Trust report, 'Preventing People with a Learning Disability from Dying Too Young', found that:
  - Over the past five years, there has consistently been a 15-percentage point difference in breast cancer screening rates and a 36-percentage point difference in cervical cancer screening rates between people with a learning disability and the rest of the population.
  - Ensuring that screening is accessible to people with a learning disability is especially important as they are more likely to encounter difficulties recognising and communicating symptoms of possible cancer, which can increase the risk of delayed diagnosis.
  - Cancer is often diagnosed at a later stage for people with a learning disability than for the general population, and these late diagnoses are sadly often made during emergency presentation at hospital. The prevalence of cancer appears lower in people with a learning disability aged 55 and over than in the rest of the population of the same age, which illustrates the extent of missed cancer diagnoses for people with a learning disability.
  - people with a learning disability have been shown to have a higher risk of developing bowel cancer than the general population, and the 2022 LeDeR report found that bowel cancer accounted for a higher percentage of cancer deaths among this population group.
- The LeDeR Annual Report 2023 (Learning from Lives and Deaths – People with a Learning Disability and Autistic People) found that:

  'Bowel cancer accounts for approximately 18% bowel cancer deaths of patients with a learning disability each year (compared to approximately 10% in the general population), and 15% of these are of people below the age of 50 years'.

[1] https://www.gla.ac.uk/news/headline_1096342_en.html

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In addition, local data shows that screening uptake by people with a learning disability is generally low across all screening programmes in the county and there was significant variation in different parts of the county. This project will not be able to show an impact on the screening uptake rates in the short term, but further interventions may have an impact in the future uptake rates.

These national priorities provide a clear mandate for targeted, inclusive approaches to improving cancer screening uptake. This project responds directly to this need by testing innovative, community-based approaches tailored to the learning disability population in Gloucestershire.

About the project (inputs)

1. Background

Artlift, a UK pioneer in **Creative Health**, has been delivering Arts on Prescription services since 2007 and, with partner the University of Gloucestershire, holds the largest known body of Creative Health wellbeing data internationally. The efficacy of these arts-based services has been proven:

'The findings confirm the value and benefits of arts interventions in primary care. As such, it adds to the current developing evidence base on the use of arts and creativity in the promotion and maintenance of public health in the community'.[2]

The minimum dataset, contributed to by 6 partners[3] in Gloucestershire Creative Health Consortium, held by NHS Gloucestershire Integrated Care Board (ICB) further evidences positive impact, including reducing reliance on NHS services, and success in engagement of underserved and marginalised communities.

Creative Cancer Awareness was a 2025 pilot project designed to test whether a Creative Health approach could improve cancer prevention and early diagnosis for people with learning disabilities in Gloucestershire. The project aimed to increase awareness of healthy living, cancer symptoms, screening programmes and treatment options, while also building confidence to discuss health concerns with carers and healthcare professionals.

Funding for the project was provided by the South-West Cancer Alliance which was processed by Gloucestershire ICB through a grant application. The cancer team also provided project oversight, design and planning to support delivery of the project.

2. Co-producers and team

A multidisciplinary Steering Group oversaw the project and included three Experts by Experience, as well as representatives from:

- Artlift, a charity that delivers Arts on Prescription services and has extensive experience in co-producing creative interventions to address health inequalities.
- Gloucestershire ICB: the Cancer Team, who lead on earlier and faster diagnosis of cancer across the county, and the Insights and Equality, Diversity and Inclusion (ED&I) Manager.
- Inclusion Gloucestershire (IG), a user-led charity that ensures people with learning disabilities are central to programme design and delivery through advocacy, mentoring and co-production.
- Gloucestershire Health and Care NHS Foundation Trust (GHC), who provide community-based services, including specialist learning disability screening support to improve access and informed decision-making regarding national screening programmes.

[2] An observational study from UK general practice. International Journal of Mental Health Nursing, 22 (3). pp. 279286. ISSN 14458330

[3] GCHC members: Artlift, Art Shape, Cinderford Artspace, Mindsong, The Music Works, Play Gloucestershire

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The project delivery team included:

- Harriet West, an Artlift Artist Facilitator, supported by Expert by Experience Patricia Bath
- Jonathan Thomas, Screening Specialist Learning Disabilities Health Screening Nurse, GHC
- Rosie Mockford from the Learning Disability Health Facilitation Team
- Charlotte Burge, a psychology student who provided evaluation support
- Harriet Roberts, LeDeR Project Coordinator, IG, who provided by additional support
- Tim Heaven and Nick Bakers, Experts by Experience with IG, who also supported the project.

Kalpna Mistry, Kathy Gibbons and Kay Barnfield from the ICB supported Artlift's Project Manager Helen Crocker with management and administration.

3. Delivery partners

The workshops were delivered to residents and members of three organisations:

- The Grange (Camphill Village Trust), Forest of Dean
- Merryden Care Centre (National Care Group), Cinderford
- Prosperity Care, Gloucester

These organisations support adults with learning disabilities, autism, mental health conditions and other complex support needs.

4. Timescale

The project was developed by the Steering Group between June and September 2025, with delivery beginning in September 2025. Workshops and associated activities continued through to early 2026, with evaluation taking place between May and July 2026.

5. Project co-design and parameters

The project was co-produced by the Steering Group. During the initial planning phase, the group met face-to-face to establish shared objectives and to shape the programme. Members also participated in a pilot workshop to refine the delivery approach.

Several key decisions informed the final design:

- Delivery would focus on rural communities, where opportunities of this type are often limited.
- Bowel cancer would be the primary focus because it affects all genders and has significant mortality rates within the learning disability population.
- Around 20% of participants would be carers or support staff as, for people with a learning disability who rely on carers or paid staff for nutritional advice, a major barrier could be the carer or staff member's own lack of knowledge on nutrition, and they may require training themselves[4]
- Existing groups would be used rather than recruiting individuals directly.
- Messaging would emphasise positive healthy living and wellbeing rather than focusing solely on risk factors.
- Pro-active steps should be taken to engage people from communities minoritised by ethnicity in the project, inclusivity should be continually assessed, and evaluation outputs should be made available in Easy Read format.

[4] 2024 Nuffield Trust report, 'Preventing People with a Learning Disability from Dying Too Young' (p.16)

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As planning progressed, several additional measures were introduced to support participants, including:

- private time with a specialist learning disability nurse following workshops,
- opportunities to collect case studies,
- access to a quiet room for anyone distressed by the subject matter, and
- on-site support from care staff where required.

Resources included arts and craft materials, educational and promotional items such as "happy poo" keyrings, stickers and tote bags, as well as accessible information in Easy Read formats.

Evaluation approach

A visual logic model was co-produced to provide a clear evaluation framework (see page 10).

The accessibility of the project was evaluated by two of the Experts by Experience, one from Artlift and one from Inclusion Gloucestershire. One of IG's experts by Experience withdrew after the first workshop as the demands of the work were more than initially communicated. Due to the sensitive subject matter, future work in this field should allow for the potential of staff turnover. Surveys were collected and collated by a Psychology student intern.

Data collected included

- Participant **surveys** to assess engagement and learning. These included a small number of questions mostly related to awareness raising.
- **Reflective practice** of the health professionals and Artist Facilitator, capturing observations and discussion content
- Two **participant interviews** after each workshop and at a later date informing case studies. Interviewees were selected by the host organisation in consultation with attendees (see pages 11-13, 16- 25 for resulting case studies)
- Project delivery team **e-mail log**, including informal feedback from Experts by Experience
- Informal **feedback via Teams** and one formal report (see pages 13-15, 17-22, 25-) from host organisation staff.
- **Photographic and video evidence**: easy read media consent forms were completed prior to each session and team members, as well as Artlift's Engagement Associate took photographs during workshops

To ensure accessibility:

- Surveys were co-designed by the Steering Group (including Experts by Experience) and produced in Easy Read format, with advice from IG on language, length, and follow-up timescales.
- Surveys used pictograms, smiley faces, thumbs up/down symbols, and images relating to food, drink, and exercise. Words were included beneath certain pictograms to further broaden accessibility.
- Surveys were distributed at the end of workshops, with support from delivery staff and care staff for participants, where required, to fill them in.
- Accessibility was assessed by participating Experts by Experience. They completed an easy-read survey after the final workshop.

IG advised that in order to gauge whether learning from the workshop was sustained, follow-up data should be collected within one week of the workshop. In practice, reliance on host organisation contacts, their availability, and participant availability meant responses were gathered between two weeks and two months later, which impacted the quality of the data.

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Workshops, activities and resources delivered (outputs)

As the project developed, the range of outputs expanded beyond the original targets, resulting in a broad set of engagement, learning, and promotional resources.

Workshops:

Three workshops were co-delivered by a Creative Health practitioner and Expert by Experience, with the learning disabilities screening nurse encouraging discussion:

- Two in the Forest of Dean
- One in Gloucester

Activities included:

- Clay modelling to explore tactile engagement (adapted based on participant comfort).
- Collage-making using the theme of healthy eating and lifestyle behaviours.
- Facilitated discussions, whilst participants were doing the creative activities, about what healthy foods might include and the importance of drinking water for example.

The Bristol Stool Chart was also used to show participants the difference between a normal stool and ones that may be concerning.

These activities were designed to:

- Encourage open discussion of sensitive topics in a safe environment
- Build confidence in recognising symptoms and discussing health concerns
- Promote understanding of when and how to access screening and healthcare services

All attendees were advised to consult a healthcare professional if they felt there were changes to their normal routine and things did not feel right.

Resources:

The following visual and creative resources were produced that can be used in future engagement and promotional activities:

- Clay items: pots and “healthy poos”
- Collages on the theme of healthy food, drink, and exercise
- Photographic and video documentation of workshops
- Easy read documentation: information document ×1, meeting agendas ×3, media consent form ×1, evaluation surveys ×4, workbooks ×3, participant and carer leaflets ×3

Wider engagement:

Awareness of the project and impact was further extended through:

- A workshop delivered at the GCH organised Big Health Day in Gloucester, a free annual event for people with physical or learning disabilities, autism, sensory loss, or mental health support needs.
- A presentation to the Gloucestershire Learning Disability Partnership Board, with information shared through partner networks.
- An Easy Read information leaflet circulated through Artlift, IG and ICB communication channels to increase accessibility and reach.

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Evaluation Findings

Participant data

The programme engaged 48* participants in the 3 workshops events:

- 35 people with learning disabilities, and
- 13 carers (N.B. c. 20% of attendees were carers or support workers, recognising their important role in supporting health awareness and access to services).

*There were places for 20 people on each workshop, but attendance numbers varied across the three workshops.

Workshops two and three struggled to recruit the target number of participants due partly to the age and NHS out of hours constraints. For workshop 3, Prosperity Care needed to recruit participants as they had no pre-existing group. This was challenging, but they had a large number of carers attending (9).

Learning around project design and evaluation

1. Recruitment and Engagement

Recruiting people with learning disabilities was significantly slower than expected, particularly in rural areas where many groups were not connected to existing networks. Key barriers included:

- Lack of a Gloucestershire-wide directory of learning disability organisations.
- Difficulty contacting and securing partner organisations due to low response rates (even from those we anticipated would respond positively) and some outdated contact details.
- Limited capacity to engage communities minoritised by ethnicity, although some Global Majority participants attended Workshop 3.

Those organisations that did engage were often already involved in health education, suggesting that people most in need of support may be the hardest to reach.

Learning for future projects: Build in time and resources for face-to-face outreach, relationship-building, and engagement with underrepresented groups.

2. Resources and budget

Additional funding was required due to:

- Significant unplanned costs for translating materials into Easy Read formats to ensure accessibility for Experts by Experience.
- Increased administrative and management demands as the project expanded beyond its original scope.
- Higher travel costs across a large geographic area.

Learning for future projects: Ensure budgets fully account for accessibility requirements, travel costs, and potential increases in project scope.

3. Evaluation

The evaluation process would have benefited from more clearly pre-agreed responsibilities, documented in agreements, and earlier identification of any coaching support needs. Also, there were delays in follow-up case studies. This impacted on timeliness and efficiency of evaluation tasks.

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Learning for future projects:

- Establish clear evaluation responsibilities and adequate budget within formal agreements from the outset.
- Ensure all team members have the required skills and support.
- Use simple and accessible evaluation tools. A three-point feedback scale is recommended, while movement-based feedback methods are not.
- Schedule dedicated follow-up visits as part of project delivery.
- Introduce longer-term monitoring to assess engagement with screening services and measure sustained impact.

4. Delivery challenges

Key delivery issues included:

- Withdrawal of an Expert by Experience after the pilot workshop.
- Absence of a screening practitioner at one session, requiring a substitute facilitator.
- A 20-minute fire alarm interruption during one workshop.

Despite these challenges, host organisations were highly supportive and facilitators adapted well. Participants appeared to understand the key messages and all sessions were completed successfully.

5. Workshop Activity Reflections

Clay activity: The sensory aspect was enjoyed by the majority but some participants disliked the texture. As some co-producers in the workshop design session found the follow-up task of modelling a recent stool uncomfortable and confusing, that aspect was not used in the workshops.

Recommendation: Offer gloves.

Healthy eating collage: This activity was well received, encouraged discussion, and supported participant engagement.

Recommendation: Continue using interactive, visual activities to support learning and discussion

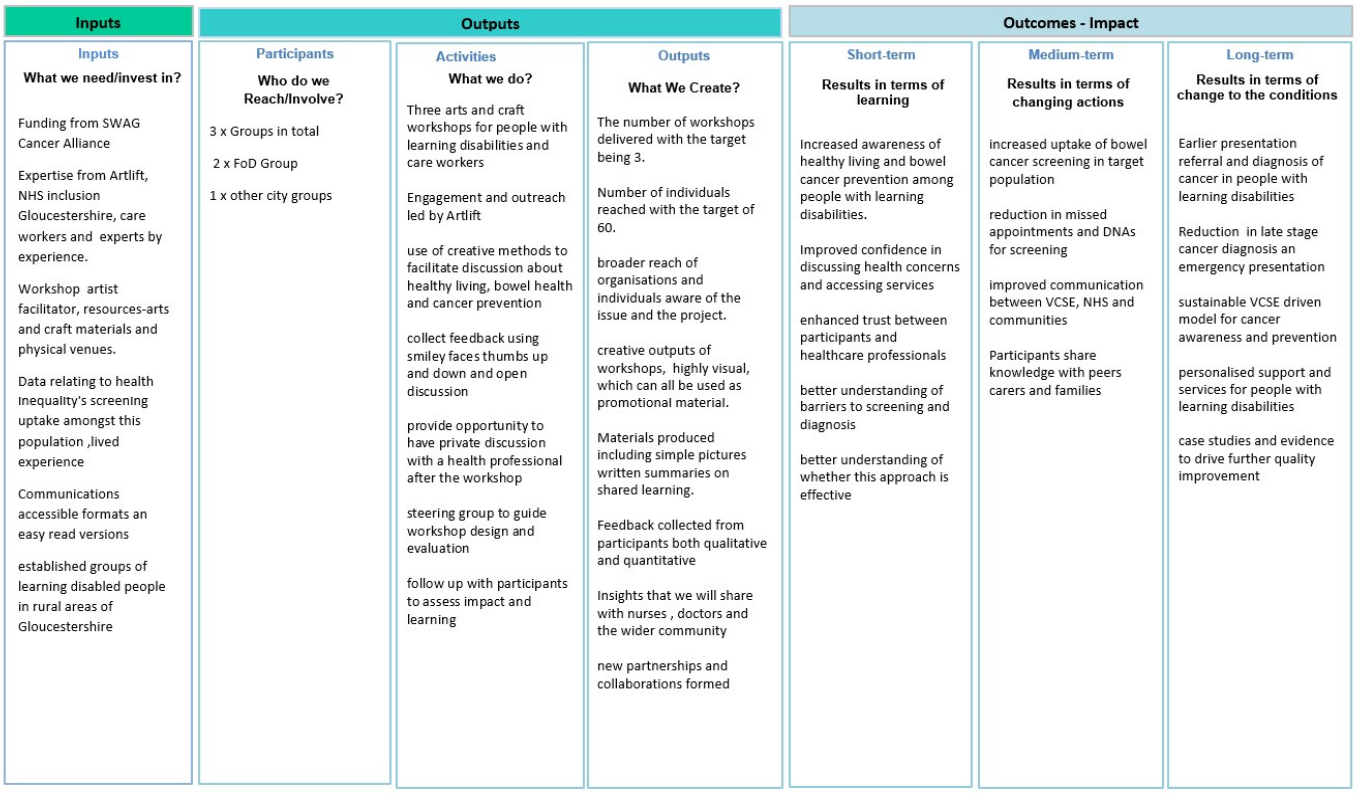
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Logic Model

A visual logic model was developed to support project planning and evaluation.

Aim: Improve early cancer diagnosis and prevention for people with learning disabilities by increasing their awareness of healthy living, bowel health and cancer screening using creative arts workshops to make health information accessible, build confidence and reduce barriers to discussing and accessing healthcare and scalability for future implementation

Reach/Target Group. 1- People with Learning Disabilities residing in Gloucestershire. 2- Care workers for people with Learning Disabilities



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Analysis of achievements against outcomes (see: Logic Model)

LOGIC MODEL — SHORT-TERM OUTCOMES

Evidence from Participant Surveys, Carer Feedback and Case Study Transcripts | 32 participants, 12 carers, 4 case studies and host organisation leads.

SHORT-TERM OUTCOME 1

Better understanding of whether a creative health intervention approach is effective

95% of participants enjoyed the workshop	**90%** said activities made it easier to discuss poo and cancer	**91%** left feeling that they knew more than before

Evidence Source	Finding
Participant surveys (32 participants, 3 workshops)	95% of all participants enjoyed the workshops — 100% in Workshops 2 and 3, and 86% in Workshop 1. 90% confirmed that the creative activities made it easier to discuss poo and cancer, and 91% self-reported that they left knowing more than before. Results improved across each successive workshop, suggesting confidence in delivery also strengthened over time. The approach consistently exceeded expectations — including with a participant in Workshop 2 who initially refused to engage but was actively contributing and laughing by the end.
Carer feedback (12 carers)	93% of carers felt the workshop made it easier for the person they support to talk — 100% in Workshops 1 and 2, and 78% in Workshop 3 (which had a larger, more varied group of 9 carers). 93% observed a clear increase in knowledge. Carers also reported feeling better equipped themselves — understanding what to look out for, how to raise the topic, and who to contact. This secondary benefit for carers is significant given their role as the primary point of contact for many people with Learning Disabilities.
Case study transcripts (4 participants)	All four participants named specific creative activities in follow-up interviews — the poo henge, the collage, the pottery — confirming that hands-on activities left a strong and lasting memory trace. Learning was expressed in participants' own words, providing qualitative evidence of genuine absorption. Two participants connected workshop content directly to their own lives: one described a personal system of healthy and unhealthy pots; another linked the healthy eating message to an existing health goal. This kind of integration indicates meaningful learning, not surface recall.

> *"This is the way that they learn best — being hands on and learning."*
> **Steph White, Regional Operations Manager, National Care Group**

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"The creative engagement is very effective at opening up sensitive topics — both poo and cancer are quite hard-hitting. As a nurse I have learned from this. People appeared to leave with a sense of pride in what they had created."

Rosie Mockford, Strategic Health Facilitator, Learning Disability Health Facilitation Team

The evidence consistently and strongly confirms that the creative health intervention approach is both effective and appropriate for people with Learning Disabilities. Hands-on, arts-based methods produced genuine, retained learning across all three workshops — corroborated independently by participants, carers and follow-up interviews. The approach worked not just as an educational tool but as a way of building a positive, memorable shared experience that participants were willing to talk about and share with others.

SHORT-TERM OUTCOME 2

Increased awareness of healthy living and bowel cancer prevention among people with Learning Disabilities and carers

51%	28%	87%
identified all 5 healthy foods correctly	Identified at least one unhealthy food correctly	correctly identified water as a healthy drink

Evidence Source	Finding
Participant surveys	Healthy food recognition improved with each workshop: 33% identified all 5 healthy foods correctly in Workshop 1, rising to 57% in Workshop 2 and 63% in Workshop 3. Fewer - 28% on average across all workshops - correctly excluded one or more unhealthy foods but 87% identified water as healthy. Critically, nobody across any workshop said they would tell no one if they noticed a change in bowel habits or blood in their poo — a strong indicator that the message about seeking help was understood and retained.
Carer feedback	Carers felt bowel health (selected by 89%) and healthy eating and drinking (93%) were the most consistently understood messages. Exercise was a persistent weak point: only 50% of carers in Workshops 1 and 2 felt the person they support had understood the role of exercise in bowel health, rising to 67% in Workshop 3. This pattern appeared in both participant surveys and carer feedback across all workshops — making it the clearest and most actionable priority for future session design.
Case study transcripts	Participants expressed awareness messages in their own words rather than reciting them: 'I have two pots — one for healthy, one for unhealthy stuff'; 'healthy eating means healthy poo'; 'I am already trying to be careful because of my eye and things'. These spontaneous, personalised expressions are a stronger indicator of genuine awareness than correct survey responses alone and demonstrate that the messages were not just heard but integrated into participants' understanding of their own lives.

"Complex and sensitive health information was delivered in a way that was understandable, engaging, and appropriate for all participants."

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Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

Awareness of healthy living and bowel cancer prevention increased meaningfully across participants and carers, with results strengthening across successive workshops. The clear, consistent gap around the role of exercise in bowel health — appearing in both participant surveys and carer feedback across all three workshops — is the single most actionable finding for future session design and should be addressed with greater visual emphasis and dedicated time.

SHORT-TERM OUTCOME 3

Improved confidence in discussing health concerns and accessing services

0
participants across any workshop said they would tell no one about symptoms

68%
would tell a doctor or nurse about blood in their poo

Evidence Source	Finding
Participant surveys	90% said the activities made it easier to talk about poo and cancer (100% in Workshop 2). The data shows not just willingness to talk, but appropriate escalation: more participants selected a doctor or nurse for the more serious symptom (blood in poo, 68%) than for constipation (54%). This escalation suggests messages were applied thoughtfully rather than passively recalled. 85% said they would tell a carer if they had difficulty going for a poo, and nobody across any workshop said they would tell no one about either symptom.
Carer feedback	93% of carers said the workshop made it easier for the person they support to talk. Carers also reported increased personal confidence — feeling better equipped to raise the topic, ask the right questions, and know what action to take. For many people with Learning Disabilities, a carer or family member is the gateway to health services, so carer confidence is a direct enabler of earlier presentation and referral — making this a particularly significant secondary outcome.
Case study transcripts	Participants who were nervous or reluctant at the start of the workshops engaged fully by the end and remained willing to discuss personal health experiences in follow-up interviews conducted sometime later. One participant expressed discomfort with the written survey format but was entirely at ease in conversation — reinforcing those verbal approaches to both delivery and evaluation work better for this group. The consistency of engagement across the gap between workshop and interview is itself evidence of sustained confidence with the subject matter.

"Even from a person who initially said, 'I'm not talking about THAT!' — lots of laughter and real discussion."
Rosie Mockford, Strategic Health Facilitator, Learning Disability Health Facilitation Team

"Everyone was buzzing, interested and glad they went. Some shared their own cancer stories."
Janet Hawkins, Co-Production Lead, Camphill Village Trust

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The workshops demonstrably improved confidence in discussing bowel health and cancer — not just in the moment, but over time and across follow-up. The creative, relaxed and often humorous atmosphere was key: it normalised a sensitive and embarrassing topic in a way that clinical settings rarely achieve. Participants did not just feel more comfortable talking — they understood who to talk to and when, which is the more clinically significant outcome.

SHORT-TERM OUTCOME 4

Enhanced trust between participants and healthcare professionals

Evidence Source	Finding
Participant surveys & host feedback	A specialist cancer nurse participated in each workshop, taking part in creative activities alongside participants rather than presenting from the front. This deliberate design choice — placing the health professional as a fellow participant rather than an authority figure — created the conditions for genuine human connection in a non-clinical setting. Participants were also offered a private conversation with the nurse after each session. Host organisation leads consistently identified this direct connection with NHS professionals as one of the most valued aspects of the project.
Carer feedback	Two host organisation leads independently identified the re-established connection with NHS healthcare professionals as a significant and meaningful outcome. Both described a gap in their direct links to health services that the project had helped to close — and expressed that these new connections gave them greater confidence in supporting the people in their care to access services. The value of this outcome extends well beyond the workshops themselves.
System-level impact	The specialist nurse offered additional free screening and awareness sessions as a direct result of relationships built through the project — an extension of clinical reach that would not have happened without the trust built through the workshops. Two host organisations distributed Easy Read health materials nationally within their organisations. New VCSE–NHS partnerships were formed that create a channel for ongoing communication and referral that did not previously exist.

> *"We now have good links with health professionals which I no longer had."*
> **Janet Hawkins, Co-Production Lead, Camphill Village Trust**

> *"The session strengthened partnership working across organisations. The NHS representative offered additional free screening and awareness sessions, with opportunities to arrange further workshops."*
> **Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics**

Trust between participants, carers and healthcare professionals was meaningfully strengthened — at the individual level through creative co-participation, and at the organisational level through new and renewed VCSE–NHS connections. The co-participation model was particularly effective: having a nurse make clay pots alongside participants broke down the authority dynamic in a way that a presentation or leaflet could not. These relationships have lasting value well beyond the workshops themselves.

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SHORT-TERM OUTCOME 5

Better understanding of barriers to screening and diagnosis

The workshops were not designed to formally measure screening barriers — the Steering Group focused on awareness-raising within the limited time available. However, conversations with participants, carers and host organisations, alongside the wider evidence base, generated a clear picture of why this community faces disproportionate disadvantage around cancer screening and diagnosis.

Evidence Source	Finding
Individual barriers (from participant conversations)	Participants and carers described: embarrassment and difficulty knowing what language to use; anxiety about what screening involves; difficulty understanding instructions for the FIT test kit; and a general lack of awareness that cancer screening is relevant to them. Some participants had never previously received accessible health information about bowel cancer in any form. Evidence from Cancer Research UK also highlights that people from lower social grade groups are more likely to delay seeking help out of fear their symptoms won't be taken seriously.
Carer and family barriers (from carer feedback)	Carers described limited confidence in raising the topic with the people they support, and limited knowledge of what screening programmes involve or how to help someone through them. Some resistance from care home to engaging with the project was noted — a cultural barrier upstream of the clinical system that has a real impact on whether residents ever reach it.
System barriers (from host feedback and literature)	Host organisations described a gap in their direct connections with NHS health professionals. The LeDeR Report (2024) found that 27.3% of adults with a Learning Disability who died in 2023 had needed at least one reasonable adjustment that was not provided, and that some had not received national screening due to practical barriers, lack of alternatives, and missed appointments that were not followed up proactively. Bowel cancer accounts for approximately 18% of deaths in people with a Learning Disability annually — nearly double the general population rate.
What the project addressed	The project directly tackled individual and relational barriers — building awareness, reducing embarrassment and anxiety, and creating new connections between participants, carers and health professionals. System-level barriers were addressed through new VCSE–NHS relationships, the nurse's offer of additional free screening sessions, and the national distribution of Easy Read materials by two host organisations. These are meaningful contributions even within a short-term project that could not formally measure screening uptake.

The project generated a clear and consistent picture of the barriers facing this community — and took meaningful steps to reduce them. A longer-term programme with dedicated follow-up capacity would be needed to measure impact on screening uptake, GP presentations and referral rates. Evidence suggests people with a Learning Disability should be offered bowel cancer screening from age 40 — a decade earlier than the general population. The awareness, confidence and trust built through this project are the foundations that make that earlier screening pathway viable.

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LOGIC MODEL — MEDIUM-TERM OUTCOMES

Evidence from Participant Surveys, Carer Feedback and Case Study Transcripts | 32 participants, 12 carers, 4 case studies

Medium-term outcomes relate to changes in actions and behaviours that begin to emerge following the workshops. By their nature, these outcomes are harder to measure directly within a short-term project. Where direct measurement was not possible, this section draws on indicative evidence from surveys, carer observations, host organisation leads, case study interviews and qualitative feedback to assess the likelihood and direction of change.

MEDIUM-TERM OUTCOME 1

Increased uptake of bowel cancer screening in the target population

Direct measurement of screening uptake was beyond the scope and timescale of this project. However, the survey evidence points clearly toward the conditions for increased uptake having been established.

91%	68%	0
self-assessed that they knew more about bowel health than before the workshop	would tell a doctor, nurse & **83%** that they would tell a carer about blood in their poo	said they would tell no one about symptoms across all three workshops

Evidence Source	Finding
Participant surveys (32 participants)	91% of participants left feeling they knew more about bowel health than before — the foundational requirement for any increase in screening behaviour. 68% said they would tell a doctor or nurse if they noticed blood in their poo, a direct precursor to referral, and 83% said they would tell a carer. Participants also showed appropriate escalation — more would involve a doctor or nurse for the more serious symptom (blood in poo) than for constipation, suggesting health messages were applied rather than merely recalled. Nobody said they would tell no one about either symptom.
Carer feedback (12 carers)	93% of carers observed an increase in knowledge in the person they support. Carers also reported feeling better equipped to support the person they care for in completing a FIT test and attending screening appointments — reducing a key practical barrier to uptake. In Workshops 1 and 2, 100% of carers felt the health messages had been understood, which is directly relevant to whether participants would act on screening information.
Case study transcripts (4 participants)	Participants expressed intentions that indicate increased likelihood of screening behaviour: 'I would probably drink more water and think more about what I eat' (Workshop 1); 'I won't drink any beer' and 'stop eating so much chocolate' (Workshop 2). While these relate to lifestyle rather than screening specifically, they reflect a shift in health-conscious thinking that is a precursor to screening engagement. Anecdotally, participants indicated during the workshops that they would be more likely to complete a FIT test as a result of what they had learned.

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This outcome cannot be confirmed without longer-term follow-up at 3, 6 and 12 months, with dedicated project staff to conduct that follow-up. The current evidence is indicative rather than conclusive, but consistently points in a positive direction. A future project should build in the capacity to measure this directly.

"The feedback I had was that people would feel more comfortable doing the test. I know when I revisited Camp Hill Village Trust two people came up to me to tell me that they had done the test after the session we had there." - **Jonathan Thomas, Specialist Learning Disabilities Health Screening Nurse**

The conditions for increased screening uptake — awareness of the issue, reduced embarrassment, clarity about who to contact, and increased trust in health professionals — were all established through the workshops. Whether this translates into measurable increases in FIT test completion and screening attendance can only be confirmed through longer-term follow-up, which this project was not resourced to deliver.

MEDIUM-TERM OUTCOME 2

Reduction in missed appointments and DNAs for screening

As with screening uptake, direct measurement of missed appointments was not possible within this project's scope. The evidence below describes the attitudinal and behavioural shifts that are the proximate causes of missed appointments — and assesses how far these were addressed.

Evidence Source	Finding
Participant surveys	Key drivers of missed appointments and DNAs — embarrassment, anxiety, not knowing who to contact, and lack of trust in health professionals — were all directly addressed by the workshops. 91% said activities made it easier to discuss the topic. Participants demonstrated clarity about who to contact depending on the severity of their symptom. 81% would tell a carer about bowel difficulties; 68% would tell a doctor or nurse about blood in their poo. This clarity is a precondition for attending rather than avoiding appointments.
Carer feedback	Carers reported greater confidence in supporting the people they care for — understanding what to look out for, how to raise the topic and what to do next. Since carers are often responsible for booking and accompanying people to health appointments, increased carer confidence and knowledge is a direct enabler of appointment attendance. On average across the three workshops, 93% of carers felt the workshop had made it easier for the person they support to talk — a prerequisite for discussing and attending screening.
Case study transcripts	Participants who were initially anxious or resistant engaged confidently by the end of sessions and remained willing to discuss health topics in follow-up interviews. This reduction in anxiety — from initial reluctance to active engagement — is precisely the shift needed to reduce DNAs. One participant who said they were 'not talking about THAT' was actively discussing cancer and bowel health within the same session.

"Increased confidence discussing personal health. Positive engagement with a new group."
Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

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Reduction in missed appointments can only be measured with structured follow-up. A future programme should track whether participants attended screening appointments in the 6–12 months following the workshops, with capacity built into the project for this — rather than relying on venue or organisation staff who may have moved on.

The attitudinal preconditions for reducing missed appointments were clearly established: reduced anxiety, reduced embarrassment, increased trust and clearer knowledge of what to do. Whether this translates into measurable reductions in DNAs requires follow-up data this project was not resourced to collect.

MEDIUM-TERM OUTCOME 3

Improved communication between VCSE, NHS and communities

3	2	100%
workshops delivered across VCSE and NHS in partnership	host organisations distributed Easy Read materials nationally	of host organisations valued the NHS connection the project provided

Evidence Source	Finding
Participant surveys & host feedback	All three workshops were co-designed and co-delivered across VCSE and NHS organisations, building on existing Steering Group connections while extending reach into new care settings. Host organisations and residential homes responded positively and welcomed the project's aims. All host organisations expressed relief at having established direct contact with NHS healthcare professionals — in some cases for the first time in years. Participants and hosts agreed that the creative context created an atmosphere of trust and cooperation that made difficult conversations possible.
Carer feedback	Carers in all three workshops identified the presence of an NHS healthcare professional as valuable and confidence-building. Two host organisation leads specifically mentioned the connection with health professionals as a significant outcome — one describing it as a link they had not had and were glad to have restored. This direct relationship, maintained through the project, creates a channel for ongoing communication that outlasts the workshops themselves.
System-level outcomes	The specialist nurse offered additional free screening and awareness sessions — extending NHS reach into VCSE settings beyond the project itself. Two host organisations requested digital copies of Easy Read workbooks and leaflets and distributed them nationally within their organisations. New partnerships and collaborations were formed. The project also surfaced important operational learning: VCSE organisations carry significantly less administrative capacity than NHS counterparts, and future joint working needs to account for this explicitly.

"We now have good links with health professionals which I no longer had."
Janet Hawkins, Co-Production Lead, Camphill Village Trust

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"The session strengthened partnership working across organisations. The NHS representative offers additional free screening and awareness sessions, with opportunities to arrange further workshops."
Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

Improved communication between VCSE, NHS and communities was one of the most clearly achieved medium-term outcomes. The project built on existing Steering Group connections, extended them into new settings, and created lasting relationships that have practical value beyond the workshops. The sustainability of these connections in the context of changes to Gloucestershire ICB structure and personnel remains to be seen — and is worth monitoring.

MEDIUM-TERM OUTCOME 4

Participants share knowledge with peers, carers and families

Direct measurement of knowledge-sharing beyond the workshops was not possible. However, the project created multiple conditions that make peer sharing highly likely.

Evidence Source	Finding
Participant surveys	95% enjoyed the workshops — and enjoyment is one of the strongest predictors of whether people share an experience. The creative outputs — clay pots, clay healthy poos, food collages — are highly visible, tactile objects that naturally prompt questions and conversation. Take-away Easy Read workbooks and leaflets provided participants with a lasting resource to share with family, carers and peers, reinforcing learning and creating opportunities for discussion at home.
Carer feedback	Carers across all three workshops reported increased knowledge and confidence following the sessions, making them better placed to continue conversations about bowel health and cancer with the people they support. 83% of carers observed an increase in knowledge in the person they support — this external validation suggests the learning was visible enough to be noticed by others, which is itself a precondition for sharing. Two host organisations distributed Easy Read materials nationally, suggesting organisational-level knowledge-sharing well beyond the original participant group.
Case study transcripts	Participants described their learning in vivid, story-like terms — 'the poo henge', 'two pots for healthy and unhealthy food' — that are inherently shareable. This kind of memorable, narrative framing makes it much more likely that participants retell their experience to others. Fun, tangible take-away items — poo keyrings, stickers, tote bags — provided visible, conversation-starting reminders of the workshop that are likely to have prompted discussion with peers and family members.

"Everyone was buzzing, interested and glad they went. They enjoyed learning and saw the benefits."
Janet Hawkins, Co-Production Lead, Camphill Village Trust

While peer knowledge-sharing could not be formally measured, the project created the conditions for it in multiple ways — through enjoyable, memorable experiences, vivid and shareable creative outputs, visible take-away materials, and better-informed carers who could continue the conversation. A longer-term project could track this through follow-up questions to participants and their networks.

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MEDIUM-TERM OUTCOME 5

Promote and develop opportunities to make informed choices regarding health screening

91%
left feeling they knew more — the foundation of any informed choice

68%
would tell a doctor or nurse about a serious symptom — a direct precursor to informed screening engagement

Evidence Source	Finding
Participant surveys	For participants to make informed choices about screening, they first need to understand what bowel cancer is, what warning signs to look out for, and what they can do about them. 91% of participants left the workshops feeling they knew more than before. Nobody said they would tell no one about symptoms. Escalation in who participants would contact depending on symptom severity shows not just awareness but applied judgement, showing genuinely informed choice rather than rote knowledge.
Carer feedback	Carers reported increased confidence in discussing health screening with people they support and in knowing what to do next. Since many people with Learning Disabilities rely on carers to help navigate health decisions, carer knowledge and confidence is a direct enabler of informed choice. The provision of Easy Read workbooks and leaflets — taken home at the end of each workshop — gave participants a lasting resource to return to when facing decisions about their own health.
Case study transcripts	Participants articulated their intentions in specific, personal terms — 'I won't drink any beer', 'stop eating so much chocolate', 'I would probably drink more water'. These are examples of autonomous, informed decision-making grounded in the workshop content. Participants also demonstrated that they knew who to contact and when — the essential practical dimension of informed choice. Anecdotally, several indicated they would be more likely to complete a FIT test as a result of what they had learned.

> *"The increase in trust with health professionals might indicate that participants would feel more confident in asking questions and more empowered to state their preferences."*
> **Project evaluation notes**

> *"Art-based learning improved understanding, recall, and confidence in discussing health topics. Increased confidence discussing personal health."*
> **Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics**

The workshops promoted informed choice by building the awareness, confidence and trust that are its preconditions. Participants left better equipped to recognise symptoms, know what to do about them, and feel empowered to raise them with carers and health professionals. A longer-term programme — with follow-up at 3, 6 and 12 months and dedicated capacity to collect data — would be able to demonstrate whether this shift in readiness translated into actual screening behaviour. The evidence from this project strongly suggests it would.

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LOGIC MODEL — LONG-TERM OUTCOMES

Evidence from Participant Surveys, Carer Feedback and Case Study Transcripts | 32 participants, 12 carers, 4 case studies, host orgaisation leads.

Long-term outcomes describe the sustained changes and systemic improvements the project is designed to contribute to over time. By their nature, these cannot be fully evidenced within a short project. This section draws on all available evidence — participant surveys, carer feedback, case study transcripts, host organisation leads and the wider literature — to assess the project's contribution and the direction of travel.

LONG-TERM OUTCOME 1

Earlier presentation, referral and diagnosis of cancer in people with Learning Disabilities

91%	68%	0
left knowing more about bowel health — the foundation for earlier presentation	would tell a doctor or nurse about blood in their poo — a direct precursor to referral	said they would tell no one about symptoms across all three workshops

Evidence Source	Finding
Participant surveys (32 participants)	91% of participants left knowing more than before — the main requirement for earlier presentation. 68% said they would tell a doctor or nurse about blood in their stool, a direct precursor to referral and diagnosis. Critically, participants showed appropriate escalation: more selected a doctor or nurse for the more serious symptom (blood in stool, 68%) than for constipation (54%), suggesting health messages were applied rather than passively recalled. Nobody said they would tell no one about symptoms.
Carer feedback (12 carers)	93% of carers observed a clear increase in knowledge in the person they support and reported feeling better equipped to recognise symptoms and support referral. Since carers are often the first to notice changes in the people they support, improved carer awareness directly strengthens the pathway to earlier diagnosis. Carers also reported greater confidence in raising the topic and knowing what to do next — reducing a key bottleneck in the referral chain.
Case study transcripts (4 participants)	Participants articulated health messages in their own words and in personal terms — connecting learning to their own lives and habits. Follow-up interviews confirmed retained knowledge over time, not just immediate recall. Participants who were initially reluctant to engage with the topic were actively discussing symptoms, diet and health by the end of each session and remained willing to do so in later interviews. Anecdotally, several indicated they would be more likely to complete a FIT test as a result of what they had learned.
Literature context	Bowel cancer accounts for approximately 18% of deaths in people with a Learning Disability annually — nearly double the general population rate — with 15% of those deaths in people under 50. Evidence suggests people with a Learning Disability should be offered bowel cancer screening from age 40. The LeDeR Report (2024) found missed appointments and lack of proactive follow-up to be key barriers. This project directly addressed the awareness, confidence and trust that underpin earlier presentation and screening engagement.

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"The session directly addressed known barriers for people with disabilities by using visual, hands-on learning rather than relying on written or verbal information alone."

Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

Earlier diagnosis cannot be confirmed without longer-term follow-up tracking screening uptake, GP presentations and referral rates at 3, 6 and 12 months. The current evidence is indicative rather than conclusive, but consistently and strongly points in the right direction.

The project established each of the preconditions for earlier presentation, referral and diagnosis: awareness of symptoms, confidence to discuss them, clarity about who to contact, and trust in health professionals. Whether this translates into measurable changes in diagnosis timing requires longer-term follow-up this project was not resourced to deliver — but the foundations are clearly in place.

LONG-TERM OUTCOME 2

Reduction in late-stage cancer diagnosis and emergency presentation

Late-stage diagnosis typically results from delays at multiple points along the pathway: failure to recognise symptoms, reluctance to discuss them, uncertainty about who to contact, and mistrust of healthcare services. The project directly addressed each of these.

Evidence Source	Finding
Participant surveys	The workshops improved recognition of warning signs (91% knew more after sessions), reduced embarrassment and reluctance to discuss symptoms (91% found it easier to talk), and increased clarity about who to contact for serious symptoms (68% would tell a doctor or nurse about blood in their stool). Taken together, these shifts reduce the likelihood of symptoms being ignored until they become severe enough to require emergency treatment. 78% of participants also correctly excluded all unhealthy foods — suggesting improved understanding of the lifestyle factors linked to bowel cancer risk.
Carer feedback	Carers reported increased ability to notice and act on changes in the health of people they support — an important safety net given that people with Learning Disabilities often rely on carers to initiate contact with health services. 83% of carers observed an increase in knowledge in the person they support. In Workshops 1 and 2, 100% of carers said the workshop made it easier for the person they support to talk — directly reducing a key barrier to timely presentation.
Case study transcripts	Participants who were initially anxious or resistant — including one who refused to discuss the topic at the start of the session — engaged actively by the end and continued to do so in follow-up interviews. This reduction in anxiety and resistance is precisely the attitudinal shift needed to reduce delayed presentation. Participants also made specific personal commitments — to drink less alcohol, eat less chocolate, drink more water — suggesting the workshops prompted health-conscious behaviour change consistent with lower cancer risk.

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System-level impact	The project strengthened local referral pathways: direct connections were established between care organisations and NHS professionals, the specialist nurse offered additional free awareness sessions, and Easy Read materials were distributed nationally. Stronger pathways reduce the risk of concerns going unactioned when they are raised — a key contributor to late-stage diagnosis.

> *"Everyone was buzzing, interested and glad they went. Some shared their own cancer stories."*
> **Janet Hawkins, Co-Production Lead, Camphill Village Trust**

The project addressed the root causes of late-stage diagnosis and emergency presentation at individual and system level. Longer-term follow-up is needed to demonstrate measurable reduction in late-stage diagnoses — but attitudinal / systemic conditions for that reduction were clearly established.

LONG-TERM OUTCOME 3

A sustainable VCSE-driven model for cancer awareness and prevention

Evidence Source	Finding
Project design & partnership model	The project was co-designed / delivered by Airlift (VCSE) in partnership with NHS professionals and VCSE host organisations — demonstrating that VCSE organisations can lead cancer awareness work with clinical credibility and community reach. The model combines NHS clinical expertise with VCSE community profile and trust. This complementary partnership supports a sustainable model.
Replicability & scalability	The creative workshop model is replicable: it requires a VCSE facilitator with arts skills, a specialist health professional, Easy Read materials, and a community venue. These components can be assembled across different settings and communities. Two host organisations already distributed Easy Read materials nationally within their organisations, suggesting organic scaling beyond the original project. The specialist nurse's offer of additional free awareness sessions provides a model for ongoing NHS engagement without significant additional cost.
Community reach	The project reached 35 participants and 13 carers in residential care and community settings — groups that standard NHS outreach rarely engages. Host organisations welcomed the project and expressed a desire for it to continue. The involvement of Experts by Experience as co-facilitators embedded lived experience into the model, increasing relevance and credibility for participants. This peer-led element is a key component of sustainable community health models.
Learning for future commissioning	The project surfaced important learning for future commissioning: VCSE organisations carry significantly less administrative capacity than NHS counterparts, and joint working models must account for this explicitly. Multi-year funding linked to outcomes — rather than short-term project grants — would enable VCSE organisations to build the relationships, infrastructure and evaluation capacity needed for a sustainable model. The common evaluation framework developed through this project provides a replicable basis for demonstrating impact.

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"Although a small project, it was extremely effective in strengthening the relationships with NHS and VCSE and the Learning Disabilities community. There was a strong desire from all concerned to find a way of improving cancer-related health outcomes for people with a learning disability."

Project evaluation notes

This project provides a proof-of-concept for a sustainable VCSE-driven model for cancer awareness and prevention among people with Learning Disabilities. The partnership model, replicable design, community reach and lived experience elements are all components of a scalable approach. Sustainability requires multi-year funding, dedicated evaluation capacity, and formal recognition within Integrated Care System planning — the evidence from this project makes the case for all three.

LONG-TERM OUTCOME 4

Personalised support and services for people with Learning Disabilities

Evidence Source	Finding
Workshop design & delivery	Every element of the workshops was co-designed specifically for people with Learning Disabilities: Easy Read materials, visual and hands-on learning methods, accessible language, a relaxed and humorous atmosphere, and the involvement of Experts by Experience. The approach was grounded in the principle that services must adapt to the individual — not the reverse. Carers were included as active participants, recognising that personalised support requires the whole network around a person, not just the individual themselves.
Participant surveys	The creative approach accommodated a wide range of learning styles and confidence levels — from participants who were initially very reluctant to those who quickly became enthusiastic contributors. 95% of all participants enjoyed the workshops, suggesting the design was broadly accessible. The provision of private conversations with the specialist nurse after each session respected individual preferences and created a space for personalised health discussion outside the group setting.
Carer feedback	Carers reported that the workshop gave them better tools to support the people they care for individually — understanding what to look out for, how to raise the topic, and how to support access to services. 93% of carers observed an increase in knowledge, with the most strongly understood messages being bowel health and healthy eating. Easy Read workbooks and leaflets were provided as take-home resources, enabling ongoing personalised reference and discussion.
Case study transcripts	Case study interviews revealed that participants connected workshop content to their own specific life circumstances — one participant related healthy eating to managing an eye condition; another described a personalised system of 'healthy pots and unhealthy pots' in their bedroom. This kind of personal integration is the hallmark of genuinely personalised learning. The follow-up interview format itself — conversational, flexible, non-threatening — also modelled the kind of personalised communication approach that health services need to adopt more widely.

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"The session directly addressed known barriers for people with disabilities by using visual, hands-on learning rather than relying on written or verbal information alone."

Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

The project demonstrated what personalised support looks like in practice for this community: co-designed, accessible, hands-on, peer-led, and built around the strengths and preferences of participants rather than the convenience of services. This model has direct implications for how NHS and VCSE services should design cancer awareness and screening support for people with Learning Disabilities going forward.

LONG-TERM OUTCOME 5

Case studies and evidence to drive further quality improvement

Evidence Source	Finding
Case study transcripts (4 participants)	Four in-depth case studies and comparison of follow-up interview responses with post-measures questionnaire data surfaces important nuances: which questions were misunderstood, where inconsistencies emerged, and what kinds of learning were most deeply retained. All four participants confirmed learning in both formats; all named specific creative activities, demonstrating genuine, retained engagement.
Participant & carer surveys	Multi-source surveys - post-workshop surveys for participants and carers, case study surveys, Expert by Experience surveys, and a co-producer end-of-project survey – provide evidence at every level of the project and provide triangulated evidence that strengthens the overall findings.
Insights for quality improvement	The evidence generated through this project identifies priorities for quality improvement in future workshops: greater emphasis on exercise and its link to bowel health; review of the drinks question wording (identified as potentially confusing by case study analysis); consideration of differentiated content for participants with higher baseline knowledge; and need for verbal follow-up with participants who find written survey formats uncomfortable or inaccessible.
System-level evidence	Beyond the workshops, the project generates evidence about systemic barriers and enablers: the importance of VCSE-NHS relationships; the administrative capacity gap between sectors; the need for multi-year rather than short-term funding; and the value of lived experience in co-facilitating health education. These insights have direct relevance for commissioning, partnership design and service development — and are documented here as evidence for future quality improvement across the system.

"Art-based learning improved understanding, recall, and confidence in discussing health topics."

Natalie Rodley Haines, Holistic Wellbeing Co-ordinator, Prosperity Holistics

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The project has generated a substantial and varied evidence base — quantitative survey data, qualitative case study transcripts, carer observations, and organisational feedback — that provides both proof of concept and a clear agenda for quality improvement. This evidence should be used to inform the design of future workshops, commissioning decisions, and the development of a sustainable long-term model. It also contributes to the wider evidence base on effective health education approaches for people with Learning Disabilities.

LONG-TERM OUTCOME 6

Accurate registration and data recording

Accurate data recording on Learning Disability status and cancer screening participation is essential for identifying inequalities, targeting resources and ensuring people receive appropriate support. This project contributes to improved data quality indirectly through several mechanisms.

Evidence Source	Finding
Increased engagement with services	By building awareness, confidence and trust, the project increases the likelihood that people with Learning Disabilities will engage with screening services — each engagement creating an opportunity for Learning Disability status to be identified, recorded and shared appropriately across GP, screening and hospital systems. 68% of participants said they would tell a doctor or nurse about a serious symptom; this increased contact with health services directly improves the visibility of the learning disabilities population within screening datasets.
Reduced missed appointments	The LeDeR Report (2024) highlighted missed appointments and a lack of proactive follow-up as key barriers to healthcare access for people with Learning Disabilities — and as a direct cause of incomplete patient records. By increasing confidence, understanding and trust in healthcare professionals, the project encourages greater engagement with screening and follow-up appointments, reducing gaps in patient records and generating a clearer picture of screening outcomes.
Stronger VCSE-NHS partnerships	The project created new direct connections between VCSE host organisations and NHS healthcare professionals. Stronger partnerships increase the likelihood that Learning Disability status is recognised and recorded consistently across different services — helping to address the longstanding problem of under-identification. Host organisations reported that these new connections gave them greater confidence in supporting the people in their care to access services and communicate their needs.
Better-informed participants and carers	As trust grows and participants feel more comfortable disclosing health needs, healthcare providers are better placed to understand and record individual requirements. Carers — better informed through the workshops — are more likely to advocate for appropriate reasonable adjustments and ensure needs are communicated to health services. When people understand why screening is offered, records are more likely to accurately reflect informed consent, informed decline, or genuine barriers, improving the quality of screening outcome data overall.

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Improvements to data recording cannot be directly measured through this project. The contributions described above are mechanisms by which the project is likely to support better data quality over time — but verification would require analysis of GP and screening records, which was outside the project's scope.

The project contributes to improved data recording and registration by increasing engagement with health services, reducing missed appointments, strengthening VCSE-NHS communication, and building the confidence of participants and carers to disclose needs and engage with screening. More people correctly identified, fewer incomplete records, and more accurately recorded outcomes — the long-term result of the awareness, trust and partnership-building this project delivered.

Conclusions

1

The Creative Health intervention approach works — and works well for this group.

Across all three workshops and all sources of evidence, the arts-based, hands-on approach was consistently confirmed as effective and appropriate for people with Learning Disabilities. 95% of participants enjoyed the workshops, said the activities made difficult topics easier to discuss and left knowing more than before. Carers independently corroborated this: 83% observed a measurable increase in knowledge in the person they support. Case study interviews confirmed that learning was retained over time and expressed in participants' own words — not just recalled in the moment. This is not a marginal result. It is a consistent, corroborated finding across multiple sources and three separate workshops.

2

The approach reaches people who are rarely reached — it meets them where they are.

People with Learning Disabilities are among the least likely groups to receive accessible health information in a format that works for them. This project reached 35 participants across residential care and community settings, many of whom had never previously encountered information about bowel cancer prevention in any accessible form. Participants who were reluctant or resistant at the start of sessions were actively engaging and laughing by the end. The creative, non-clinical, peer-led environment lowered barriers that formal health settings routinely fail to overcome. Reaching this group is not a minor operational achievement — it is a significant equity outcome in its own right.

3

The project established the preconditions for earlier presentation, referral & diagnosis.

Earlier diagnosis requires awareness, confidence, clarity and trust — and the project built all four. 91% of participants left knowing more about bowel health and warning signs. 90% found it easier to discuss the topic. Nobody across any workshop said they would tell no one about symptoms. Participants demonstrated appropriate escalation — more would tell a doctor or nurse about blood in the stool (68%) than about constipation (54%) — showing that health messages were applied rather than passively recalled. These are the behaviours associated with earlier presentation. Whether this translates into measurable changes in diagnosis timing cannot be confirmed without longer-term follow-up — but the conditions for it are in place.

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4	**Trust between participants, carers and healthcare professionals was strengthened.** The involvement of a specialist cancer nurse — participating in creative activities alongside everyone else rather than presenting from the front — was one of the most effective project design choices. It created genuine human connection in a non-clinical setting and broke down authority dynamics that formal healthcare encounters rarely dissolve. All host organisations expressed relief at having re-established direct links with NHS professionals. Two independently identified this as one of the most valued outcomes. The nurse's subsequent offer of additional free screening and awareness sessions is a direct and tangible result of that trust. These relationships have lasting value well beyond the workshops themselves.
5	**Carers are not a secondary audience — they are a critical part of the intervention.** 93% of carers said the workshop made it easier for the person they support to talk about the topic, and the same percentage observed an increase in knowledge. Carers reported feeling better equipped to notice changes, raise the topic, and support access to services. For many people with Learning Disabilities, a carer or family member is the gateway to health services — their knowledge and confidence is a direct enabler of earlier presentation and referral. The project recognised this by including carers as active participants, not afterthoughts. Any future model must continue to do so.
6	**Exercise and unhealthy foods are gaps that need addressing in future sessions.** Across all three participant surveys and all three carer feedback reports, exercise was the weakest area. Only 29% of participants identified both exercise images correctly; only 55% of carers felt the exercise message had been understood. Only 7% of participants identified all unhealthy foods. As physical activity is directly linked to bowel health and cancer risk, and its consistent under-recognition across all three workshops suggests it needs more prominent treatment in future session design. This is a clear and actionable recommendation, especially as Artlift delivers dance and movement based activities in other programmes.
7	**Written surveys alone are not sufficient for this group — verbal follow-up is essential.** Case study analysis revealed that written questionnaires sometimes missed nuance that interviews surfaced clearly. One participant was comfortable discussing the topic verbally but found the survey format uncomfortable and gave a different response in each format. Another left several answers blank that they addressed fully in interview. The drinks question was misinterpreted by at least one participant in a way the written survey did not reveal. This highlights a structural limitation of written evaluation tools for people with Learning Disabilities. Future projects should build in verbal follow-up as standard.
8	**The project generated system-level impact beyond the workshops themselves.** The reach of this project extended well beyond the 35 participants and 12 carers directly involved. Two host organisations distributed Easy Read materials nationally within their organisations. The specialist nurse offered additional free awareness sessions. New VCSE-NHS partnerships were formed. A further workshop was co-delivered at a large-scale GHC event. Important operational learning was generated about capacity differences between sectors. The Steering Group connections built across the project create a platform for future work. This system-level impact — often unmeasured in short projects — is as important as the individual participant outcomes, and arguably more durable.

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9	**The project is a proof-of-concept, not a finished model — and it requires sustained investment to fulfil its potential.** This project demonstrated clearly that the creative health intervention approach works. What it could not do, within its timescale and budget, is measure longer-term outcomes: screening uptake, GP presentation rates, referral patterns, or changes in diagnosis staging. To demonstrate these outcomes — which are the ultimate goal — a longer-term programme is needed, with follow-up at 3, 6 and 12 months, dedicated evaluation capacity, and multi-year funding linked to outcomes rather than short-term project grants. The evidence from this project makes a strong case for that investment. The model exists. The partnerships are in place. The next step is scale.

What the Evidence Does Not Yet Tell Us

It is important to acknowledge that there are limits to what a short-term project can demonstrate. The following questions remain open and should drive the design of any future programme:

Did screening uptake increase? — The project established the preconditions for increased FIT test completion and screening attendance, but direct measurement was not possible within the project's timescale. This is the most important unanswered question and requires structured follow-up at 3, 6 and 12 months to answer.

Were there fewer missed appointments or DNAs? — The attitudinal shifts observed (reduced anxiety, greater confidence, increased clarity about who to contact) are the proximate causes of DNA behaviour. Whether they translated into measurable reductions in missed appointments can only be confirmed through NHS appointment data linked to participants.

Did participants share knowledge with peers and families? — The conditions for peer knowledge-sharing were created (memorable creative outputs, take-home materials, visible and shareable items), but this could not be formally measured. A future evaluation should include questions to participants' networks, not just participants themselves.

What will happen to the VCSE-NHS connections post-project? — Partnerships formed are valuable but fragile, particularly given ongoing changes to Gloucestershire ICB structure and personnel. It is vital to maintain and build upon these partnerships to enable continuation of this work.

Final Conclusion

People with Learning Disabilities die from bowel cancer at nearly twice the rate of the general population, often younger, and often because of delays that accumulate across the entire pathway from awareness to diagnosis. These delays are not inevitable — they are the consequence of a health system that has not yet found consistent ways to reach, inform and support this community.

This project shows what is possible when it does. A small, well-designed, co-produced creative intervention — delivered in partnership between a VCSE organisation and NHS professionals, grounded in lived experience, and built around the strengths and preferences of participants — produced genuine, retained learning, increased confidence, reduced embarrassment, strengthened trust and built lasting connections across sectors.

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The evidence is consistent, corroborated and compelling. The model works. The gap it addresses is urgent. The case for continued, sustained and properly resourced investment is clear.

> *"The creative engagement is very effective at opening up sensitive topics. As a nurse I have learned from this. People appeared to leave with a sense of pride in what they had created."*
> **Rosie Mockford, Strategic Health Facilitator, Learning Disability Health Facilitation Team**

This project is not the end of something — it is the beginning of a sustainable, community-led approach to reducing cancer inequalities for people with Learning Disabilities. The foundations are built. The evidence is there. What is needed now is the will and the investment to take it forward.

Recommendations

These recommendations arise directly from the evidence gathered across this project — participant surveys, carer feedback, case study transcripts, host organisation leads, logic model outcomes assessment and qualitative observations from the delivery team and host organisations. They are directed at different audiences and grouped by theme. Each recommendation includes the evidence that underpins it and a clear proposed action.

ESSENTIAL — act now	HIGH — next programme	MEDIUM — within 12 months	DEVELOPMENTAL — longer term

1. Workshop Design and Content

1

Give exercise and its link to bowel health much greater prominence
Priority: ESSENTIAL Directed at: Artlift / Future Delivery Teams

WHY

Exercise was the weakest area across all three participant surveys and all three carer feedback reports. Only 29% of participants identified both exercise images correctly, and only 55% of carers felt the exercise message had been understood by the person they support. This is the single most consistent gap across the entire evaluation — it appeared in every workshop and was corroborated by both participants and carers independently.

RECOMMENDED ACTION

Redesign the exercise element of the workshop to give physical activity dedicated, prominent and visually compelling treatment. Consider a specific creative activity focused on exercise (e.g. movement-based activity or a dedicated collage), rather than including it as one item among several food and drink images. Ensure the link between exercise and bowel health is explicitly made and reinforced.

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2

Review and rephrase the drinks question and related evaluation items
Priority: ESSENTIAL Directed at: Artlift / Future Delivery Teams

WHY

Case study analysis across Workshops 1 and 2 identified that the drinks question ('what would you drink differently now?') was misunderstood by at least one participant, who answered in terms of their general drinking habits rather than identifying healthy options. This may have affected the reliability of responses from other participants who did not flag it verbally.

RECOMMENDED ACTION

Rephrase the drinks question to make it clearly about choosing healthy drinks rather than changing personal habits. For example: 'Which of these drinks would help make a happy poo?' Test rephrased questions with Experts by Experience before the next programme. Review all evaluation questions for similar ambiguity.

3

Develop differentiated content for participants with higher existing knowledge
Priority: HIGH Directed at: Artlift / Future Delivery Teams

WHY

Workshop 2, Case Study 2 noted that content felt 'a bit simple at times' — the only instance of this feedback across the project but a valid signal that some participants arrive with a higher baseline of health knowledge and may not be sufficiently stretched by the standard content.

RECOMMENDED ACTION

Design a simple baseline knowledge check at the start of each workshop to identify participants who may benefit from more advanced content. Develop a supplementary layer of content — on cancer biology, the FIT test process, or the screening pathway — that can be introduced flexibly for those who are ready for it without disrupting the experience for others.

4

Strengthen and expand the FIT test content within the workshops
Priority: HIGH Directed at: Nurse health practitioner / Future Delivery Teams

WHY

Anecdotally, participants indicated they would be more likely to complete a FIT test as a result of the workshops, but the surveys did not include specific questions about FIT test knowledge or intentions. Given that FIT test completion is a direct and measurable precursor to earlier diagnosis, it deserves dedicated treatment.

RECOMMENDED ACTION

Include a specific, hands-on explanation of what the FIT test is, why it matters for people with Learning Disabilities specifically, and exactly how to complete it. Use Easy Read instructions and consider a practical demonstration. Add FIT test intentions to the evaluation survey to track impact.

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2. Evaluation Design

5

Make verbal follow-up a standard part of evaluation — not an optional extra
Priority: ESSENTIAL Directed at: Artlift / Evaluation Team

WHY

Case study analysis showed that written surveys missed nuance that interviews surfaced. One participant, comfortable discussing the topic, gave different answers in the written format. Others left answers blank in the survey that they addressed fully in interview. Written surveys are a structural limitation for this group, not just an individual preference issue.

RECOMMENDED ACTION

Build verbal follow-up interviews into the standard evaluation framework for all future workshops, not just for identified case study participants. Consider a short structured conversation (10–15 minutes) with a sample of participants from each workshop as a minimum. Train delivery staff or volunteers in simple qualitative interview techniques. Ensure the evaluation budget reflects this.

6

Build in longitudinal follow-up at 3, 6 and 12 months with dedicated capacity
Priority: ESSENTIAL Directed at: Commissioners /Artlift / Evaluation Team

WHY

The project could not measure the medium and long-term outcomes — screening uptake, GP presentation rates, referral patterns, DNA rates — because its timescale and budget did not allow for structured follow-up. These are the outcomes that matter most for demonstrating impact on cancer inequalities, and without them the evidence base remains incomplete.

RECOMMENDED ACTION

Design any future programme from the outset with formal follow-up at 3, 6 and 12 months. Allocate dedicated project staff time for follow-up — do not rely on venue or organisation staff who may have moved on. Develop a simple follow-up survey that can be administered verbally and which tracks: screening uptake, symptom reporting behaviour, and confidence in discussing health concerns. Agree data sharing protocols with host organisations at the start of the project.

7

Extend evaluation reach to participants' networks — peers, family and carers
Priority: HIGH Directed at: Artlift / Evaluation Team

WHY

The project could not formally measure peer knowledge-sharing — one of the logic model's medium-term outcomes. Yet the conditions for it were clearly created, and its impact could significantly multiply the reach of the intervention beyond direct participants.

RECOMMENDED ACTION

Add a short follow-up question to carers and host organisations at 3 months asking whether the person they support has discussed the workshop content with others. Design a simple peer-report tool for use with family members or friends where appropriate. Track national distribution of Easy Read materials by host organisations as a proxy measure of reach beyond the workshop group. This needs to be reflected in the budget.

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8

Collect demographic data including ethnicity, age and support needs
Priority: MEDIUM Directed at: Artlift / Evaluation Team

WHY

Workshop photos and observational notes suggested limited ethnic diversity among participants, but no demographic data was collected. Without this, it is not possible to assess whether the project is reaching all parts of the Learning Disabilities community equally, or whether certain groups require additional outreach or tailored approaches.

RECOMMENDED ACTION

Include brief, accessible demographic questions in the Easy Read evaluation surveys. Disaggregate results by demographic group where sample sizes allow. Use this data to inform outreach strategy and ensure the programme reaches those most at risk of cancer inequalities within the Learning Disabled community. This needs to be reflected in the budget.

3. Commissioning and Funding

9

Commission a longer-term, properly resourced programme — not another short project
Priority: ESSENTIAL Directed at: Gloucestershire ICB / Commissioners

WHY

The greatest limitation was timescale and budget. A project of this kind requires time to build relationships, refine content, reach new communities, and for follow up to measure lasting impact. In addition, a higher access budget was needed to account for Easy Read translation and travel allowance for Experts by Experience, especially due to rural locations. Short-term project grants produce short-term evidence. A longer-term programme would better demonstrate measurable change in screening uptake, referral rates and cancer outcomes.

RECOMMENDED ACTION

Commission a minimum two-year programme with multi-year funding linked to outcomes including screening uptake, GP presentations and referral rates. Include a formal evaluation budget (minimum 15% of total project cost) with capacity for longitudinal follow-up. Specify that the programme must be co-designed with people with Learning Disabilities, delivered in VCSE–NHS partnership, and evaluated using both quantitative and qualitative methods.

10

Recognise and account for the administrative capacity gap between VCSE and NHS
Priority: ESSENTIAL Directed at: Gloucestershire ICB / Commissioners

WHY

VCSE organisations carry much less administrative capacity than NHS counterparts. Joint working models that treat them as equivalent create an unfair burden. As the scope of the work broadened, IG reported the additional work requested would cost more than budgeted and Artlift led engagement, outreach, co-design, delivery and evaluation — roles that in an NHS-led project would be distributed across multiple staff members. Artlift contracts mostly Self-Employed staff so contracts / capacity have to be renegotiated when project parameters change. Also, whilst NHS partners had the required staffing at the commencement of the project, considerable organisational change meant members the original team departed before the end of the project. Partners discussed what felt unrealistic within originally agreed

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parameters / budget, and commissioners were understanding and supportive, including sourcing more funds for additional VCSE capacity and resources mid-project.

RECOMMENDED ACTION

When commissioning VCSE-led health programmes, explicitly resource the administrative and coordination functions required. Do not assume VCSE organisations can absorb significant additional reporting and administrative requirements without additional capacity funding. Develop partnership agreements at the outset that clearly specify each organisation's responsibilities and resources.

Sustain and formalise the VCSE-NHS partnerships built through this project
Priority: HIGH Directed at: Gloucestershire ICB / VCSE Partners

WHY

11 All host organisations valued their reconnection with NHS healthcare professionals — some described it as a link they had not had for years. The specialist nurse's offer and delivery of additional free awareness sessions, and the distribution of Easy Read materials nationally by two host organisations, demonstrate that these partnerships have value and momentum beyond the project itself. This momentum must not be lost.

RECOMMENDED ACTION

Find a mechanism — a steering group, network or forum — for ongoing VCSE-NHS collaboration on cancer awareness and prevention for people with Learning Disabilities in Gloucestershire. Ideally, use existing mechanisms with which it's realistic for capacity-poor VCSE organisations to engage. Ensure the specialist nurse and key VCSE partners are included. Document and share the partnership model as a template for other areas. Monitor the sustainability of connections as ICB structure and personnel continue to change.

4. System and Service Development

Use the Easy Read materials developed through this project — and develop more
Priority: HIGH Directed at: NHS Gloucestershire / Primary Care

WHY

12 A comprehensive suite of Easy Read materials was developed and tested through this project, including information documents, evaluation surveys, media consent forms and meeting agendas. Two host organisations requested digital copies and distributed them nationally, demonstrating that the materials have value beyond the immediate project. There is currently a shortage of high-quality, co-produced Easy Read cancer health information for people with Learning Disabilities.

RECOMMENDED ACTION

Make all Easy Read materials developed through this project freely available to NHS services, VCSE organisations and care providers across Gloucestershire and beyond. Develop additional Easy Read materials covering the FIT test process, what to expect from a bowel cancer screening appointment, and how to request reasonable adjustments. Ensure materials are updated when screening guidance changes.

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13

Improve reasonable adjustments for bowel cancer screening for people with a learning disability

Priority: MEDIUM Directed at: NHS Gloucestershire / Screening Services

WHY

The LeDeR Report (2024) found that 27.3% of adults with a Learning Disability who died in 2023 had needed at least one reasonable adjustment that was not provided. Participants and carers described practical barriers including difficulty understanding FIT test instructions, transport difficulties, and a lack of alternative examination methods. These are system failures, not individual failures.

RECOMMENDED ACTION

Audit the reasonable adjustments currently available within Glos bowel cancer screening services and identify gaps. Develop and implement a reasonable adjustments protocol specific to people with Learning Disabilities, including Easy Read instructions for the FIT test, proactive follow-up for missed appointments, support for carers to accompany participants, and alternative examination methods where standard methods are not accessible.

14

Develop a sustainable VCSE-led cancer awareness and prevention model

Priority: DEVELOPMENTAL Directed at: NHS Gloucestershire / Commissioners

WHY

This project is a proof-of-concept. The evidence demonstrates that a VCSE-led, co-produced, Creative Health education model can reach people with Learning Disabilities, produce genuine learning, build trust and strengthen system connections. Scaled up, with sustained funding and proper evaluation infrastructure, this model has the potential to make a measurable difference to cancer outcomes for this community.

RECOMMENDED ACTION

Commission a feasibility study for a sustainable VCSE-led cancer awareness and prevention model for Gloucestershire, incorporating community cancer champions with lived experience; VCSE-led hubs within ICS structures; multi-year outcome-linked funding; and a common evaluation framework. Use the evidence, materials and partnerships from this project as the foundation. Consider how the model could be adapted for other underserved communities facing similar barriers.

"There was a strong desire from all concerned to find a way of improving cancer-related health outcomes for the learning-disabilities community. It remains to be seen where and how these can be maintained with the changes in the structure and personnel."

Project evaluation notes

These recommendations span immediate improvements to workshop design and evaluation, through to longer-term commissioning and systemic change. The most urgent — reflected in the four ESSENTIAL recommendations — are those that would most directly strengthen the evidence base and the model for the next programme. Without longitudinal follow-up, a longer-term commission, and proper resourcing of the VCSE partners who deliver this work, the potential demonstrated by this project will remain unrealised.

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