healthwatch Middlesbrough

Cancer Screening Uptake in Middlesbrough

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Contents

1.Background

1.1 What is Healthwatch?

Healthwatch Middlesbrough is a patient and service user voice organisation.
We listen carefully to people's experiences and views of local health and social care services. We use this information to influence how services are planned and delivered now and in the future to ensure they meet the needs of those people using them.

We gather the views and experiences of people in a number of different ways including, but not exclusive to, face to face engagement, online surveys, Facebook and Twitter as well as by attending local events.

Healthwatch Middlesbrough is an independent organisation steered by a Board of volunteers and commissioned by the Local Authority and accountable to the public.

Healthwatch has:

- The statutory right to be listened to. Providers and commissioners must respond to us within 20 days of submissions of requests for information or reports
- The statutory power to Enter & View health and social care services
- A statutory seat on the Health and Wellbeing Board

Our aim is to strengthen the collective voice of local people and to enable them to find the right health and social care services by providing appropriate information, advice and signposting. We are the only non-statutory body whose sole purpose is to understand the needs, experiences and concerns of people who use health and social care services and to speak-out on their behalf.

1.2 National Cancer Screening Programme

What is cancer screening?

"Screening is designed to reduce the risk or impact of disease in a defined population. Screening programmes aim to identify the individuals most at risk of a disease so that they can be offered early treatment. Screening programmes are based on careful calculation, including who will benefit, the scope for treatment, and the level of accuracy of the tests". (Sense about Science-Making Sense of Screening, 2015)

They are different from diagnostic tests as they are used to identify potential increased risk of future illness within given populations. Sometimes following screening, people can then be offered information, further tests and treatment to reduce their risk and/or any complications arising from the disease or condition.

There are three national cancer screening programmes for adults in England:

- NHS Breast Screening
- NHS Cervical Screening
- NHS Bowel Cancer Screening

There is no reliable screening test for prostate cancer at present. However, the Prostate Cancer Risk Management Programme provides information to explain existing tests and treatments. (NHS Choices, 2015)

1.3 Cervical Cancer Screening *

The programme makes sure that if you are a woman aged between 25 and 64, you will automatically receive an invitation. Your name will be obtained from your General Practitioner's register. This means it is important that your doctor always has your correct name and address. After your first cervical screen, you will receive invitations every three years between the ages of 25 and 49 and then every five years between the ages of 50 and 64.

Like all screening, cervical screening is not a diagnostic test for cervical cancer. Rather, it is a test to check the health of the cervix, which is the lower part of the womb (often called the neck of the womb). Cervical cancer can often be prevented. Screening aims to detect signs that a cancer may develop.
Around 750 women die of cervical cancer in England each year. However, many of those who develop cervical cancer have not been screened regularly. Not going for cervical screening is one of the biggest risk factors for developing cervical cancer. Early detection and treatment can prevent around 75% of cancers developing but, like other screening tests, it is not perfect.

1.4 Breast Cancer Screening *

Breast screening uses an X-ray test called a mammogram to check the breast for signs of cancer. It can spot cancers that are too small to see or feel. All women aged 50 to 70 are invited for breast screening every 3 years. Some older and younger women are also being invited as part of a study of screening in different age groups. At risk women over the age of 70 can still have screening but it is not automatically offered.

Screening saves about 1 life from breast cancer for every 200 women who are screened. This adds up to about 1,300 lives saved from breast cancer each year in the UK.

1.5 Bowel Cancer Screening *

The NHS Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 69. Bowel cancer screening aims to detect bowel cancer at an early stage (in people with no symptoms), when treatment is more likely to be effective.

You carry out the faecal occult blood (FOB) test which is the screening test sent through the post to be carried out in the privacy of your own home. The screening kit provides a simple way for you to collect small samples of your bowel motions.

About1 in 20 people in the UK will develop bowel cancer during their lifetime.

It is the fourth most common cancer in the UK, and the second leading cause of cancer deaths, with over 16,000 people dying from it each year (Cancer Research UK, 2012).

It is predicted that the bowel screening programme will save over 2000 lives each year by 2025 (Cancer Research UK, 2012).

* **Reference: - http://www.cancerscreening.nhs.uk/**

2. Aim of the Report

2.1. Background and Rationale

Middlesbrough has great variation in health and wellbeing outcomes across wards. Life expectancy for both men and women is lower than the national average. Within Middlesbrough there are significant inequalities, with a man residing in the least deprived areas of the Borough living, on average, 16 years longer than a man in the most deprived area. For women that difference is 11 years (Office for National Statistics, 2014). The starkness of inequality can be observed from the top of Ormesby Bank looking down towards the Tees and the docks: for every mile travelled from Nunthorpe to Pallister, there is a two-year reduction in life expectancy (Middlesbrough JHWS 2013-2023).

Middlesbrough Joint Health and Wellbeing Strategy 2013 - 2023 states that key causes of early death (and significant causes of illness) in Middlesbrough are cancer.

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Early deaths from cancer have fallen less slowly in Middlesbrough than in England as a whole. Disease rates are generally higher in areas of greater deprivation (except breast cancer), as are the risk factors for these disease i.e. smoking, poor diet, lack of physical activity and alcohol. Tees Valley Public Health Shared Services show Middlesbrough have one of the lowest national uptake of all three national cancer screening schemes. Collectively these facts do not make good reading. (NYCRIS Cancer Profile Middlesbrough, 2012)

Cervical screening coverage Tees Valley					
	Darlington	Hartlepool	Middlesbrough	R & C	Stockton
2008/09	81.3	76.8	74.1	80.1	79.5
2009/10	81.4	76.6	75	79.6	79.1
2010/11	81	75.2	73.1	78.9	78.2
2011/12	81.1	75.6	73.4	79.6	78.5
2012/13	81	75.8	72.9	79.6	78.3
2013/14	80.95	76.08	73.11	79.48	78.29

NHS Breast Screening Programme: Estimated uptake of invitations to screen for women aged 50-70 by Local Authority, at 31 March 2014			
Hartlepool	72.3	Hartlepool	72.3
Middlesbrough	70.4	Middlesbrough	70.4
Redcar and Cleveland	73.7	Redcar and Cleveland	73.7
Stockton-on-Tees	76.6	Stockton-on-Tees	76.6
Darlington	76.8	Darlington	76.8

As part of our investigation, Healthwatch Middlesbrough aimed to gather the views of local people who had accessed screening services and those who had not in order to determine what was working well and what could be improved in the current provision. The inquiry also aimed to ascertain from the public how a future service could better suit their needs and what would encourage more people to take up cancer screening. The findings formed the basis for the changes recommended in this report. It is intended that this report will inform the work of local commissioners and ultimately contribute towards helping to improve the health of the residents of Middlesbrough. It is acknowledged that local commissioners are already working in this area including the formation of the working group Tackling Cancer Together.

It should be noted that the comments included in this report are from members of the public who contributed and therefore not always the opinions of Healthwatch Middlesbrough. We acknowledge that some of the recommendations and requests from the public may not adhere to medical opinions and research. However, it is still important that their voice is heard.

3. Methodology

Healthwatch used several data collection methods to ensure a good overview of public perceptions of the current cancer screening provision including:

- A general cancer screening survey which was conducted over the period October 2014 to March 2015.
- A Survey Monkey questionnaire was distributed via our Website, Facebook, Twitter and directly to a selection of Teesside University Staff.
- The public were asked to contribute intelligence directly via our Facebook and Twitter.
- A prostate specific survey was also carried out as a request from the public during engagement.

In addition targeted focus groups were held with the following community groups

- Straightforward – Female genital mutilation (FGM)
- Regional Refugee Forum North East
- North of England Refugee Service (NERS)
- Prostate Cancer Support Group
- Breckon Hill Community Centre

Targeted sessions were designed to support people to evaluate their experiences of using screening services and to listen to any perceived barriers.

Healthwatch staff also visited a stall at James Cook University Hospital ran by the James Cook Prostrate Cancer Group. We listened to the experiences of patients who had been diagnosed with prostate cancer to see if those diagnosed had different views of screening services.

4. Findings

4.1 A total of 144 general surveys were competed. All responses were collated via Survey Monkey in order that they could be analysed. (Please note all of the following findings relate to the general cancer intelligence. Stand-alone findings regarding prostate cancer will be included under a separate heading).

A total of 24 questions were on the survey with an additional box to add any anecdotal evidence.

The online survey automatically took the person to the correct questions bypassing unnecessary or irrelevant questions. For example if a respondent indicated they were male, the cervical and breast cancer questions were skipped.

A detailed breakdown of responses to each question can be found in the Appendix 7.1. Both quantitative and qualitative data were collected. This data provides a deeper insight into issues affecting people when making an appointment. It must be noted that the information gathered was a snapshot and not intended to be comprehensive.

Over 99% respondents were registered with a GP at the time of completing the survey.

37.14% were age 25 - 49 years with 23.57% aged 50 to 59.

71.13% were female. Therefore a greater number completed the breast and or cervical cancer sections than did not.

4.2 Cervical Cancer Screening

83 of those who completed the survey stated that they had been invited to cervical screening. Of those who had not been invited (this could have been an age factor) more than 50% would have liked an invitation. 82.47% of those invited attended their appointment at their GP surgery.

When asked why they did not attend the appointment the most common reasons given were:

- Not old enough at time of completing the survey
- Timing of clinics
- Did not want to
- Work commitments
- Felt uncomfortable

When asked what could be done to improve the uptake of cervical cancer screening and the service the following comments were gathered:

- More information about what the procedure involves and the importance of attending
- Work should give you time off to attend
- Older women should be offered screening
- Offer screening on a weekend or evening
- I was allowed screening in Scotland but refused in England as I was under 25 despite a family history
- For those of working age attending screening in working hours can be challenging. Why can cervical screening not be available in venues other than GP surgery and sexual health clinics? I would be too embarrassed to attend a sexual health clinic
- If someone doesn't attend their appointment, send information on cervical cancer
- Have screening available in town centre venues such as the Life Store

4.3 Breast Cancer

Of those who completed the survey;

- 53.26% had been invited to breast cancer screening
- Of those who had been invited 81.03% attended their appointment
- 79.41% of women who did not receive an invite would have liked one

Most appointments were attended at hospital or the One Life Centre. Not being within the age range was given as the main reason for not attending a screening session.

4.4 Bowel Cancer

Of those who completed the survey;

- 24.56% had been invited to take part in the screening programme
- 56.67% would have liked to have taken part
- 66 people invited had received a sample collecting kit
- 81.44% of those using the kit stated that it was easy to use

People who had not been sent the kit did receive screening via their GP or hospital due to medical concerns or not being in the age group.

When asked how the service could be improved suggestions were:

- Lower the age limit
- Make mobile screening available
- Making the kits available at walk in places such as the Life Store

- More frequent screening

4.5 Prostrate Cancer-general survey

Prostate cancer is not included as part of the national screening service.
We only included two questions on the general survey.
However, we have carried out a separate survey, findings below.

Only 23.68% of those who completed the general survey had received prostate cancer screening. 12 people received screening after they presented at their GP's with symptoms or family history of the disease.

General comments regarding all services included:

- *Screening for younger men should be introduced*
- *No advertisement in GP's. I would suggest you promote signs and symptoms of prostate cancer on the back of men's toilet doors*
- *Cervical screening is not necessarily a pleasant experience, but vital Perhaps some background music in surgery would put patients at ease*
- *More efforts should be made to dispel myths and fears about cancer, it no longer necessarily means a death sentence, catching it early means more chances of survival. Information should be seen in every type of venue not just public services or local government services*
- *Invites on pink paper would make me take more notice*

4.6 Prostate Cancer Survey

This subsidiary survey ran from 3rd April 2015 for 2 weeks. The survey comprised of 9 questions and was completed by 26 people all who had been diagnosed with prostate cancer. The age range of the men who completed the survey was 45-82 with an average age of 66 when diagnosed.

When asked how they were diagnosed most stated by Prostate-Specific Antigen (PSA) test via their GP or James Cook.

14 stated that no other members of the family had been diagnosed with prostate cancer, one didn't know and 11 identifying close family members having been diagnosed. One had 3 family members and one had 2 family members.

Most stated that the information given was clear, however a few less positive comments were received including:-

- *No, not at GP level. No initially at JCUH, eventually specialist cancer nurse answered any questions adequately but this took time.*
- *No, it was my son who found the information for me. Then when joined a local prostate cancer group discussions, provided more information and still does.*

- *Mainly literature (folder/prostate pack) seemed to be too generalised, not specific enough for my personal circumstances/stage, a little too impersonal perhaps. Though I realise the coverage had to be pretty encompassing to all patients.*

When asked "Did you feel the advice and information you received was sufficient enough for you to make informed decisions about your treatment?" Comments received included:

- *"No. The consultation does not allow for the explanation of the diagnosis. Further information session should be part of the treatment."*
- *"Much more information given by PCUK, and the support group in particular, have enable me understand the strands of treatment."*
- *"Yes I received information about removing the prostate then about radiotherapy I was then able to make an informed decision based on the treatment and other medical problems I had including high blood pressure and previous stroke."*
- *"I feel from my consultation that treatment had been already mapped out for me. I put my trust in the team/doctors specialist knowledge, that their recommended form of treatment was the best for me."*

When asked what could be done to promote early diagnosis of prostate disease suggestions included:

- *Mail shots to all men over 50 also could be part of the bowel cancer screening programme. Include prostate cancer literature in the same pack.*
- *Automatic PSA test from age of 60 as happens in USA and Europe. "I am aware of the question marker against this but feel that money should not prevent early diagnosis."*
- *Advertising aimed at sporting events. All public bars/hotels etc.*
- *All males at 50 years should be blood screened at a 'well man' clinic.*

Additional information added by those who completed the survey:

- More information should be given to patients about follow up treatments if cancer returns
- Many GPs do not realise that patients have a right to ask for and receive PSA tests. Urologists should give information on all options available even if no available at their particular hospital.
- More credit should be given to the great work that is given by support groups, also working together with NHS staff giving talks to groups.
- Why, if diabetics can get a "finger prick blood sugar reading kit", can't the NHS provide similar for a PSA reading?

A detailed breakdown of responses to each question can be found in the Appendix.

4.7 Findings from targeted focus groups

The findings from the focus groups were categorised as;

- Lack of knowledge about the screening service
- Lack of knowledge around the process of screening
- Reluctance to make and attend appointments
- The need to educate groups around cancer-related myth and prejudice
- The concern about lack of information and screening tests for prostate cancer
- Use different colour paper for invitations for cancer screening to make them more noticeable

5. Summary

Of the people interviewed, the majority of those who had been invited to screening attended. The main reasons for non-attendance were forgetting to make appointments, lack of flexibility in appointments, embarrassment and lack of knowledge of the importance and health benefits of screening.

In general there was a lack of understanding around what screening services were, what was available and what different procedures involved. This was particularly true of the asylum seeker and refugee groups we spoke to. There was an appetite to learn more and for involving community leaders in delivering messages.

It was apparent that those with sight problems found using the bowel cancer testing kit problematic.

6. Recommendations

Based on the intelligence gathered, people we spoke to, or from those who completed one of the surveys, Healthwatch Middlesbrough make the following recommendations:-

- A pilot scheme to be introduced to ascertain if the use of pink paper for cancer screening invites and reminders (sent out locally) results in a greater uptake of screening. The small additional cost to implement this will be more than readily absorbed by less people being diagnosed with cancer at a later date.
- Public Health work with local groups such as the Macular Degeneration Support Groups to see how people with sight issues can be better supported to take up screening, in particular bowel screening.
- Public Health Middlesbrough trial a pilot scheme targeting men with a letter and/or information about prostate cancer, highlighting where the prostate is, understanding warning signs and how to get help. As prostate cancer mainly affects men over 50, and the risk increases with age, it is suggested the information be sent during their 50th year via their GP surgery.
- Women indicated that one of the things that stopped them attending cervical screening was that of opening hours at the GP. If they could not attend their GP they felt uncomfortable attending the alternative on offer-a sexual health clinic. Healthwatch Middlesbrough suggest alternative venues be considered such as pharmacies. Several comments indicated that women felt uncomfortable attending for cervical screening.
- Healthwatch Middlesbrough suggests that Public Health Middlesbrough carry out further investigation to find out exactly why they feel uncomfortable, the environment, accessibility or location?
- Public Health work closely with community leaders to jointly plan how best to educate asylum seeker and refugees of the importance of cancer screening and why they should attend.

7.Acknowledgements

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8.References

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9. Appendix

9.1 General Cancer Survey Results

1. Which area of Middlesbrough do you live in?

Thorntree	8.33% (12)
North Ormesby & Brambles Farm	6.25% (9)
Park End	3.47% (5)
Pallister Park	4.17% (6)
Beckfield	0.69% (1)
Other	77.08% (111)
Total	144

2. Are you registered with a GP?

Yes	99.28% (138)
No	0.72% (1)

3. What is your age group?

Under 24	5% (7)
25-49	37.14% (52)
50-59	23.57% (33)
60-69	18.57% (26)
70 and over	15.72% (22)

4. Are you male or female?

Male	28.87% (41)
Female	71.13% (101)

5. Cervical Cancer Screening - Women have you ever been invited for cervical cancer screening?

Yes	85.57% (83)
No	14.43% (14)

6. If no, would you have liked to have receive an invitation?

Yes	53.33% (8)
No	46.67% (7)

7. Did you go for screening?

Yes	83.33% (75)
No	16.67% (15)

8. If yes, where did you go?

GP	80.00% (60)
Did not get an invite	1.33% (1)
Hospital	9.33% (7)
One Life	6.67% (5)
Sexual Health Clinic	2.67% (2)

9. If no, what stopped you from going?

Work commitments.
Did not want to go.
Felt uncomfortable.
Times.
Not old enough.
Did not fancy it.
Did not go for the last one but have gone for previous ones at my GP.
Had hysterectomy.

10. Do you have any suggestions on how the service can be improved?

More information about what it involves and why you are invited to attend.
Leaflets have to be advertised in different languages.
No.
Older people should be screened.
More staff.
Work should give times for GP's.
Flexibility.
More often.
More friendly staff, warm room.
Sat,Sun service and on an evening.
Screening younger. Previously I lived in Scotland and had two smears, moved to England to be told even with a family history and previous smears I could not have one as I was under 25.
No.
For those of working age attending screening in working hours can be challenging. Why can cervical screening in particular not be available in venues other than GP surgery and sexual health clinics which I find would be unacceptable to attend?
None.
No.
Age limit reduced - lady had abnormal cells picked up aged 20 - when screening was done with under 25's.
No.
Saw nurse at GP practice who had difficulty doing my smear test - didn't actually do it - stressful experience for me - sent me to Health Village - nurse there was very good. More training for practitioners required.

Screening could start before the age of 25.
Under 25 year olds should be screened.
If someone doesn't attend, send info on cervical cancer.
No.
Very happy with service.
No.
No.
None.
More advertising.
No.
Have screening available in town centre venues such as the Life Store.
No.
Yes give more flexibility on venues the test is available such as the Life Store.
More information about what it involves and why you are invited to attend.
Leaflets have to be advertised in different languages.
No.

11. Breast Cancer Screening - women Have you ever been invited for breast cancer screening?

Yes	53.26% (49)
No	46.74% (43)

12. If no, would you have liked to have receive an invitation

Yes	79.41% (27)
No	20.59% (7)

13. Did you go for breast cancer screening?

Yes	81.03% (47)
No	18.97% (11)

14. If yes, where did you go?

One Life.
James Cook.
n/a.
Kings Hospital London.
Fabian Road, Eston.
Hospital Car Park.
General Hospital, One Life.
One Life.
Skelton Health Centre.
North Tees.

One Life.
One Life.
North Tees Hospital.
Old General.
One Life.
North Tees.
Hospital, North Tees.
Not old enough.
Stockton, North Tees.
One Life, Linthorpe Road.
One Life North Ormesby.
Hospital mobile.
One Life mobile unit a while ago - recently found a lump and awaiting results of biopsy.
One Life Hartlepool (Mobile Unit).
New Life Centre.
One Life Centre.
James Cook.
One Life Centre.
One Life Centre.
One Life.
One Life.
One Life.
One Life - goes regularly every 3 years.
Borough Rd, Mobile unit near school.
One Life.
One Life Centre.
Mobile unit in Stokesley - 10/15 years ago.
One Life Centre.
JCUH.
One Life Centre.
Mobile unit at Abingdon Rd One Life Centre.
One Life.
North Tees hospital.
One Life Centre, Middlesbrough.
Hospital.
North Tees hospital.
One Life Centre.
One Life.

15. If no, what stopped you from going?

I never asked for one.
Breast cancer the age may be above?
Just new here.
Not eligible.
Haven't been yet, just got invite but will be going.

Very aware. Not in age range, but would go when invited.
NA.
One Life Centre.

16. Prostate Cancer - men only. Have you ever been screened for prostate cancer?

Yes	23.68% (9)
No	76.32% (29)

17. If yes, how did you find out about this?

Had problems with waterworks so went see my GP.
I had no awareness of this cancer it was not until I was diagnosed I found out that we had a family history. I should have been sent a letter with information about prostate cancer when I reached a certain age even if there is no screening programme.
Friend.
Blood Test.
Doctors.
GP.
Due to other health issue, got screened.
Receiving treatment for prostate cancer which was picked up by GP in 'general' consultation.
Aware of prostate cancer -granddad died of this.
Blood test - positive - done whilst in hospital for bowel issues.
Had symptoms, went to for blood test. Had 37 radiotherapy sessions.
Had prostate cancer so did father who died from this. State prostate cancer hereditary. Was invited for blood test - PSA high, had biopsy at JCUH and treatment 5/6yrs ago. Blood test every six months - all ok. (Brother also screened - all ok).
Had problems with waterworks so went see my GP.
Friend.

18. Have you ever been invited for bowel cancer screening?

Yes	24.56% (28)
No	75.44% (86)

19. If no, would you have liked to have receive an invitation?

Yes	56.67% (34)
No	43.33% (26)

20. Were you sent a 'kit' to collect samples?

Yes	39.39% (26)
No	60.61% (40)

21. If yes, was this process easy to follow?

Yes	81.48% (22)
No	18.52% (5)

22. If you were not sent a 'kit' where did you go for screening?

I had a camera due to bleeding, all clear.
I failed to use it, I regret it now.
Had other tests for BC symptom's in past.
Not in age range for screening.
NA, not in age range.
Test done in hospital.
Went to GP.
Had endoscopy and polyps removed from bowel

23. Do you have any suggestions on how the service can be improved?

Regrettably I failed to follow the instructions at the time. I regret it now and would like now to complete the test. Public Health information about "Have you missed your screening……………"
Talk about it.
Mobile screening and information in more place.
No.
Lower the age for screening.
Once every six months, if you are an older person.
Would like them to reply after kit test.
No.
More quicker responses if positive or negative.
Invite more people on a more regular basis.
Regularly, and older people who are left out should be allowed screening.
Staff could be friendlier, explain to us this is a worrying time for us.
If it was available at the Life Store, as a walk in I would go as would be convenient when in the town already. It would prompt me.
No.
Should be screened more frequently.
Should be more often.
Regularly, still should be offered for people aged over 70.
Every year.
Every 6 Months offer screening.
More screening for citizens.
No.
When waiting, promote the screening service on screen on TV at GP/hospitals and clinics.
Regular availability.
Ongoing and regular screening.

Automatic invite.
Automatic invite.
Automatic invite.
Automatic.
Every 3 years.
Every Year.
Staff could be a lot friendlier, spend a little more time explaining things.
Screening opportunities should be more prominently displayed in GP Practices, community 'bumping grounds' and other facilities (public and private) to encourage people to attend.
Regular screening as with breast and cervical screening.
I am 55 don't think I am old enough, the point is I do not know.
No.
Just received kit and haven't done screening as yet.
Not in age range. Aware, family history of bowel cancer - having blood test at moment for other issues.
Sent kit but didn't do it.
Didn't do sample - too much going in, timing not good.
Pot with scoop.
None.
None - a good service.
None.
No.
No.
Open it up to younger.

24. Additional information (optional) If you have any further comments to make please let us know.

Have I missed my opportunity to complete the test for bowel cancer?
Learn a lot today.
Screening invites should be on pink paper to make them stand out.
Screening for younger people should be introduced.
No advertisement in GP's I would suggest you promote signs and symptoms of prostate cancer on the back of men's toilet doors, above hand dryers and sinks in men’s loos
No.
No.
Had ongoing cancer screening at James Cook Hospital. Part of big nationwide screening, blood tests.
No.
Invite and allow screening more often.
How can I re apply for bowel cancer screening? A promotional exercise what to do if you have missed your chance.
Every Year.

Cervical screening is not necessarily a pleasant experience, but vital. Perhaps some background music in surgery would put patients at ease.
Having had Lymphoma in my 20's I would like to be given the opportunity to be screened for other types of cancers to ensure I continue to stay healthy.
More efforts should be made to dispel myths and fears about cancer, it no longer necessarily means a death sentence, catching it early means more chances of survival. Information should be seen in every type of venue not just public services or local government services.
Not too happy about what is happening to Hartlepool Hospital.
Cervical screening not good experience due to position of cervix, nurse told about this but did nothing to help or easy distress of this procedure.
Don't like sound of prostate cancer screening. Wife died of cancer.
Cervical cancer diagnosed at 20 yrs during routine smear test, followed by hysterectomy in early 20's. Strong advocate for reducing age of screening. Young people are more sexually active these day's
Invited twice for bowel cancer screening. Didn't do the tests, did want to. Kit seemed ok, straightforward.
17 years old. Aware of cervical screening via school - injections given to year 9/10. Awareness raised via Jane Goody (Big Brother).
Aware of screening for breast and bowel cancer and will go when called.
OK with health care received so far.
I think cervical cancer screening should start before the age of 25 years.
Don't smoke so didn't bother with bowel cancer screening.
Option to pay for cervical screening - had first screening around 16yrs old, when pregnant. Cervical cancer picked up when 24yrs, had laser treatment at JCUH. Hereditary, has 2 daughters under 25yrs and they should be screened, Feels very strongly about this - what price is a life!
Bowel Cancer screening would do this only if required. Has appoint on 18 Nov for smear, should have gone in August. Was sent follow up letter to attend.
Not in age range for other screening.
Not in age range for other screening.
Aware of prostate cancer. Not in age range for bowel cancer screening.
Has regular blood tests for various issues - nothing picked up about prostate cancer. Not in age range for bowel cancer screening.
Bowel cancer screening - had some problems so went to GP, receiving treatment at present.
No age limit on any cancer screening.
None

Further test for bowel cancer recently due to having blood test for other issues concerning bowel, going for operation in few weeks
Service at JCUH fantastic
No

9.2 Prostate Cancer Survey Results

The prevention, detection and treatment of cancer are key issues for NHS Middlesbrough. In addition to the research Healthwatch Middlesbrough is carrying out on screening for breast, cervical and bowel cancer we are looking into how prostate disease is diagnosed and what can be done to promote early diagnosis. Your views will be used to help shape future services.

1. How old were you when you were diagnosed with prostate disease?

60
64
51
66
69
68
66
Between 45-50 years (1977) enlarged prostate
67
60
66
50
55
66
45
66
67
82
65
66
56
60
64- now 74. Had treatment in 2004
73

2. How was this diagnosed? (GP, PSA test, or other tests you were having......)

- By GP after PSA tests and course of antibiotics to ensure the high reading was not caused by infections.
- PSA test at GP.
- Hospital referral. PSA test.
- A series of PSA tests and DREs followed by a biopsy.
- GP.
- PSA test via GP following my concerns with bladder frequency and control.
- Other test.
- GP and South Cleveland Hospital now JCUH.
- GP first then PSA test and biopsy.
- PSA.
- GP PSA monitoring over 15 years.
- Presented with erectile dysfunction Dec 2008 (PSA/4.8) bi annual PSA, leading to biopsy July 2011 Trus exam Glenson 3 + 3.
- GP examination followed by PSA test.
- PSA test.
- PSA test.
- Went to see my GP because I was having trouble passing water. He referred me to a consultant urologist at the JCUH and was diagnosed after biopsies test and scans.
- GP referred.
- GP unsure, sent me to hospital under 2 week rule as PSA test was 5.8.
- GP.
- PSA test and GP.
- I had a blood test at JCH. My GP told me the bad news.
- PSA test.
- PSA by GP, then biopsy by urologist.
- Elevated PSA x 2 TRUS biopsies - negative then saltwater biopsies - adeno carcinoma .
- PSA tests - rising over some years - GP - too long in referral (to JCUH) biopsy & MRI scan confirmed. PC (confirmed within prostate) Gleeson 7 (3+4).
- By my son insisting that my GP take a blood sample to test my PSA.

3. Do you know if any other members of your family have or have had prostate disease?

- No, first known member of the family to have been diagnosed.
- None.
- Brother.
- One cousin.
- Brother.
- No.
- No.
- None that I knew of.
- No don't think so, my mother died from breast cancer.
- No.
- No.
- My mother’s brother died aged 70, 35 years ago approx.

- Think grandad.
- None as far as I know.
- Yes, 2 brothers.
- There are three members of the family who have been diagnosed with prostate cancer.
- They haven’t.
- Yes my father died from prostate cancer in 1991.
- Don't know.
- Father.
- None.
- None.
- Father had prostate or something similar when I was about 10 so I don't know exactly what it was.
- No.
- None so far.
- No.

4. Was the information provided to you by medical staff about prostate disease clear and concise?

- No, one booklet given at the consultation when the results were given. Researched more information and options myself.
- Somewhat confusing, perhaps because of my own lack of knowledge (not now) I didn't even know where or what my prostate was.
- No not really.
- Yes.
- Not really.
- Yes and given choices as well as advice and documentation.
- Yes.
- I was only told enlarged prostate, no other information was given. I joined Middlesbrough PC group in 2000. Find any information and help in any way I could.
- This is my 15th year with them. My PSA to date is 1.5
- So, so.
- Yes.
- It took time to take it all in. All in all satisfied with medical advice.
- Yes.
- Yes, very.
- Information was clear but not enough info given.
- Yes.
- Not at the time.
- Yes very clear sister xxx and Mr Cxx are a great team.
- To an extent when told the diagnosis all the literature was of little use until I had. MRI scan and was then able to make sense of all the information.
- Mainly literature (folder/prostate pack) seemed to be too generalised, not specific enough for my personal circumstances/stage, a little too impersonal perhaps. Though I realise the coverage had to be pretty encompassing to all patients.
- Yes.
- Yes, very clear.

- Clear information.
- The information they provided was, but could have been more comprehensive.
- Yes.
- No - at GP level No - initially at JCUH Eventually specialist cancer nurse answered. any questions adequately.
- No, it was my son who found the information for me. Then when joined a local prostate cancer group discussions, provided more information and still does.

5. Did you feel the advice and information you received was sufficient enough for you to make informed decisions about your treatment?

-No. The consultation does not allow for the sinking in and acceptance of the diagnosis. Further information session should be part of the treatment.
Much more information given by PCUK, and the support group in particular, have enable me understand the strands of treatment.
-Yes.
-No, the information supplied was limited by the length of the consultation (15 mins for a surgeon and then oncologist) A lot more reading was then required.
-Yes.
-A grounded yes - would have done with a range of pros and cons on each treatment
-No, had to research options myself.
-No. I was prescribed Alfrozin 1.5mg tabs, now on Tamulsin 400mg caps, changed 2013 after kidney operation for stones.
-Not sure.
-Yes, but also discussed this with family.
-Yes.
-Yes - but attending the support group helped me to make a decision. Mr Palit at N Tees helped me a lot.
-Yes.
-Not at the time received more support and information from Ken and Tina who were running prostate cancer support group at the Acklam, Middlesbrough which was of extremely great help in making an informed decision. Also received help and advice from group later by Robin, Maurice and Tina. Feel hospital needs to offer more info and support.
-Not entirely. Consulted support group and PCUK.
-I was offered only one course of treatment from the results of my biopsies and scans. Hormone therapy followed by radiotherapy.
-Yes.
-Yes I received information about removing the prostate then abut radiotherapy I was then able to make an informed decision based on the treatment and other medical problems I had - high blood pressure and previous stroke.
-I feel from my consultation that treatment had been already mapped out for me. I put my trust in the team/doctors specialist knowledge, that their recommended form of treatment was the best for me.
-Yes.
-Some of it was, but I was in shock for about 6 weeks.
-Yes.
-Not really, I had to do a lot of further research online.

-Yes.
-Most information and guidance in this respect was from 1st meeting at prostate support group.
-No.

6. What do you feel could be done to promote early diagnosis of prostate disease?

-Mail shots to all men over 50 also could be part of the bowel cancer screening programme. Include prostate cancer literature in the same pack.
-Automatic PSA test from age of 60 as happens in USA and Europe. I am aware of the question marker against this but feel that money should not prevent early - diagnosis.
-PSA tests for 50 year olds. My doctor did not test me for this he said I was too young.
-I was not informed of the Teesside prostate cancer support group until I was about to be discharged following surgery. I deeply regret this as a more informed decision on treatment may have been possible.
-All males should be tested (PSA etc.).
-Promotion of warning signs that should not go unheeded.
-Regular PSA test encouraged by doctors.
-A more precise test is needed for PSA and at age 45? All male should be give this test and more information published on TV and newspapers.
-It can happen at any age so you never know. In 1998 prostate cancer was a taboo subject nowadays there is always something in newspapers every week.
-Advertising aimed at sporting events. All public bars/hotels etc.
-Information targeting - gents toilets, public, sports venues, pubs etc.
-Regular PSA screening for men over 50.
-More information through radio, TV and other orgs and also regular stands in supermarkets, shops etc.
-PSA screening for men at high risk i.e. family connection or female? Family with BRAC1 or BRAC2 breast cancer.
-The PSA test is the only means of detecting the disease at this time and should be available to all men from the age of 50.
-Encourage more men to talk to each other and find out more from those who have had the disease.
-Yes men and families should be better informed I'm getting there but still a way to go. Also people who request a PSA test especially those with a family history should not be fobbed off by GP's or refused the test.
-All males at 50 years should be blood screened at a 'well man' clinic.
-Regular medicals for men at GP surgeries.
-Compulsory for males over 50.
-Encourage people to go to well men equivalent or similar.
-Regular PSA testing for men over 50.
-A PSA screening programme for all men over 45yrs of age. More health education aimed at men as regards prostate problems and how to recognise possible symptoms. How about more Wellman Clinics?

-Guidelines for GP's to be emphasised in 'baseline' PSA level at 45yrs plus. Phasic. If symptoms/hereditary possibilities exist with regular re-check (6mths - 1 yr) to detect any rapid increase in PSA + understanding of PSA 'doubling take'.
-I assist at the JCUH at the prostate clinic with information leaflets etc. If any person comes look a same.

7. Additional information, if you have any further comments to make please let us know.

-The options offered by a health trust only appear to cover what they can offer are other treatment options should be offered.
-The prostate cancer support group has been incredible help to me and feel that all men when diagnosed should be directed to it I only found out because my wife worked in this field.
-More information should be given to patients about follow treatments when cancer returns.
-I have had radiation treatment (37 daily sessions) now I am on 3 yr hormone treatment (tablets) but I am not 100% certain the treatment was successful.
-If in doubt contact the nearest PC support group, they have a wide experience and can answer questions from sound experience. I am a member of M'bro PC support group and Cancer Patients group t JCUH. Mobility problems at 80yrs will limit me from any more involvement.
-Many GPs do not realise that patients have a right to ask for and received PSA tests. Urologists should give information on all options available even if no available at their particular hospital.
-More credit should be given to the great work that is given by support groups, also working together with NHS staff giving talks to groups.
-In my case my wife made sure I had PSA taken regularly.
-Availability of cancer nurse specialist invaluable, always keep that service
I received brachytherapy at Leeds this treatment was not mentioned to me at JCUH. Feel there are various treatments in different parts of the country and this should be told to people who are newly diagnosed.
-It's important that men know to access other support and help after their diagnosis. I've had a lot of help with a photography course, lifelong friends now
Why? If diabetics can get a finder prick blood sugar reading kit, can't the NHS provide similar for a PSA reading?
-More information about existence of local support groups! I was unaware until a few months ago! 4yrs after diagnosis and treatment. The group would have been a great help in the time following diagnosis and treatment.
-I was diagnosed in April 2004. Had some treatment (to reduce size of prostate) from 25 May 2004 casoduex (2wks) then zoladex. Brachytherapy (radioactive seed implants) 1 Oct 2004 followed by 20 x external beam radiotherapy (Nov) severe. Lt. Side effects from ext beam radiation.

9.3 Targeted Focus Groups-Straight Forward Community Group

Refugee and Asylum Seeker Community's health issues-Cancer Screening

Notes from Event on 13.3.15

- Come to groups to tell us about the health benefits of screening and what the process involves.
- Tell people what is cancer screening.
- Invite to screening letter should have appointments on already and you need to change it then you can ring up to make one which is more convenient. That way you do not waste time delaying making an appointment.
- I am not a cancer patient so why do I go? – Is it painful.
- Health visitors to tell parents about screening when they have appointments with them.
- Make invites and reminders stand out by printing them on coloured paper for example pink.
- Breast Cancer Screening if I receive a letter and then I have to phone GP or hospital for an appointment, I would not probably ring because I am lazy/reluctant to book.
- Make appointment in advance then send letter to me complete with time, venue and day.
- Are you able to offer the letter offered in different languages, along with a leaflet explaining the process for example - What happens? Is it painful?
- If someone is already identified that their first language is not English e.g. French – all letters should be sent out in French.
- Preferred language of communication* - Emphasise the importance of being screened as part of letter. Further outreach from cancer awareness post. Targeted awareness.
- Maybe the letter should be sent out on pink paper to indicate that this is a screening letter – people could be told to look out for this.
- Public Health + Community – could work together to teach each other.
- Put all screening letters on pink paper and educate the public that pink = important – contact your GP-act now.
- People from Africa – not very likely to have smear test.
- Fear that the test may find out I have cancer would put me off having the test.
- Policy Makers need to engage with Community to educate and encourage
- Education that this could save your life.
- Leaders to frame the whole strategy. E.g. involve people in the drafting of questionnaires.
- Fear around what actually happens – give the opportunity to walk through – showing us the equipment and how it will be used. We have never seen it in our country.

- GP to talk you through the process to make you feel at ease, show us the equipment.
- Education around screening - people feel that having the test might damage you internally.
- Support and training for community leaders.
- Support for changing attitudes in the community.
- People who know the language.
- Stats of uptake from the asylum seeker refugee community – Virginity is very important - stigma .People feel that having a smear test would impact this
- Registering with GP 1st appointment - give details at that point - Balance over whether this is appropriate - what are people taking in?
- Stigma of screening in African communities. Virginity is very important – smears can have a stigma attached because of this reason.

9.4 North of England Refugee Service (NERS) meeting March 2015

- Come to groups to tell us what screening services are available and why it is important to take up the offer.
- Tell people what is cancer screening, what it involves-equipment etc.
- Letter should have appointments on to go for the appointment and if you cannot make that appointment you ring if you need to change it.That way I would not forget to ring. If I do not have credit on my phone I will still get an appointment. Even better if they are on pink paper to make them stand out.
- I am not a cancer patient so why do I go - is it painful. If I feel like that many others will be. It is not part of our culture. Talk to the community leaders.
- Health visitors to tell parents about cancer screening when we take the children to appointments for other things.

9.5 Regional Refugee Forum

- Policy Makers need to engage with Community to understand cultural issues and the best way forward.
- You need to stress that education that this could save your life.
- Work with community leaders to frame the whole strategy not just in delivering the message once it is written.
- Involve people in the drafting of questionnaires, leaflets and information letters, staff training.
- Use coloured paper to send out invites so we look out for them.
- There is a fear around what actually happens - walk through the process at information sessions and show us the equipment that will be used.
- GP to talk you through the process to make you feel at ease.
- Education around screening - people feel that having the test damage you

- Support and training for community leaders-this needs to be financial as well to enable us to spread the word.
- Support for changing attitudes in the community.
- Make the relationship between public health, healthcare professionals and community leaders more equal, like a triangle all sides the same.
- Utilise people who know the language.
- It should be part of the education during the first check up at a GP when entering the country. This should be monitored to see if people actually take the information in at this stage.
- Publicise the statistics of uptake from the asylum seeker refugee community – Virginity is very important – stigma. People feel that having a smear test would impact this.

9.6 Prostrate Support Group

- Until there is a national screening service for prostate cancer men in certain age groups should receive information letters and information leaflets explaining where their prostrate is and any signs or symptoms to look out for. The letter should explain what tests can be carried out and how this is done.