

Increasing Awareness of Gynecological Cancer Symptoms and Reducing Barriers to Medical Help Seeking: Does Health Literacy Play a Role?

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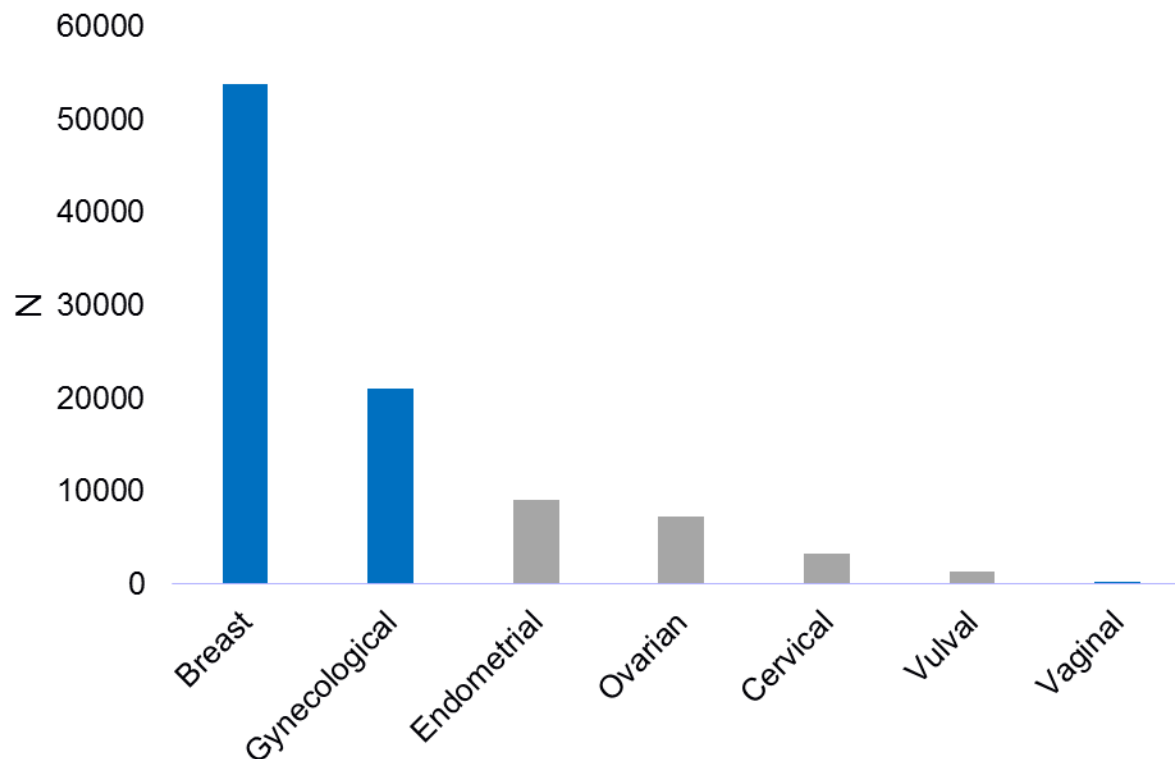
- Background to gynaecological cancer
- Introduction to model of help-seeking
- Intervention study on increasing awareness & reducing barriers to help-seeking
- Discussion

Background



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- Over 20,000 gynecological cancers per annum in UK
- Second highest cancer incidence in women (combined):





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theguardian
website of the year

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Cancer

UK cancer survival rates trail 10 years behind other European countries



EXPRESS

Home of the Daily and Sunday Express

Cancer care shame as UK survival rate is one of EU's worst

**WE ARE
MACMILLAN.
CANCER SUPPORT**

UK CANCER SURVIVAL RATES "STUCK IN THE 1990S" SAYS CHARITY

MailOnline

Cancer survival rates 10 years behind Europe: British figures still well below other countries despite billions being spent to improve situation over the last 15 years

- UK has poor 5-year cancer survival relative to other comparable countries e.g...

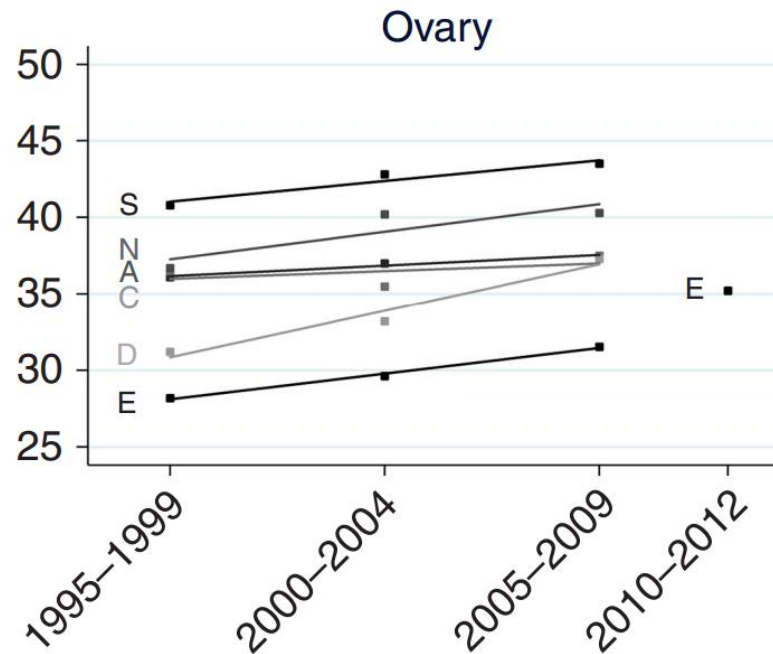


Figure: 5-year net survival of ovarian cancer in Australia (A), Canada (C), Denmark (D), England (E), Norway (N), Sweden (S). Source: Walters et al., 2015, BJC

Symptoms and help-seeking



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- Symptoms present before diagnosis (e.g. abdominal distension, bloating etc) (Hamilton et al., 2009)
 - 85% of cases (15% controls) reported at least 1 symptom pre-diagnosis
- However, most symptoms are common and with low PPV
- NHS clinical guidelines have lowered threshold for referral
- To be effective, patients must recognise and act on symptoms

Symptoms and help-seeking



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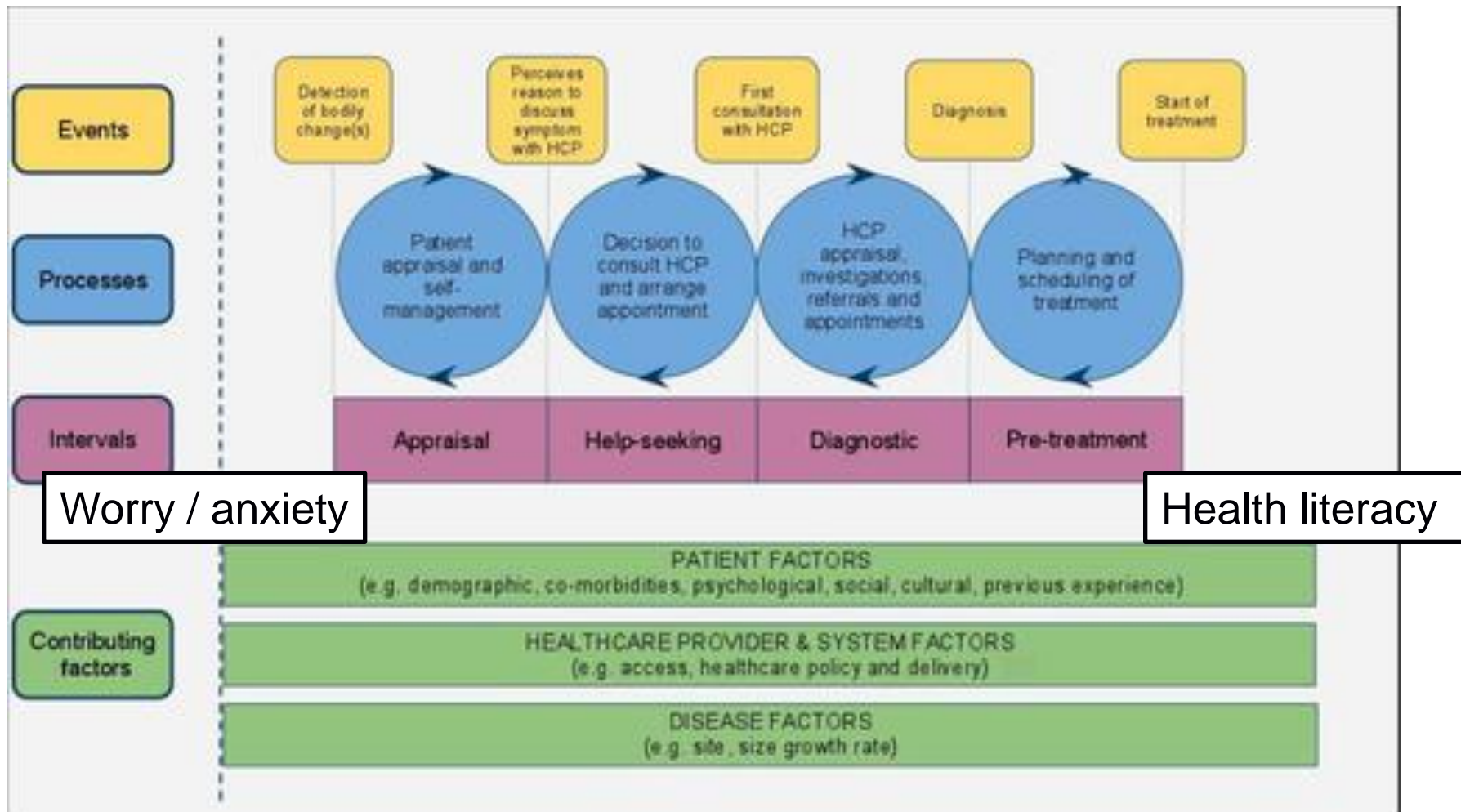


Figure: Scott & Walter (2010) Help-seeking for symptoms

Symptoms and help-seeking



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- Not all symptoms of gynae cancers are well-recognised (e.g. feeling full quickly, difficulty eating) (Low et al., 2013)
- Attribute symptoms to benign causes rather than cancer (Low et al., 2015)
- Low awareness and failure to attribute symptoms to cancer can result in anticipated delays to help-seeking (Quaife et al., 2014)
- Few interventions have attempted to tackle this issue

Promoting help-seeking



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- Written health information sent via general practice is one way of reaching a mass population with simple and engaging messages
- >95% population registered with a GP in UK
- Information must be balanced with considerations of population's health literacy...
- And the importance of not inducing undue anxiety, which itself can be a barrier to help-seeking (Robb et al., 2006)

Aim of study



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- To evaluate a primary care based leaflet aiming to increase appropriate presentation of symptoms associated with gynaecological cancers

- Flesch-Kincaid = 5.5
 - SMOG index = 7
- } ~11 to 13 years
-
- Tested in 3 focus groups
 - 2 non-symptomatic groups
 - 1 group of gynae cancer survivors
 - Expert opinion from 6 gynae cancer specialists

- Techniques to promote and enable engagement
 - ‘Chunking’ information to reduce cognitive load
 - Narratives / patient stories
 - GP endorsement
 - Patient prompt list of symptoms to promote activation
 - Attempts to address worries and barriers (e.g. female doctors)

LOGO HERE

A MESSAGE
FROM YOUR GP



GYNAECOLOGICAL CANCERS

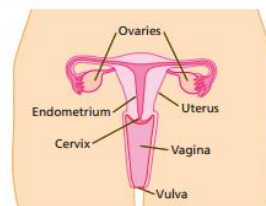
know the signs

Information for Women

What are gynaecological cancers?

A **gynaecological cancer** is a cancer that occurs in your **reproductive system**:

- Uterus (womb) including endometrium (lining of womb)
- Cervix (neck of womb)
- Ovaries
- Vagina
- Vulva (outside part of the vagina)



Early signs of gynaecological cancers

The most common symptoms of gynaecological cancers are:

- Abdominal or pelvic pain
- Bleeding between periods, after sex or after the menopause
- Vaginal discharge that is smelly or bloodstained
- Longer or heavier periods
- Bloating, gas or constipation that doesn't go away
- Pain during sex
- Lower back pain that doesn't go away
- Pain, lump, ulcer, soreness or persistent itching of the vulva
- Needing to go to the toilet more urgently and frequently than normal
- Feeling full quickly or loss of appetite

These are important if they are new for you or if they don't go away.

If you are embarrassed or worried...

- You can ask to see a female doctor or ask to have a female member of staff accompany you to your appointment.
- Remember, your GP is used to dealing with sensitive issues and can support you.
- It can help to discuss your concerns with someone you trust among your friends or family.
- You can discuss with your GP any tests that may be offered to you before you choose whether to have them.

The earlier cancer is diagnosed, the better the chances of survival.



"Cervical cancer never crossed my mind. I was really fit and healthy. I thought people like me didn't get cancer."

Sandra, 64, cervical cancer survivor



"I thought a normal smear test meant that I was ok. I didn't realise that you could get cancer in other parts."

Meera, 51, ovarian cancer survivor

Dear Patient,

I'm sending this leaflet to all women in my practice because I think that it is important that everyone knows about the symptoms of gynaecological cancers.

Every year around 18,000 women of all ages in the UK are diagnosed with a gynaecological cancer.

*I want you to feel able to come to see me if you notice anything that is **not normal for you**.*

*In this leaflet you will find a **symptom checklist** that will help you to see if you need to make an appointment.*

*If you are experiencing **any** of these symptoms please don't delay. **Come to see me**.*

*If you are worried about gynaecological cancer, please speak up. **You will not be wasting my time**.*

Yours sincerely,

(GP's signature)

Dr. XXXXXXXXXXXX

Do you have any of these symptoms?

If the answer is **yes** to even **one** of these symptoms, it is important to make an appointment with your GP **today**.

It might help you to fill out this checklist and bring it to your appointment. This will make it easier to give your GP as much detail as possible on your symptoms.

Symptom	Tick if you have symptom	When did it start?
Abdominal or pelvic pain		
Bleeding between periods, after sex or after the menopause		
Vaginal discharge that is smelly or blood stained		
Longer or heavier periods		
Bloating, gas or constipation that doesn't go away		
Pain during sex		
Lower back pain that doesn't go away		
Pain, lump, ulcer, soreness or persistent itching of the vulva		
Needing to go to the toilet more urgently or frequently than normal		
Feeling full quickly or loss of appetite		

Make a promise to yourself:

If I have **any** of these symptoms I will make an appointment with my GP **today**.

Call our surgery on: 0207 xxx xxxx

Today's date _____

Date and time of your appointment _____

Common concerns

- Even if you don't feel ill, you should have your symptoms checked.
- These symptoms can seem mild and unimportant, but if you have any of these symptoms, it is important that you see your GP.
- You might think that your symptoms will just clear up on their own but it is **better to see your GP**.
- Even if you have been to your pharmacist or GP already, **you should visit them again if your symptoms haven't gone away**.

It is likely that these symptoms are not due to cancer, but it is important to have them checked.

You can find more information about gynaecological cancers at:

www.cancerhelp.org.uk

Or by calling **0808 800 4040** (Mon-Fri 9am-5pm) to speak to a Cancer Research UK nurse

- Recruitment
 - 10 Cancer Awareness Roadshows
 - 7 cancer fundraising events for women

- Women aged over 18 years

- Pre-post design
 - T1 – Health literacy, awareness and barriers
 - Intervention
 - T2 – Sociodemographic, awareness and barriers

- Newest Vital Sign (Weiss et al., 2005)
- Cancer awareness measure (Stubbings et al., 2009)
 - Symptom awareness
 - List of 12 symptoms (all correct)
 - Barriers
 - Emotional – embarrassed, scared, worried about what the doctor might find, confidence discussing symptom (4 items)
 - Practical – too busy, too many worries, transport (3 items)
 - Service – wasting time, difficulty making appointment, difficulty talking to doctor (3 items)
- Sociodemographic items and participant characteristics



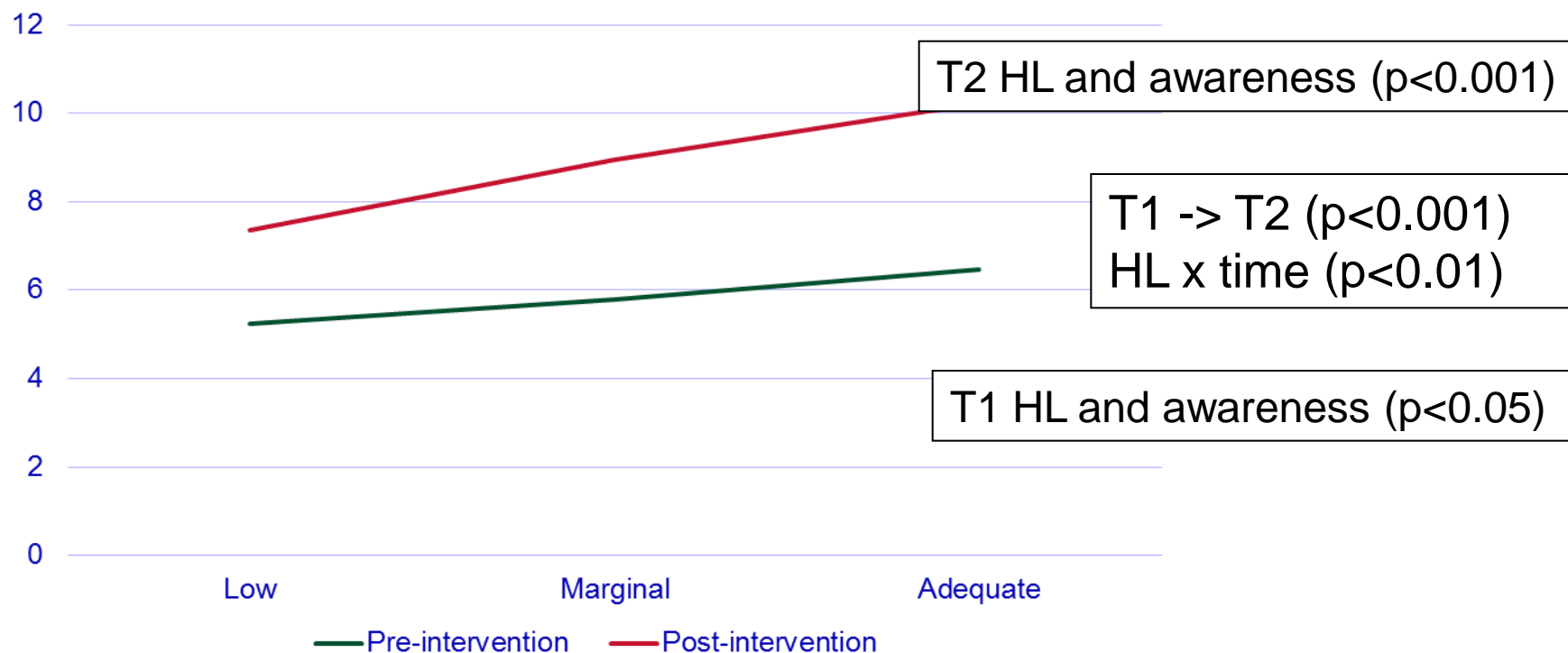
	N	%
Total	451	100
Health literacy		
Low	61	13.5
Marginal	115	25.5
Adequate	275	61.0
Age		
18-30	125	27.7
31-40	87	19.3
41-50	88	19.5
51+	98	21.7
Education		
<Bachelor's	170	37.7
Familiar with gynae cancer		
Yes	171	37.9

Results - awareness



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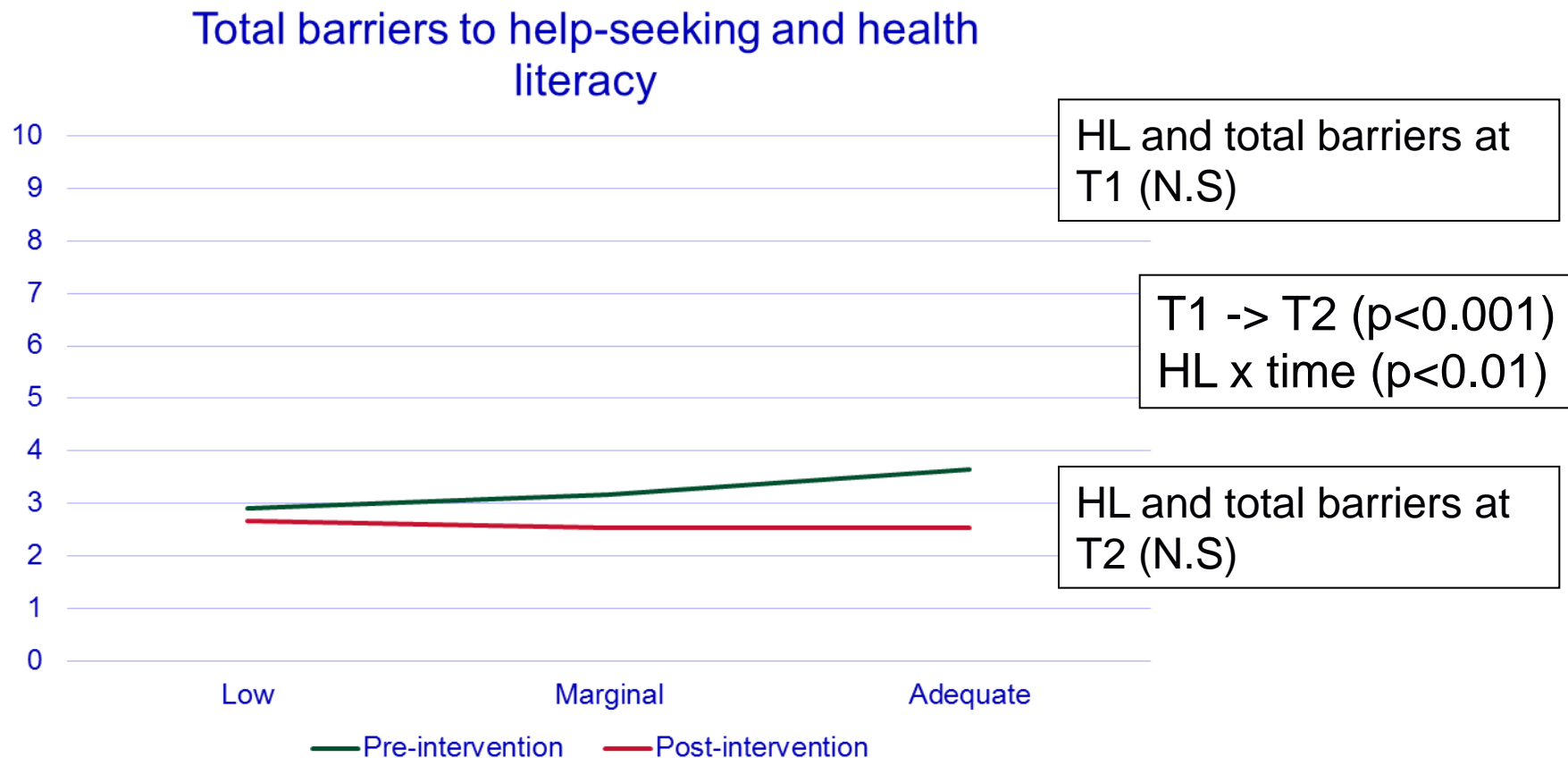
Awareness of gynae cancer symptoms and health literacy



Results – total barriers



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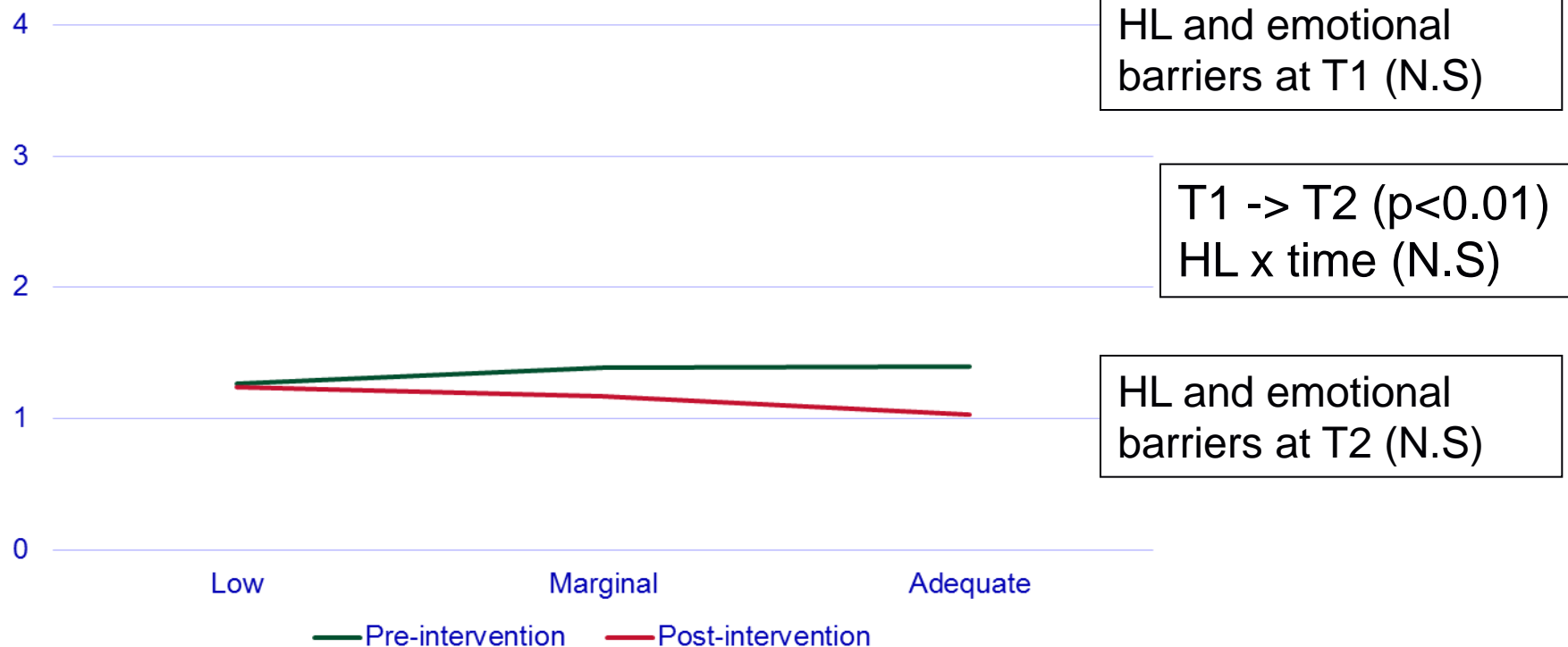


Results – emotional barriers



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Emotional barriers to help-seeking and health literacy

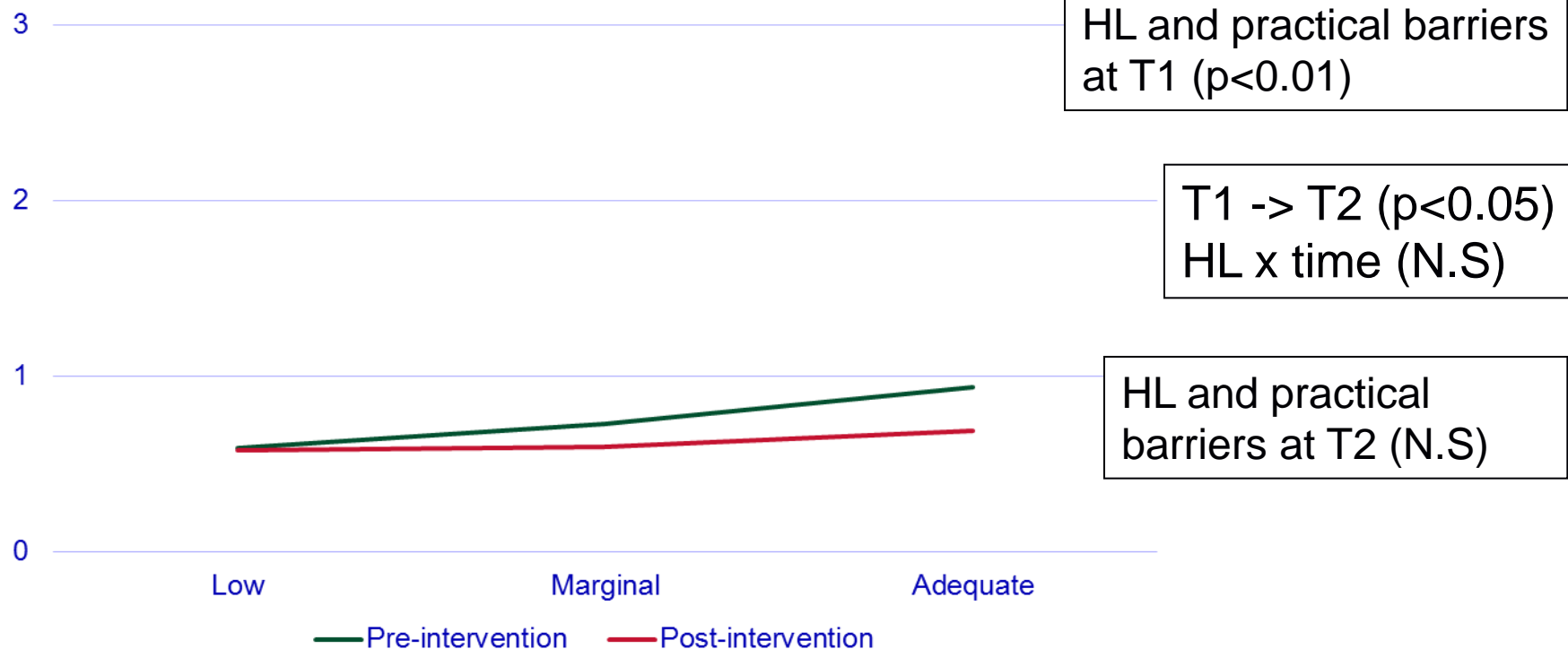


Results – practical barriers



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Practical barriers to help-seeking and health literacy

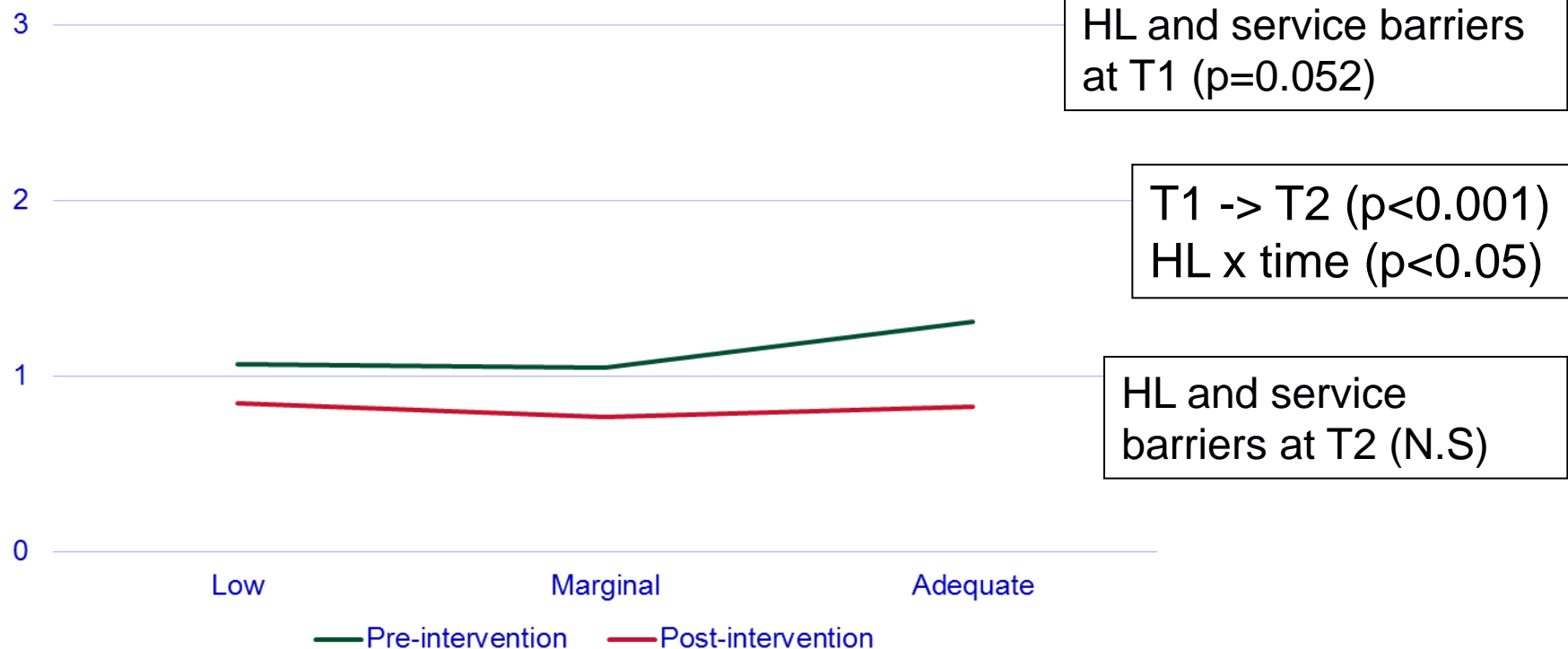


Results – service barriers



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Service barriers to help-seeking and health literacy



Results - summary



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- Awareness improved, but greater gains among adequate HL
- Adequate HL group reported more barriers, but also greater reductions
- HL unrelated to emotional barriers (e.g. embarrassed, scared, worried)
 - Emotional barriers reduced overall, and N.S. interaction

-
- Leaflets and patient prompt lists may be effective overall, but monitoring inequalities is necessary
 - Identifying ways of adapting and tailoring interventions to ensure all patients benefit – what didn't work here?
 - Understanding counterintuitive relationship between barriers to help-seeking and health literacy important
 - Boxell, Smith, Morris et al., 2012 JHC
 - Morris, Friedmann Smith, Boxell et al., 2016 BMC Public Health

Limitations



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- Opportunistic sample
 - low N across literacy groups
 - Not tested in primary care

- Floor effect for barriers
 - Was sample generalisable?

- Lack of long-term follow-up
 - Duration of effects?

Acknowledgements



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