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The Introduction of Cancer Screening Within an Enhanced Physical Health Clinic for People With Intellectual Disabilities and Mental Health Difficulties

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ABSTRACT

People with intellectual disabilities (ID), particularly those with co-existing mental health difficulties, experience health inequalities and premature mortality. Cancer is a prominent cause of mortality, partially due to the difficulties this population faces in accessing screening. This paper explores the rates of colorectal, breast, cervical and prostate screening over a 28-month period within an Enhanced Physical Health Clinic (EPHC) set within a specialist ID psychiatry service in Essex, United Kingdom (UK). We examined completion of, and any barriers to screening among EPHC patients ($n=463$), and compared this to population-wide screening data in the UK among people with an ID. The EPHC facilitated support with screening by providing reasonable adjustments, including providing easy-read leaflets or booking appointments. The number of patients eligible for screening was colorectal ($n=83$), breast ($n=73$), cervical ($n=120$) and prostate ($n=50$), respectively. In comparison to the population-wide data available for people with ID, successful screening by EPHC patients was significantly higher for colorectal (93% vs. 78%), breast (74% vs. 53%) and cervical screening (40% vs. 31%). While there is no national prostate screening programme to generate comparison figures, 98% of those eligible accessed screening through the EPHC. These results suggest that the EPHC, which operates within a specialist ID psychiatry service in secondary care, is an innovation that may help improve cancer screening rates.

1 | Introduction

Among people with intellectual disability (ID), cancer is the second highest cause of mortality, recorded in 14.6% of adult deaths reviewed by the Learning from Lives and Deaths: People with a Learning Disability (LEDER) (White et al. 2023). People with ID have a 1.6-fold increased risk of cancer before the age of 43 (Liu et al. 2021), with females having an increased risk compared to males, specifically in younger age groups (Heslop et al. 2022). People with ID are frequently diagnosed in late stages of the cancer disease (Heslop et al. 2022). Accordingly, elevated mortality

rates are reported for cancer patients with ID compared with the general population (Sappok et al. 2025).

Sappok et al. (2025) summarised several factors that impact the susceptibility of people with ID to cancer and poorer outcomes from the disease. ID may be an under-recognised driver of cancer mortality. Difficulties accessing healthcare and differences in cancer treatment decision-making may further contribute to increased mortality rates. The authors reported that for several cancer types, consistently lower rates for surgery, chemotherapy or radiotherapy were provided for people

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with ID. In many cases, cancer is diagnosed as an incidental finding during an emergency (Sappok et al. 2025). Additional problems such as barriers in communication, lack of training and knowledge of clinical staff, and discriminative attitudes further increased poorer outcomes. Further factors include poorer quality of cancer care, poorer access to state-of-the-art care or curative therapies, delays in treatment, undertreatment or overly invasive treatment, poorer access to inpatient services, reduced utilisation of specialists and inadequate quality of care at the end of life (Tosetti and Kuper 2023). Studies, therefore, consistently highlight the need to improve preventative measures such as cancer screening in people with ID (Liu et al. 2021).

Although early cancer diagnosis is improving for those with ID, difficulties with screening and diagnosis remain (Satgé et al. 2020). It has been stated that people with ID 'participate less frequently' or have 'lower participation' in screening programmes (Sappok et al. 2025; Satgé et al. 2020). This language suggests a level of active disengagement from screening among individuals with ID. Yet people with ID are rarely independent in managing their own health, relying considerably on family or paid carers (Greaves et al. 2023). Taking part in screening remains the personal choice of the individual, considering the associated risks (such as false positive results and discomfort with certain tests). However, there is a need for assertive, proactive engagement of people with ID in order to provide equitable access to screening, and the onus for this is on healthcare providers.

Indeed, the most recent LEDER review (White et al. 2023) highlighted that some people with ID had not received health screening in keeping with national programmes, which may have delayed the early identification of disease. Reviewers mentioned that screening was missed because of practical issues (such as transport to and from appointments), a lack of reasonable adjustments or alternatives (such as different examination or investigation methods) and a lack of proactive follow-up when screening appointments were missed (White et al. 2023). As such, these are modifiable reasonable adjustments¹ that can be targeted within screening interventions.

It is likely that these issues particularly affect patients with ID under the care of secondary psychiatric services, due to co-existing mental illnesses, other neurodevelopmental disorders, personality difficulties, complex trauma and substance misuse (Alexander et al. 2021). Traditionally in the UK, cancer screening invitations require the person to be registered with a primary care provider, and appointments are offered by mainstream secondary health services, which may not have experience in supporting people with ID and their comorbidities. There is therefore a case to explore whether people with ID and psychiatric comorbidity would benefit from support to access screening from services that they already access for mental healthcare. The Enhanced Physical Health Clinic (EPHC) is an innovation offering a range of physical health services, including screening for cancer, within a secondary care setting offering community mental health services for people with ID and co-existing psychiatric or behavioural difficulties. In the UK, bowel, breast, cervical screening are available within the national screening

programme, alongside an 'informed choice' programme called prostate cancer risk management (NHS UK 2024a). As such, we will focus on these screenings among people with ID and the specific barriers to screening for these observed in this population.

2 | Aim

This paper is a descriptive account and service evaluation of the cancer screening programme facilitated by an EPHC attached to a specialist psychiatry of ID service in Essex, UK. The structure, staffing and preliminary evaluation of the EPHC have been described elsewhere (Sawhney et al. 2025).

3 | Method

3.1 | Participants/Setting

Participants were patients treated within the EPHC hosted by Hertfordshire Partnership University NHS Foundation Trust (HPFT). The EPHC service is designed to improve physical health outcomes for patients within secondary care specialist ID services in Essex and who are on psychotropic medications. Participants were the caseload of patients supported by the EPHC during the timeframe of the team being operational, from 2021 to 2023 ($n=463$ patients).

The patient cohort was predominantly male, with 288 men (62%) and 175 women (38%), and no patients were transgender or non-binary. The average age of the population was 44, with a range of 17–85. The females in this sample were significantly older than the males (45.7 ± 15.53 years vs. 42.23 ± 16.8 years; $t[454] = 2.198$, $p = 0.028$). Regarding the levels of ID, recorded for 415 patients, one patient had a borderline level; the majority had a mild degree of impairment ($n = 184$, 44%), followed by moderate ($n = 123$, 30%), severe ($n = 107$, 26%) and no patients had a profound level.

3.2 | Measures and Procedure

Data for each patient assessed by the EPHC was recorded on a database by the clinic team. The database recorded socio-demographic variables, physical and mental health diagnoses according to ICD-10 criteria (World Health Organization 1993), and records of tests and assessments offered through the clinic. The EPHC offers two main functions: (1) cardiometabolic monitoring and monitoring of factors potentially related to psychotropic medication side effects and (2) comprehensive health assessment, through which a wide range of tests are offered to patients, including access to screening.

Of the 11 national screening programmes (NHS UK 2024a) offered by the National Health Service (NHS) in the UK, three are for cancers: bowel, breast and cervical. The EPHC offers input to increase access to these three, as well as prostate cancer screening. While data suggest people with ID have a reduced risk for prostate cancer (Ward et al. 2024), this is not necessarily an indicator of reduced risk, as this population

has low awareness of their prostate health needs (Hogg 2015). There was an opportunity to offer proactive screening within the clinic, and this was implemented. Over a 28-month period between 2021 and 2023, breast, cervical, bowel and prostate screening was offered to all eligible patients. Box 1 details the relevant procedures involved in the four screenings supported by the EPHC.

In terms of supporting patients to access screening, the EPHC provided health education to increase knowledge and awareness of patients and carers, provided easy read health information leaflets, provided practical support with booking appointments, utilised social stories, made home visits for more anxious patients and liaised with professionals in specialist screening services to request reasonable adjustments.

3.3 | Analysis

Patients eligible for each cancer screening were identified. They were divided into two subgroups. The first was those who had received the screening for which they were eligible (screening was recorded complete if the person successfully had the screening or been booked in). The second was those who had not received the screening they were eligible for, with reasons recorded. Reasons included those who refused screening, those who professionals concluded as not suitable for screening after a best interest assessment, those whose screenings were unsuccessful due to health barriers and those where enough information was not available.

We used chi-square tests to determine whether a patient's age or level of ID (mild, moderate, severe) (where recorded) predicted the likelihood of successfully receiving screening. The two proportion Z-test was used to compare the screening rates in our EPHC study sample, with previously reported population-wide UK data on screening rates for people with ID (NHS Digital 2019). This information is collected on people with and without ID and represents around half of GP practices in England between 2014–15 and 2017–18 (NHS Digital 2019). Significance was set as $p < 0.05$. The population sample size is not stated but we can reasonably infer that it is at least 10 times greater than our own sample size, and we therefore used the z-test for two proportions method to determine whether our rates were significantly different to the population data (we assumed population size to be 1000 cases, which is a conservative estimate). For bowel screening, the number of patients who did not complete their screening was too low ($n=6$) to permit comparison via chi-square.

4 | Ethics

The study was registered with the Practice Audit and Clinical Effectiveness team at Hertfordshire Partnership University NHS Foundation Trust. As the study utilised routinely collected data, it meets criteria for a service evaluation, thus not requiring approval from an NHS Research Ethics Committee (Health Research Authority 2017).

BOX 1 | Procedures for bowel, breast, cervical and prostate screening in the NHS.

Breast	Mammograms (breast X-rays) assessing cancers that are smaller and more difficult to detect (NHS UK 2024b). Screening is offered to anyone registered with a General Practitioner (GP) as female between the ages of 50 and 71 every 3 years. If a patient identifies as a trans man, trans woman or non-binary they may be either invited automatically or need to talk to their GP surgery (NHS UK 2024g). At the appointment, a mammogram is taken for each breast. The mammographer places the breast onto the X-ray machine into two pieces of plastic to keep the breasts still while the X-ray is taken. The appointment lasts approximately 30 min (NHS UK 2024e)
Cervical	A 10-min appointment to check the health of the cervix is offered to women and people with a cervix aged 25–64 every 5 years (NHS UK 2024c). During the screening, a speculum (a smooth, tube-shaped tool) is gently put into the vagina. The speculum is opened so the cervix can be seen, and a small sample of cells is taken with a soft brush (NHS UK 2024f)
Bowel	Conducted via a faecal immunochromatographic test (FIT) which looks for blood in a sample of poo, which could indicate bowel cancer, and is offered to everyone aged 54–74 every 2 years. The test is taken by the patient, with a bowel cancer screening home test kit (NHS UK 2024a). For bowel screening, the EPHC service proactively ordered bowel kits for the patients
Prostate	Offered through a Prostate Specific Antigen (PSA) test, a blood test which helps to check for prostate conditions, including prostate cancer. In the UK at present, there is no national prostate screening programme. Instead, there is an 'informed choice' programme called prostate cancer risk management, where men aged 50, or anyone aged 50 or over with a prostate, can ask their GP for the screening (NHS UK 2024d). For the PSA screening in the EPHC clinic, the test was completed as part of the patient's routine blood tests, a separate blood test for this was not needed

TABLE 1 | Screening completions/non-completions within EPHC.

	Bowel (colorectal) screening	Breast screening	Cervical screening	Prostate screening
Eligibility	People aged 60–74	People who have breasts, due to either naturally occurring oestrogen or oestrogen hormone therapy aged between 50 and 70	People with a cervix and aged between 25 and 64	People with a prostate aged 50+
Number eligible	83	73	120	50
Screening completed or booked	77 (93%)	53 (73%)	48 (40%)	49 (98%)
Screening not completed or booked due to:				
Refusal by patient	1 (1%)	1 (1%)	4 (3%)	0
Considered not in best interest	1 (1%)	3 (4%)	4 (3%)	0
Unsuccessful due to health barriers	1 (1%)	13 (18%)	55 (45%)	0
Exempt/not enough information	3 (4%)	3 (4%)	9 (8%)	1 (2%)

TABLE 2 | Screening uptake comparisons.

	EPHC service	Previously reported screening rates in people with ID (NHS Digital 2019)	Comparison
Bowel (colorectal) screening completed or booked	93%	78%	<i>p</i> =0.002*
Breast screening completed or booked	73%	53%	<i>p</i> =0.001*
Cervical screening completed or booked	40%	31%	<i>p</i> =0.045*

*Statistically significant.

5 | Results

5.1 | Screening

Screening rates during a 28-month period between 2021 and 2023 are summarised in Table 1.

Table 2 compares the screening rate in our EPHC study sample with the population-wide data (NHS Digital 2019). Within the EPHC sample, rates of completion were significantly higher for all three screenings for which there is available comparison data (bowel, breast and cervical). As there is no national screening programme in the UK for prostate cancer, comparison data is not available. For prostate cancer screening, 50 patients were eligible, 49 (98%) completed screening and data were missing for one patient.

5.2 | Screening by Age and Sex

We further examined our data to look at sex and age. For breast and cervical screenings, the samples were entirely female. For bowel screening, the numbers of male/female patients in the

two groups were too small to permit statistical analysis, and there is no obvious trend in the data.

We examined whether there was a difference in the average age of patients who completed or who did not complete screening. The mean ages of these two groups were very similar for the bowel, breast and cervical screening, with none approaching statistical significance ($p>0.1$ for all). As the rate of completed prostate screenings was so close to 100%, there was no need for comparison between groups.

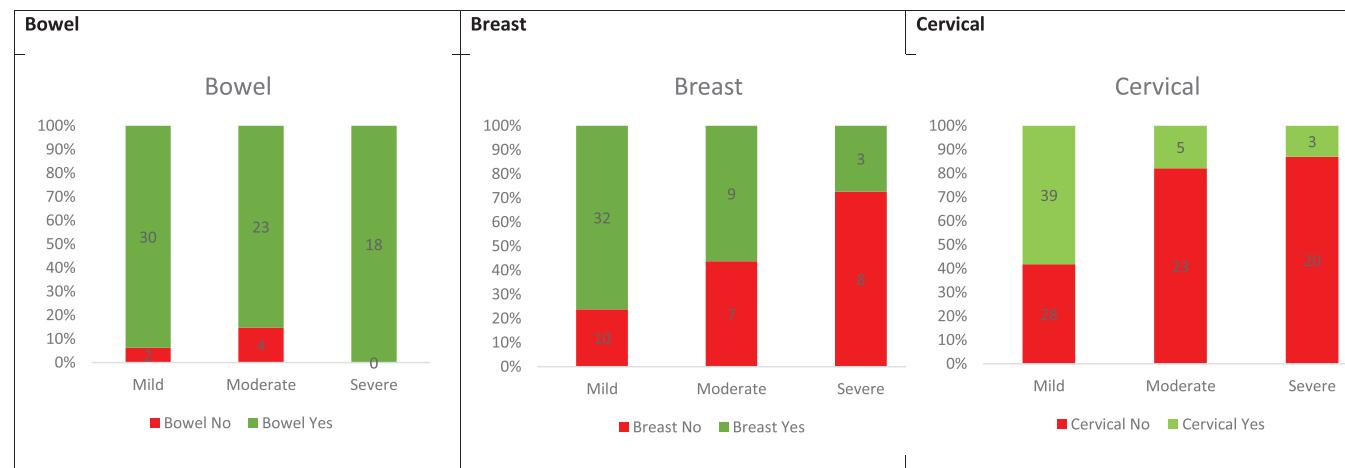
5.3 | Screening by Degree of ID

Finally, we examined whether the degree of ID (mild, moderate, severe) predicted successful screening. The frequencies within each degree of ID are displayed in Table 3 and Figure 1. The frequency totals in Table 3 are slightly lower than those in Table 1 as there were some patients for whom the ICD-10 code for ID was missing. For both breast and cervical screenings, there was an association between screening and the level of ID: people with mild-ID were significantly more likely to have completed the screening. Since the rate was close to 100% with

TABLE 3 | Screening by level of intellectual disability.

Screening type	Completed?	Mild	Moderate	Severe	Chi-square, p
Bowel	No	2	4	0	Sample too small to test
	Yes	30	23	18	
Breast	No	10	7	8	9.54, 0.009*
	Yes	32	9	3	
Cervical	No	28	23	20	21.97, 0.0002*
	Yes	39	5	3	

Note: The asterisk denotes statistical significance.

**FIGURE 1** | Screening by level of intellectual disability.

prostate screening, there was no need for comparison between groups.

6 | Discussion

This study has evaluated whether an EPHC, offered through a secondary care psychiatry service in the UK, which supports patients with ID and psychiatric or behavioural difficulties, has utility in increasing screening. The EPHC challenges the traditional assumption that physical health screening for this population should be viewed solely as a primary care responsibility. The preliminary evaluation has suggested success in facilitating access to healthcare in a particularly disadvantaged patient population (Sawhney et al. 2025). In this study, we examined rates of completed bowel, breast, cervical and prostate screenings facilitated through the EPHC, as compared to previously reported population-wide UK data on screening rates for people with ID (NHS Digital 2019).

For the screenings where comparative data was available (bowel, breast and cervical), the EPHC completed significantly higher rates than those previously reported in this population (NHS Digital 2019). For bowel screening, the proportion of completed screenings facilitated through the EPHC reached 93%, as compared to 78% previously. Completed breast screenings in the EPHC reached 73%, compared to 53% previously. Rates of cervical screenings were 40% vs. 31% previously. In those receiving input through the EPHC, completed prostate screening

was 98%. There were no significant differences in the average age of patients who completed and those who did not complete screening. We could not assess the impact of sex due to the small sample sizes within subgroups. Overall, these findings suggest that the proactive support and reasonable adjustments offered by the EPHC went some way to improving screening rates among a population of people with ID and additional psychiatric comorbidity.

However, results were not consistent across screenings, with the highest rates observed for prostate, bowel, breast and cervical cancer being the lowest. These findings are not unique to this study and represent factors such as discomfort within tests, alongside other barriers to completed screenings. We also observed a relationship in the rates of successful screenings, the degree of ID (mild, moderate, severe) and whether bowel or breast screening was completed, with people with mild ID being more likely to have received screening compared to those with moderate-profound levels of difficulty. A similar but non-significant trend was observed for cervical screening. These findings need further research, although we offer some preliminary explanations. Those with the higher degrees of ID experienced the most difficulty with understanding the requirements of the screening, for example, what was happening to them. Many barriers to screening affect those with more severe degrees of disability to a greater degree. For example, staff concerns around communication, capacity and consent disproportionately affect this group. The government has described these

barriers in a guidance document designed to better support women with ID to access screening and provided suggestions for increasing rates that include liaison between cervical screening clinics and ID services, best interest decision meetings and other reasonable adjustments (HM Government 2019).

This paper has some limitations which should be considered when evaluating its findings. It was a service evaluation conducted at a single centre within one NHS provider organisation, and our data were collected retrospectively from existing case records. It was not a research study, and so the only comparison data was previous screening rates collated by NHS Digital (2019). The data which informs these statistics is taken from NHS systems which have received some criticisms, such as difficulties integrating care records and in data transfer between primary and secondary care. Patients may be lost to follow-up as they move between GP practices and areas, and some groups, such as those who are homeless, are not represented due to not having a GP registration. Some patients choose to be screened privately or abroad, which is not recognised in the UK, so would appear to have not attended screening. Factors such as this can limit the reliability of this data (Lewisham Council 2024). This limits the extent to which the evaluation's findings can be generalised.

Nonetheless, our paper describes a model where a group of patients with ID and co-existing psychiatric or mental health difficulties achieved higher screening rates and physical health outcomes through input from a secondary care psychiatric service. It is widely recognised that greater attention on the disparities in cancer care for individuals with ID is long overdue (The Lancet Oncology 2024). As the heterogeneity within the ID population challenges precise cancer risk assessment at the population level, more personalised approaches in cancer screening within the ID population are necessary (Banda et al. 2024). The EPHC, working in liaison with existing structures in primary care, is an example of a person-centred approach. The authors feel that the therapeutic relationship that patients already have with professionals within this secondary care provision has the potential to increase the motivation of eligible patients to engage in the screening process. This is further aided by the practical support offered by the EPHC, such as easy read health education resources to increase knowledge and awareness of patients and carers, support with health/screening anxiety, booking appointments and liaison to request reasonable adjustments. Future studies that evaluate the efficacy or otherwise of similar services are needed.

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The authors have nothing to report.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Endnotes

¹Reasonable adjustments are positive measures that can be implemented at an organisational, system or individual level to address the healthcare inequalities experienced by people (Heslop et al. 2019).

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