The Introduction of Cancer Screening within an Enhanced Physical Health Clinic for People with Intellectual Disabilities Prescribed Psychotropic Medication

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ACKNOWLEDGEMENTS

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OVERVIEW

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Cancer Screenings & Enhanced Physical Health Clinic

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Background

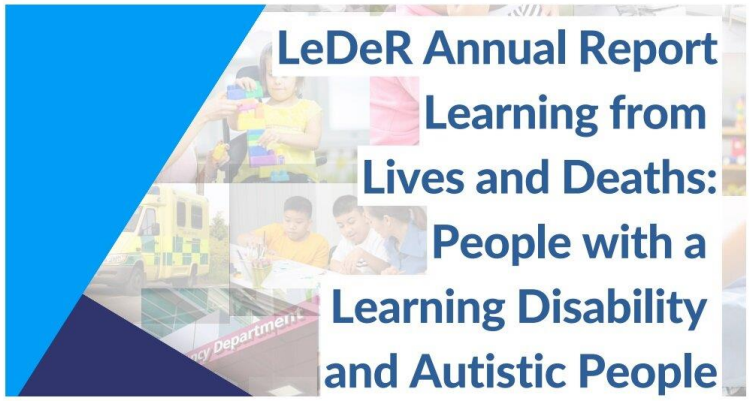
Background

People with intellectual disabilities (ID), particularly those with co-existing mental health difficulties, experience considerable health inequalities.

Cancer is a prominent cause of premature mortality in this group.

A contributor to the latter is the difficulty in accessing screening and early identification.

Background



According to LeDeR, in those with ID and autism, cancer is the second commonest cause of mortality and is recorded in **14.6% of all deaths**

Background

A Swedish study showed that people with ID were at a 1.6-fold increased risk of cancer before the age of 43.

Females with ID have an increased risk of cancer compared to males, with this mainly being seen in the younger age groups.

Background

The MENCAP report, **Death by Indifference**, identified how treatable causes of physical illnesses including cancer were not identified by clinicians.

Tuffrey- Wijne & Hollins (2014) identified reasonable adjustments as the key to preventing these.

Background

What are the factors that increase the susceptibility of people with ID to cancer?

1) Physical health
2) Genetic
3) Social
4) Psychological

Background

Physical Health Factors

Cancer diagnosis and subsequent treatment might be potentially delayed in patients with existing physical multi-morbidities

The presence of other chronic diseases may affect participation in seeking help for any newly discovered/changing symptoms, cancer screening, and the clinicians' decision-making regarding use of investigations

Background

Genetic Factors

Genetic syndromes, such as Down's syndrome and neurofibromatosis, are associated with ID and carry an increased risk for cancer.

There are reports of an increased risk of cancer in patients with autism due to pleiotropic genes (underlying genes that affect autism and genes that affect cancer)

Background

Social Factors

People with ID are vulnerable due to social limitations, such as being less able to communicate pain and self-advocate for their needs

A lack of accessible guidance and public health messaging for patients with ID can also delay diagnosis

Background

Psychological Factors

Often have co-existing mental health difficulties and diagnoses including mental illnesses, other neurodevelopmental disorders, personality difficulties, complex trauma, and substance misuse

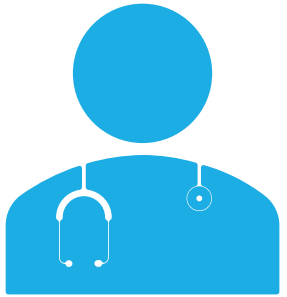
They have an increased chance of being prescribed psychotropic medication and may experience more side effects

The stigma around mental health difficulties may lead to physical health checks and access to primary care, being less prompt than ideal

Enhanced Physical Health Clinic

Enhanced Physical Health Clinic

At present, the monitoring of physical health conditions related to mental health difficulties or use of psychotropic medication are carried out in primary care



Service users who are currently open to a secondary care intellectual disability mental health team

On psychotropic medications

THE CLINIC

To improve the physical health outcomes by supporting patients to uptake eligible screening

Appropriate treatment of any identified health needs

CANCER SCREENINGS OFFERED

There are 11 national screening programmes offered by the NHS which includes 3 for cancers- bowel, breast, cervical

The EHPC offers input to increase access to these three

In addition, prostate cancer screening was added by the service to the list of cancer screenings

AIM OF THIS STUDY

This is a service evaluation of the cancer screening programme facilitated by the EPHC attached to a psychiatry and mental health service in Essex, UK.

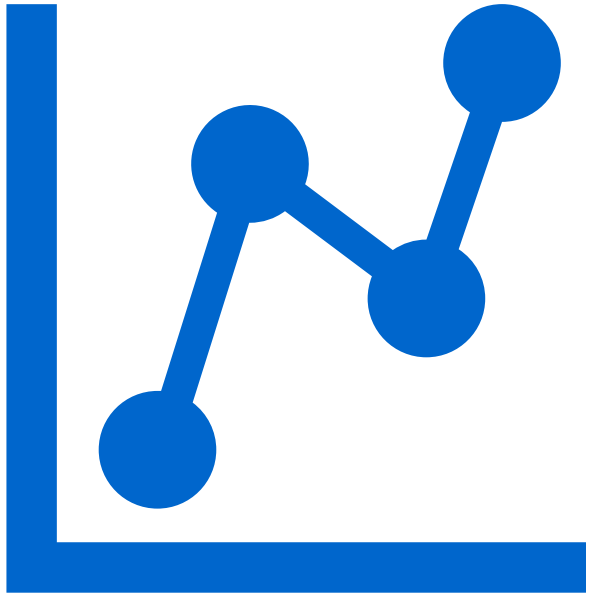
It gives a descriptive account of the cancer screening programme implemented with support from the clinic.

PARTICIPANTS AND SETTING

n = 463

2021-2023

DATA



Data for each patient assessed by the EPHC was recorded on a database.

The database collected:

Socio-demographic variables

Physical and mental health diagnoses

Records of tests and assessments

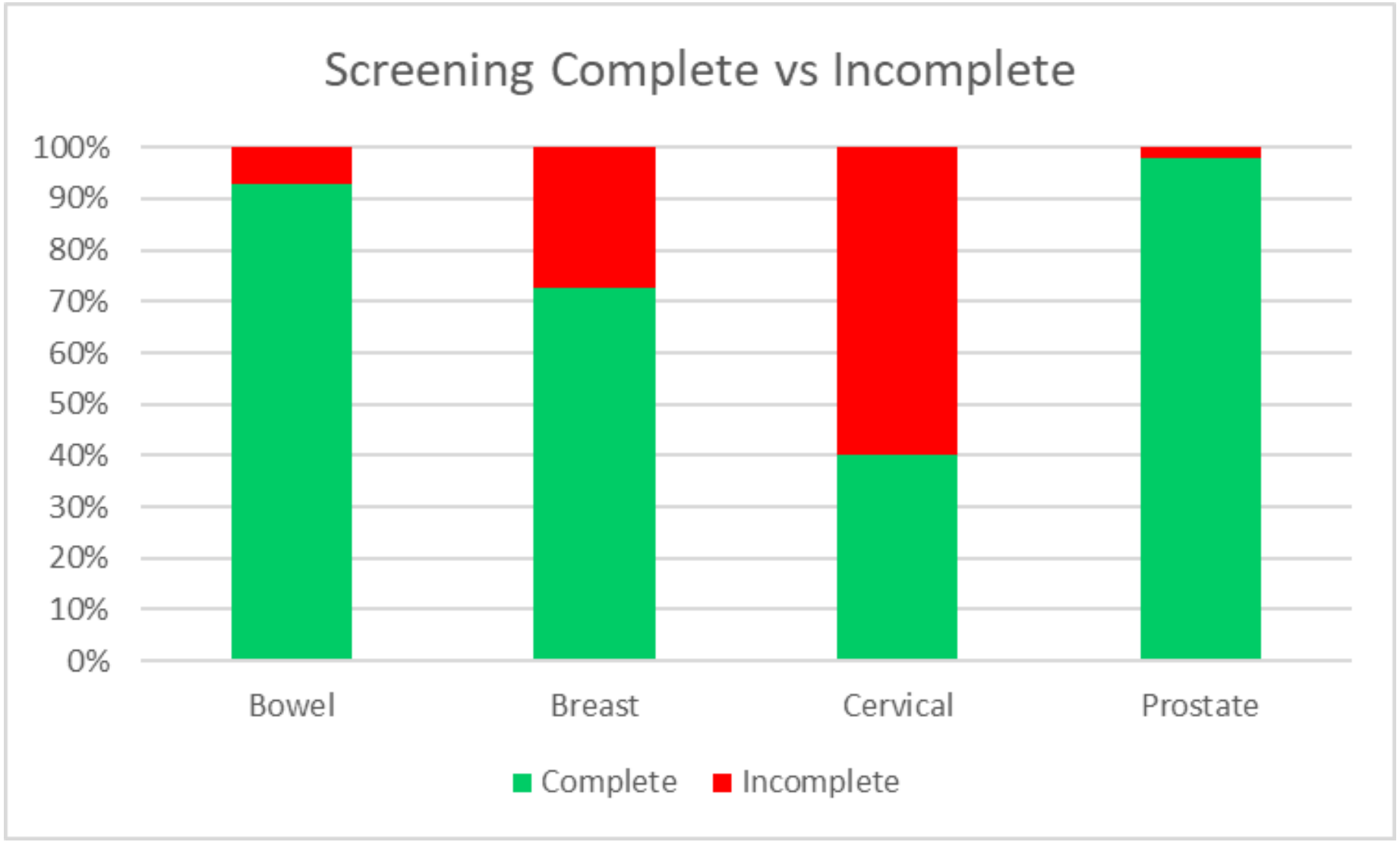
ANALYSIS

Patients eligible for each cancer screening were identified

Within that group, the numbers of the following categories were identified:

A. Screening completed/booked
B. Screening not completed/booked
i. Those who refused screening
ii. Those who professionals concluded as not suitable for screening after a best interest assessment
iii. Those whose screenings were unsuccessful due to health barriers
iv. Not enough information

Results


Screening Complete vs Incomplete
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Bowel
Breast
Cervical
Prostate
Complete
Incomplete

	Bowel (Colorectal) Cancer Screening	Breast Cancer Screening	Cervical Cancer Screening	Prostate Cancer Screening
Eligibility	Men & Women Age 60-74	Women Age 50-70	Women Age 25-64	Men Age 50 or above
a) Number eligible	83	72	122	50
b) Screening completed or booked	77 (93%)	53 (73%)	49 (40%)	49 (98%)
c) Screening not completed or booked	6 (7%)	20 (27%)	73 (60%)	1 (2%)
i. refused by patient	1 (1%)	1 (1%)	4 (3%)	0
ii. considered not in best interest	1 (1%)	3 (4%)	4 (3%)	0
iii. unsuccessful due to health barriers	1 (1%)	13 (18%)	55 (45%)	0
iv. not enough information	3 (4%)	3 (4%)	10 (8%)	1 (2%)

COMPARISON WITH PREVIOUS ID DATA

	EPHC service (This study sample)	Previously reported screening uptake in people with an intellectual disability (Mencap 2023 b)	Previously reported general population
Bowel (Colorectal) Cancer Screening completed or booked	93%	78%	83.7%
Breast Cancer Screening completed or booked	73%	53%	64%
Cervical Cancer Screening completed or booked	40%	31%	69%

Discussion

What does the EPHC do?

Innovative approach

Focuses on patients with ID and co-existing psychiatric/behavioural difficulties

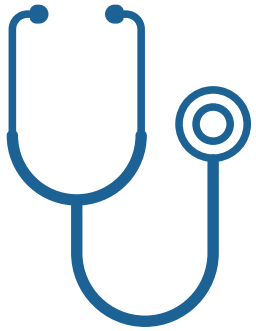
Disadvantaged group when it comes to equity of access and equity of treatment outcomes in healthcare

Offered through secondary care

Challenges the traditional assumption that physical health screening for this population should be seen solely as a primary care responsibility

Therapeutic relationship that patients already have with professionals within this secondary care provision allows them to be better motivated to engage in the screening process

What does the EPHC do?



The EHPC provided a service which included:

- Health education to increase knowledge and awareness of patients and carers
- Providing easy read and other leaflets
- Alleviating any anxiety
- Helping with booking appointments if needed
- Engaging with professionals to request reasonable adjustments

All this was offered in close collaboration with primary care and the preliminary evidence suggests that it has been successful.

Summary – Bowel cancer screening

At 15.8%, bowel cancer is the highest contributor to cancer mortality in people with ID in the UK and may be contributed to by risk factors like lack of exercise, obesity, and poor diet.

This highlights the need to improve screening rates

The uptake rate for bowel cancer screening in the EPHC was 93% as compared to 70.2% for the general population in England.

Summary – Bowel cancer screening

This finding is remarkable

Previous literature has suggested several barriers for bowel screening in the group:

- Embarrassment to conduct screening test
- Not having someone to talk to
- Discomfort in discussions regarding the topic

The services delivered through the EPHC included many of the above elements and this may have contributed to its success in bowel cancer screening

Summary – Breast cancer screening

People with ID have risk factors that contribute to breast cancer development, as they tend to be:

- physically less active
- overweight
- less likely to breast feed
- more frequently nulliparous (less likely to have given birth)

Summary – Breast cancer screening

Breast cancer appears earlier in women with ID with patients being younger and having a more advanced breast cancer stage (at the time of diagnosis)

This is frequently associated with poorer clinical outcomes

Ensuring breast cancer screening is accessible for people with ID therefore, is important to prevent delayed diagnosis

Summary – Breast cancer screening

There are multiple barriers identified including:

- ❑ Consent issues
- ❑ Literacy problems
- ❑ Problems with transport
- ❑ Lack of accessible information on breast cancer and mammography

Carers play a key role supporting and informing patients regarding breast cancer screening in this population

There is a lack of research and practice guidelines for women with ID at every stage of the breast cancer care pathway

Summary – Breast cancer screening

The uptake rate for breast cancer screening facilitated through the EPHC was significantly higher than that previously reported in people with ID

Comparable to the 64.6% rate reported in the general population in England

Summary – Cervical cancer screening

The uptake rate for cervical cancer screening facilitated through the EPHC was not significantly different from that previously reported in women with ID (40% and 31% respectively)

The contrast with the uptake figure of 68.7% in the general population is quite stark

Highlights the need to further explore the barriers in this area

Summary – Cervical cancer screening

The key barriers encountered could be divided into patient factors and system factors

Patient factors:

General lack of awareness and knowledge

Specific aspects of the screening programme (e.g. the equipment used)

Feelings of fear and pain during the screening

Risk of sexual assault is increased for women with ID

- more likely to be fearful
- particularly smear tests

Summary – Cervical cancer screening

System factors

- ❑ **Difficulties using appointment systems and waiting rooms**
- ❑ **Uncertainty about whether general practitioners or specialist teams are responsible for routine care**
- ❑ **Poor liaison with specialist services**
- ❑ **Perceived difficulty in obtaining consent for screening**

Summary – Prostate cancer screening

Looking at prostate cancer, uptake rates were 98% in our cohort, with comparison rates not available for prostate cancer screening.

Instead of a national screening programme, there is an “informed choice” programme called prostate cancer risk management, where healthy men aged 50 or over can ask their GP about prostate specific antigen (PSA) testing.

The rates reported in this study are positive, and again likely to be attributed to the availability of the EPHC, which proactively supported patients to access this test.

LIMITATIONS

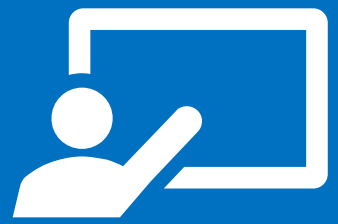
This is a service evaluation conducted at a single centre

It relied on a retrospective collection of data from existing case records

There was no control group

The generalisability of the study's findings is therefore uncertain

Conclusions



Conclusions

- The clinic was an attempt to **address significant health barriers** experienced by this population
- It has offered **cancer screenings, health advice, signposting** and **referrals** to a very hard to reach client group
- Findings highlighted that these **tests uncovered unmet needs, especially in cervical cancer screening**
- Further work will build on this by **focusing on areas of testing that were uptaken less by patients**
- Future research should **focus on the areas of need highlighted by this project**

Future Research

Tailoring cancer screening procedures to patients with ID may be a solution to detecting cancer more quickly and effectively

There is a lack of training and educational resources regarding cancer and intellectual disability

Ongoing need for multi-format resources to aid people with ID to understand the importance of screening as a preventative health measure

Thank you for your time

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