

Bowel Cancer Screening Programme Guideline for Learning Disabilities

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Key Documents Owner:	Emma Duggan	Bowel Cancer & Bowel Scope Screening Manager
Approved by:	Endoscopy Governance Meeting	
Date of Approval:	4 th September 2024	
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Key Amendments

Date	Amendment	Approved by
September 24	New document	Endoscopy Governance

Quick Reference Guide:

Please use appendix 1 and 2 when completing positive assessments, surveillance reviews and investigations for all patients with learning disabilities and/or those with additional learning needs.

Introduction

This operational guideline has been developed to provide BCSP staff with the knowledge and tools to ensure high quality standardised practice. Objectively to empower patients, enable inclusion, thus preventing discrimination and ensuring all BCSP patients human rights are protected at all times in conjunction with Mental Capacity Act (MCA) 2005, Worcestershire Hospital Acute Trust (WHAT) – Learning Disability Policy and Service Specification no26 Bowel cancer screening Programme.

The guideline will also address a number of important issues which include equality of access, easy to understand information, capacity and best interest decision making.

Additionally, the SOP will also provide key documents for referrals and professional development.

Scope of this document

This guideline ensures that the appropriate pathway is followed by administrative staff, Specialist Screening Practitioners (SSPs) and Screening Colonoscopists working within the Herefordshire & Worcestershire Bowel Cancer Screening Programme. It may also be used for reference by all staff in Worcestershire Acute Hospitals NHS Trust Endoscopy Units.

Abbreviations:

Bowel Cancer Screening Programme – BCSP.
Standard Operating Procedure - SOP.
Specialist Screening Practitioner - SSP.
Learning Disabilities - LD.
Mental Capacity Act – MCA.
Independent mental capacity advocate - IMCA

Definitions

The UK Department of Health and Social Care (DHSC) defines a Learning Disability LD as 'a significantly reduced ability to understand new or complex information, to learn new skills, with a reduced ability to cope independently, which started before adulthood with a lasting effect on development. The severity may be mild, moderate, severe, or profound, depending on the person's IQ range, language, practical skills and ability to self-care.

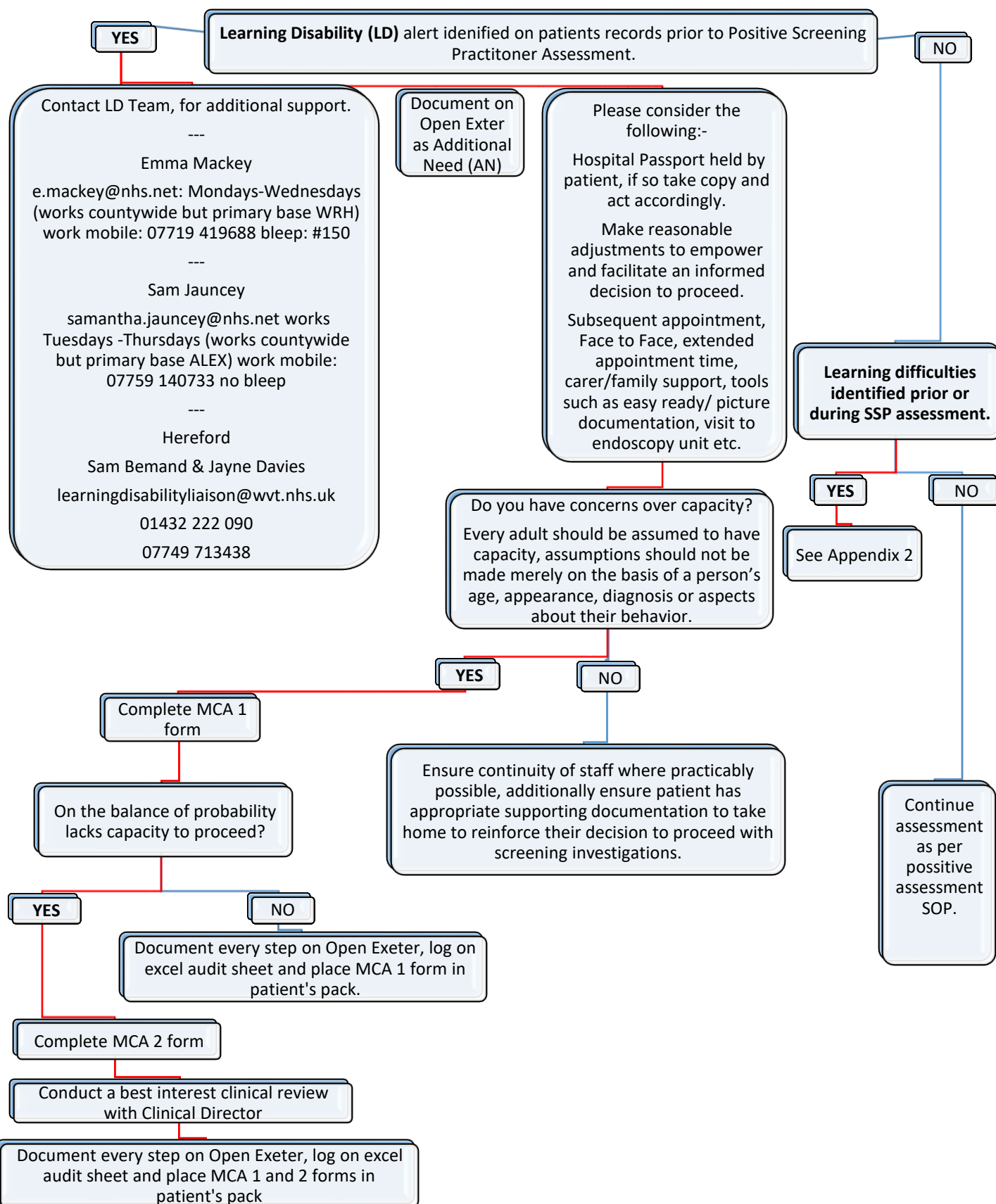
Responsibility and Duties

SSPs, BCSP Administration staff and Screening Colonoscopists working with BCSP.

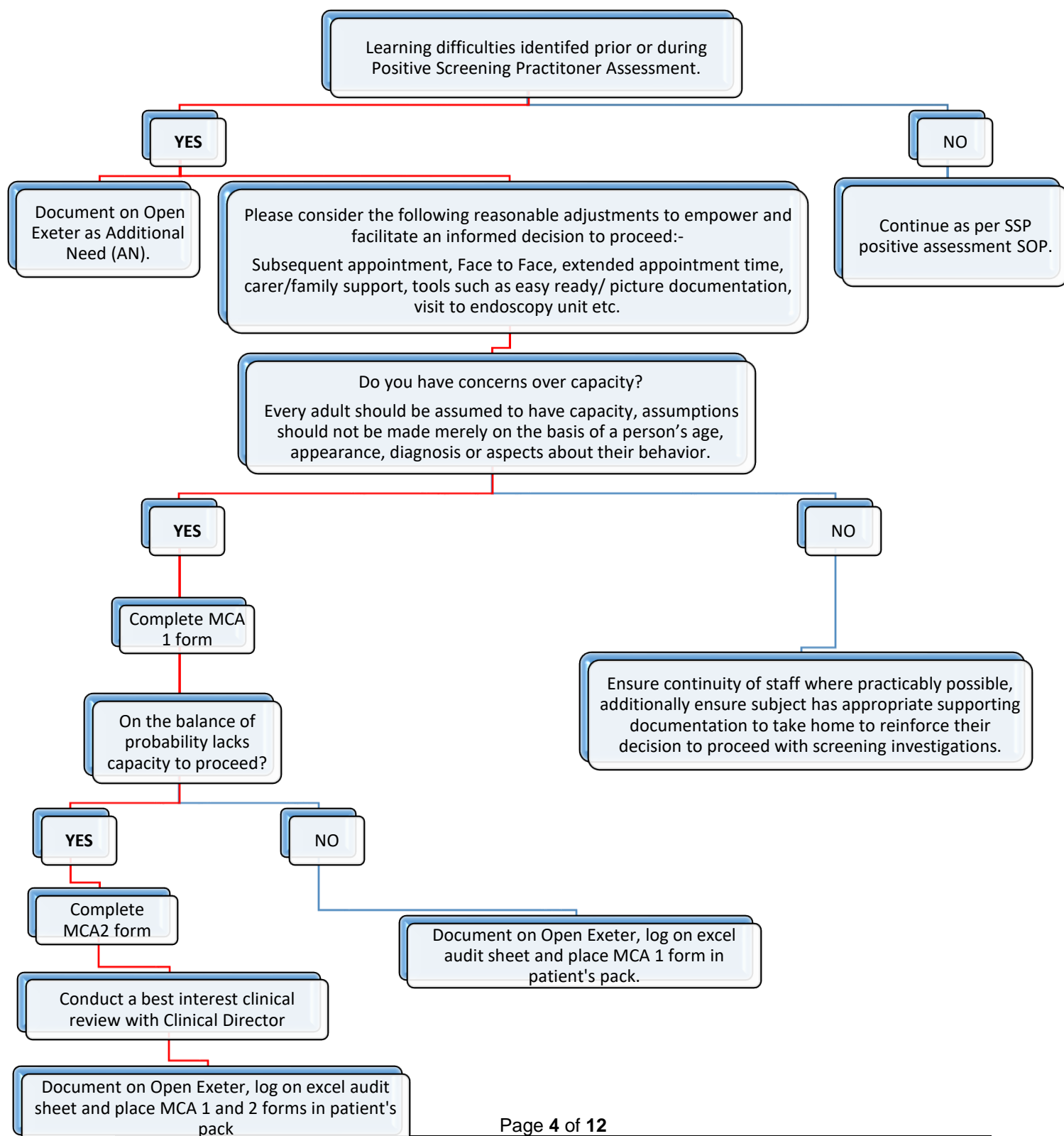
Guidance Review

This guidance should be reviewed on a 3 yearly cycle by BCSP.

Appendix 1:



Appendix 2:



Hospital Passport.

It's good practice for people with a LD and autistic people to have a health and care passport which can be regularly updated in response to changes in their health and wellbeing and interaction in the health and care services they use. How, when and who to involve in completing and updating a passport should be guided by the person who owns the passport.

Benefit of the hospital passport:

- Empowers patients and carers – enabling better informed clinical decisions and shared decision making
- Improves patient safety
- Provides consistent, clear, patient centred information
- Reduces health inequalities
- Supports best interest decision making if they have been assessed as not having capacity.

[Hospital Passport Link](#)

Reasonable Adjustments

Small changes that help people with a LD or learning need to be treated equally. The law says that reasonable adjustment should be put in place.

Please consider the following reasonable adjustments to empower and facilitate an informed decision to proceed:

- Subsequent appointment, Face to Face, extended appointment time, carer/family support, tools such as easy ready/ picture documentation, visit to endoscopy unit etc.

Constipation.

NHS England reported that 23% of people with a learning disability who died in 2019 had constipation as a long-term condition.

People with a learning disability may also be less likely to recognise the symptoms of constipation and be able to communicate their symptoms, increasing the risk of serious consequences (see easy read constipation leaflet).

Easy Read Leaflets

The following links are from GOV.UK website, upon which provides leaflets and letter templates upon which have been developed by and for people with learning disabilities.

- [Bowel cancer screening – An easy read guide \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414841/bowel_cancer_screening_-_an_easy_read_guide.pdf)
- [BCSP FIT easy read invitation letter template final July 2019.odt \(live.com\)](https://live.com/BCSP_FIT_easy_read_invitation_letter_template_final_July_2019.odt)
- [Bowel cancer screening colonoscopy easy guide \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414841/bowel_cancer_screening_colonoscopy_easy_guide.pdf)
- [CTC scan easy guide.pdf \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414841/CTC_scan_easy_guide.pdf)
- [Bowel screening S2 no further tests easy read final.odt \(live.com\)](https://live.com/Bowel_screening_S2_no_further_tests_easy_read_final.odt)
- [Bowel screening A183 further tests easy read final.odt \(live.com\)](https://live.com/Bowel_screening_A183_further_tests_easy_read_final.odt)
- [Constipation Easy Read.pdf](#)

Beyond Words Picture Story Leaflets

The link below provides picture storyline leaflets on bowel cancer screening and having a colonoscopy for those who cannot or do not like written words:

[Beyond Words bowel cancer screening picture story](#)

The Mental Capacity Act 2008

The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. It makes it clear who can take decisions, in which situations, and how they should go about this. It enables people to plan ahead for a time when they may lose capacity.

The Five main principles of the Mental Capacity Act:

- ✚ Presumption of capacity.
- ✚ Support to make a decision.
- ✚ Ability to make unwise decisions.
- ✚ Best interest.
- ✚ Least restrictive.

The Mental Capacity Act (MCA) is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. It applies to people aged 16 and over.

Independent mental capacity advocate (IMCA)

When treating people with a learning Disability or those who lack capacity, we must ensure that we engage with all professionals and services involved in their care including IMCA if applicable following best interest review with BCSP Clinical Director. Ensuring we apply and follow the principles of the Mental Capacity Act at all times when making decisions about their care and treatment.

IMCA services support people who can't make or understand decisions by stating their views and wishes or securing their rights. Further information and relevant documentation can be found on the Trust Intranet:

<http://nww.worcsacute.nhs.uk/departments-a-to-z/mental-capacity/>

Referral Forms, Checklist and Protocols.

MCA Assessment Form 1: <http://nww.worcsacute.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=55955>

MCA Assessment Form 1 Example:

<http://nww.worcsacute.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=87844>

MCA 2 – Best interest form:

<http://nww.worcsacute.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=55954>

MCA 2 – Example

<http://nww.worcsacute.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=87845>

Assessment

IMCA Referral Form

<http://nww.worcsacute.nhs.uk/EasySiteWeb/GatewayLink.aspx?allId=55956>

Support for carers.

Web Address: [Support for carers | Worcestershire County Council](#)

Do you care for someone?

Do you help to look after someone a few hours a week (or more) that rely on you for any of the following?

emotional care and support

medical care and support

personal care

or help with domestic tasks

Then you could be a carer and would possibly benefit from support. One in five people will become a carer at some point in their lives.

The level of caring can vary in its intensity, frequency and may fluctuate and can vary depending on each individual.

As a Carer you have the same rights to support as the people you care for. Adult carers can be supported and assessed under the Care Act 2014 and for Parent Carers also under the Children and Families Act 2014.

You can also be assessed and supported under children's law If you are a young carer or parent carer.

National information, advice and guidance can be found at GOV.UK Care Act 2014 factsheet 8: the law for carers

If you are in need of help

If you need either of the following:

to discuss what support might be available to you as a carer

an assessment of your needs as a Carer to get support

You can self-refer to Worcestershire Association of Carers online using the Worcestershire Adults Portal:

Worcestershire Adults Portal for Carers

Alternatively, you can speak with our Carers Hub.

The Carers Hub provides information, advice and support on behalf of Worcestershire County Council you can visit their website Worcestershire Association of Carers or give them a call 0300 012 4272 (Monday to Friday 9am to 7pm, Saturday 9am to 12pm).

References and key documents:

Care Act 2014 – Web: [Mental Capacity Act 2005 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2014/9/contents/enacted)

Equality Act 2010 – Web: [Equality Act 2010 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2010/15/contents/enacted)

Government Services and Information – Web: [NHS bowel cancer screening: identifying and reducing inequalities - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/nhs-bowel-cancer-screening-identifying-and-reducing-inequalities)

Mencap 2023 – Reasonable Adjustments – Web: About reasonable adjustments.

Mental Capacity Act 2005 – Web: [Mental Capacity Act 2005 \(legislation.gov.uk\)](https://www.legislation.gov.uk/ukpga/2005/9/contents/enacted)

[NHS England » Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\)](#)

[NHS England » Constipation resources for people with a learning disability](#)

“No decision about me, without me” - Web: [Liberating the NHS: No decision about me, without me \(publishing.service.gov.uk\)](https://publishing.service.gov.uk/government/consultations/no-decision-about-me-without-me)

[Learning disabilities | Health topics A to Z | CKS | NICE](#)

Positive Assessment – SOP – Trust Intranet: [index](#)

Public Health (England 2019). Service Specification no26 Bowel cancer screening Programme. – Web: [NHS public health functions agreement 2019-20 \(england.nhs.uk\)](https://www.england.nhs.uk/publication/nhs-public-health-functions-agreement-2019-20/)

Public Health England Screening inequalities strategy 2019 – Web: [PHE Screening inequalities strategy - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/consultations/phe-screening-inequalities-strategy)

Worcestershire Acute Policy for Supporting Adults with Learning Disabilities when accessing Acute Hospital Services – Trust Intranet: [http://www.worcsacute.nhs.uk/departments-a-to-z/mental-capacity/Policy for Supporting Adults with Learning Disabilities when accessing Acute Hospital Services.PDF](http://www.worcsacute.nhs.uk/departments-a-to-z/mental-capacity/Policy%20for%20Supporting%20Adults%20with%20Learning%20Disabilities%20when%20accessing%20Acute%20Hospital%20Services.PDF)

Worcestershire County Council – Support for Carers. – Web: [Support for carers | Worcestershire County Council](#)

CONTRIBUTION LIST

Key individuals involved in developing the document

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Circulated to the following CD's/Heads of dept. for comments from their directorates / departments

Name	Directorate / Department
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Dr Lovegrove	CD Endoscopy
Lynne Mazzocchi	Directorate Manager

Circulated to the chair of the following committee's / groups for comments

Name	Committee / group
Mr S P Lake	BCSP Operational Meeting
Dr Lovegrove	Endoscopy Directorate Meeting

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Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

		Yes/No	Comments
1.	Does the policy/guidance affect one group less or more favourably than another on the basis of:		
	Race	No	
	Ethnic origins (including gypsies and travellers)	No	
	Nationality	No	
	Gender	No	
	Culture	No	
	Religion or belief	No	
	Sexual orientation including lesbian, gay and bisexual people	No	
	Age	No	
2.	Is there any evidence that some groups are affected differently?	No	
3.	If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?	No	
4.	Is the impact of the policy/guidance likely to be negative?	No	
5.	If so can the impact be avoided?	N/A	
6.	What alternatives are there to achieving the policy/guidance without the impact?	N/A	

7.	Can we reduce the impact by taking different action?	No	
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If you have identified a potential discriminatory impact of this key document, please refer it to Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact Human Resources.

Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	Yes/No
1.	Does the implementation of this document require any additional Capital resources	No
2.	Does the implementation of this document require additional revenue	No
3.	Does the implementation of this document require additional manpower	No
4.	Does the implementation of this document release any manpower costs through a change in practice	No
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments:	No

If the response to any of the above is yes, please complete a business case and which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval