Grabrovaz, Meaghan ORCID: https://orcid.org/0000-0002-0309-2890 , Simpson, Glenn, Goodwin, Victoria ORCID: https://orcid.org/0000-0003-2372-9067 and Grimwood, Tom ORCID: https://orcid.org/0000-0001-8099-6191 (2019) Northern Cancer Alliance Vague Symptoms Pathway. Evaluation report. Health and Social Care Evaluations (HASCE). (Unpublished)

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Northern Cancer Alliance

Vague Symptoms Pathway

Evaluation Report

This report was authored by Dr Meaghan Grabrovaz, Dr Glenn Simpson, Vicki Goodwin and Dr Tom Grimwood.

November 2019

Contents

Abbreviations

2WW	Two Week Wait
A&E	Accident and Emergency
ACE	Acceleration, Coordination and Evaluation
CCC	Cancer Care Co-ordinator
CCG	Clinical Commissioning Group
CHS	City Hospitals Sunderland
CT	Computerised Tomography
DNA	Did Not Attend
FDS	Faster Diagnosis Standard
GP	General Practitioner
IMD	Index of Multiple Deprivation
MDC	Multidisciplinary Clinic
MDT	Multidisciplinary Team
NCA	Norther Cancer Alliance
NHS	National Health Service
NuTH	Newcastle-upon-Tyne Hospitals
RDC	Rapid Diagnostic Clinic
SCAN	Suspected Cancer Pathway
vMDT	Virtual Multidisciplinary Team
VSP	Vague Symptoms Pathway

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1 Executive Summary

1.1 Context

In 2018, Health and Social Care Evaluations (HASCE) at the University of Cumbria was commissioned by the Northern Cancer Alliance (NCA) to evaluate the delivery of the NCA programme entitled 'Vague Symptoms Pathway' (VSP). The aim of this programme was to address a perceived problem for patients who present to their General Practice/Practitioner (GP), unwell, but with vague symptoms which do not neatly fit the two-week wait criteria.[1] This creates a challenge for GPs in identifying an appropriate route forward into secondary care for those patients. The NCA offered a funding pot for some localities to bid into in order to pilot projects with the aim of creating and enabling expedited access to testing, and assessment for these patients, to establish whether further cancer investigations are required.

1.2 Methodology

This evaluation work, which began in 2019, utilised a mixed-methods approach; using quantitative data collated from project returns and analysed using descriptive statistics, along with semi-structured interviews to collect qualitative data, which was then subjected to template analysis. The data collection was informed by a realist approach to evaluation; this aims to build an understanding about what works for whom, in what context and the mechanisms and outcomes around this.

1.3 Findings

Below is a short summary of the key areas of findings, these are explored in more detail in the body of the report.

1.3.1 Three project pathways

South Tees, Sunderland and Newcastle have each designed pathways underpinned by the context above. All three designs seek to address the problem facing the GP, of knowing where to refer patients; unaddressed, this issue can lead to delays, either through monitoring patients for longer before referral to see how symptoms develop, or as patients are referred between specialities.

The three areas have synergy with regard to the broad context and inherent challenges of managing patients with vague symptoms, however, each area has adapted its design to fit its perceived needs,

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[1] See https://www.nice.org.uk/guidance/ng12/resources/suspected-cancer-recognition-and-referral-pdf-1837268071621

as is summarised in the following sections. Additionally, all three projects use appropriate ‘vague’ symptoms in their referral criteria but have different eligibility criteria with respect to age.

1.3.2 Primary and secondary care feedback on the implementation of VSP

The evaluation has found the significant majority of clinicians and professionals with operational responsibilities for the intervention are enthusiastic about the pilot. What is more, some medical professionals, especially in radiology, have been proactive in supporting the VSP. Qualitative data collected from the clinicians is strongly suggestive that patients are having positive experiences of the intervention, although this is anecdotal. Patient experience of the programme was captured in a separate evaluation (see Appendix 1).

There were initial concerns among project leaders in all pathway areas that the intervention could lead to a surge in patient volumes, with the potential to cause an overstretch of resources, especially in radiology departments. This does not appear to have been the case at the time of this evaluation.

4.4 Primary and secondary care feedback on the implementation of VSP

The intervention has been well received in each pathway area among all clinical groups and professions and the concept underpinning the intervention is widely supported. In particular, the pathway is seen as addressing an important gap for those patients who do not easily fit with existing two-week rule pathways and, also, reducing the need for multitude of investigations requested by primary care.

An operational issue to note is the reported reliance on the ‘goodwill’ of hospital personnel to facilitate the VSP, as Radiology departments and clinical staff are often supporting the VSP on a ‘best efforts’ basis. This matter is also identified in MDC pilot projects (ACE Programme 2019 c, p. 4). The longer-term implications of this could be considered, as there appears to be an acknowledgement across the pathways that increases in patients could test the capacity and resources of the system to cope.

4.6 Number of referrals and pathway uptake

A total of 226 patients have been referred to a VSP during the period of this evaluation. Analysis of referral rates, demographic and socio-economic profiles of participating GP practices identified some findings that may be related to equitable access to VSP and/or provide contextual information to differences in performance and outcomes of different VSP projects. For example, small and large GP practices do not make referrals in proportion to their occurrence frequency. Small GP practices tend to make up to 50% fewer VSP referrals, proportionate to how often they occur in the project. Similarly, large practices tend to make nearly twice as many VSP referrals, proportionate to their occurrence frequency. This trend is consistent across projects, despite the differences between GP practices related to age, deprivation, ethnic and rural-urban profiles. A more detailed profile of the project areas is provided below, in Section 4.8.4.

1.3.5 4.9 Appropriate use of the pathway

Referrals are reviewed in only two of the operating pathways. To date, a rejection rate of 15.4% has been recorded in this project. There is no significant evidence that referrals are being made inappropriately, although projects may not be monitoring rejection rates.

4.10 Characteristics of patients referred to the VSP

Data from both operating pathways identified five characteristics of patients referred to the VSP are summarised in this section. These characteristics are:

- Gender: of the 226 patients referred to the VSP to date, 55% were female and 45% were male; and,
- Age: 52% of all patients referred to the combined VSP projects were aged 70 or over.

Co-morbidity data is only available for one VSP project.

Presenting symptoms: data on how many and which symptoms each patient presented with at the point of referral is available from South Tees. This shows:

- Nearly half (42%) of patients presented with one symptom;
- Over a third (35%) presented with two;
- 17% presenting with three symptoms; and,
- 6% presenting with four symptoms.

More patients (61.5%) presented with weight loss as at least one of their symptoms, than any other symptom. One fifth of patients presented with fatigue (20.6%) and/or abdominal pain (19.1%) with a range of other symptoms following (captured in detail in the body of the report).

It is useful to note that only 11.8% of patients presented at referral with GP 'gut' feeling as a symptom, despite this being identified as the most critical factor in referral decisions.

1.3.7 4.9 Diagnostic tests

Most patients seen in the VSP (88.5%) to date have had a CT scan of the chest, abdomen and pelvis.

4.10 Diagnosis outcomes

A critical area of interest is the outcomes for the patients referred on to a VSP, some headline findings are shared here:

- The Conversion Rate (CR) – which is the proportion of VSP referrals resulting in a cancer diagnosis - is 10.3% (combined data) for the project to date. This is consistent with of the range of individual MDC project levels CRs of 4-11% and higher than the 8% CR at MDC programme (ACE Programme, 2019b, p. 13).

- A fifth of patients (21.4%) were diagnosed with a new non-cancer condition, which is lower than the rate reported for the MDC programme where one third of cases were diagnosed with a non-cancer condition (ACE Programme, 2019b, p. 14).
- Over half (55.3%) of patients were discharged as 'all test normal' and 9.2% of patients were either still undergoing ongoing tests or were still on the pathway. 3.4% of referrals were rejected and 0.4% diagnosed a recurrence of cancer.
- The VSP combined project CR of 10.3% exceeds the rate for all 2WW pathways for 2013/14 - 2017/18 in Sunderland CCG (7.4%); Hambledon, Richmond and North Yorkshire CCG (9.8%) and England (8%) (2WW Referrals, Cancer Services, PHE).

1.3.9 4.11 Types of cancer diagnosed

Of the 28 cancers diagnosed to date as a result of referral to VSP:

- 14.3% were lung cancer;
- 10.7 % were haematological cancer;
- 9% were prostate, colorectal or pancreatic cancer; and,
- One case (3.6%) of each of the other types of cancers was recorded: hepatocellular, angiosarcoma, gallbladder, renal, stomach, breast, oesophageal, bladder, liver cell carcinoma, Non-Hodgkin's Lymphoma, lung cancer and peritoneal mesothelioma. One case of recurrent cancer (residual CLL) was also recorded.

1.3.10 4.11.1 Common, rare and less common cancers diagnosed

Of the cancers diagnosed by the VSP to date, 68% have been Less Common or Rare cancers, which is somewhat higher than the 56% of Less Common or Rare cancers diagnosed by the MDC programme (ACE Programme, 2019b, p. 13).

1.3.11 4.12 Staging of cancers diagnosed

A major objective for VSP projects is to improve the diagnosis of cancers at earlier stages of cancer and improve treatment options and outcomes and patient experiences (ACE Programme, 2017, p. 1).

Of cancers diagnosed to date by the VSP to date, 82% have staging information, which shows that:

- 35% of cancers were diagnosed at Stage 1;
- 9% at Stage 2;
- 9% at Stage 3; and
- 48% at Stage 4.

Overall, 44% of cancers were diagnosed at early stage (stages 1 or 2), compared to 26% in the MDC programme (ACE Programme, 2019b, p. 15).

1.3.12 Non-cancer diagnoses

The combined project data shows that 20.6% of patients referred to the VSP were diagnosed with a non-cancer condition.

1.3.13 4.14 Time to diagnosis

The median number of days from referral to the first diagnostic test in the Sunderland VSP was 13 days in Quarter 1 and 14 days in Quarter 2. In the South Tees VSP, the median number of days from referral to first diagnostic tests was 2.5 days in Quarter 1, 7 days in Quarter 2 and 3.

The qualitative data provides a rich reflection in support of the quantitative data shared above and brings an understanding to the operations and benefits of the pathways, as perceived by those working in and around them.

1.5 Conclusions and 5.3 Recommendations

The evidence presented above illustrates that the overall aim of the programme is being met – clearly, the pathways present a highly appropriate and effective option to GPs when faced with a patient with vague symptoms. It is also evidenced via the quantitative and qualitative data that expedited access is generally being achieved, with those who are staffing the pathways and associated activities feeling very positive about their effect and potential. Importantly, that expedited access is reducing the time to diagnosis for patients, thus enabling more rapid care, for cancer, or identifying another condition.

Overall, the evaluation team feel that the pathways considered here, at their individual stages, are successful, that the programme has been well implemented and is delivering against its core aims. However, in all programmes, particularly those that are piloting new approaches, lessons can be learned and, with this mind, thirteen recommendations arise from this evaluation report as follows:

1. The NCA monitors uptake of the VSP by GP practices for the remainder of the project to identify whether further promotional activity needs to take place and to enable uptake rates to be captured by the programme or project leads.

2. It would be useful for the programme to continue monitoring a number of metrics, to include: trends relating to GP practice size and proportion of VSP referrals; trends relating to GP practice size, age, deprivation profiles, ethnic diversity, geographic profile, are monitored with regard to equitable access or to provide information on performance and outcomes against different variables.

3. Referral rejection rates are monitored throughout the project to identify whether repeat/revision of guidance on referral criteria or other action is needed.

4. VSP configurations where minimal referral information is available and/or no clinic assessment is performed, consider how they can how they can obtain sufficient referral and patient information in order to evaluate referrals and monitor inappropriate referral rates.

5. The age distribution, and particularly the frequency of patients < 50 years of age, is monitored and investigated if the current unexpected trend continues.

6. The Project Steering Group considers whether co-morbidity data for all patients on the VSP is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

7. The Project Steering Group considers whether performance status data is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

8. The project(s) continue to monitor and investigate trends and variations in the percentage of patients presenting with each symptom type (and particularly GP gut feel) and reports this data on an individual project level as well as combined data for all VSPs.

9. The Project Steering Group considers whether the Detection Rate of the pathway should be monitored and if they wish to disseminate that information further.

10. The Project Steering Group considers whether staging information linked to type of cancer should, and can be, provided by projects. If so, projects should be asked for staging information, linked to type of cancers for previous data returns. Furthermore, the data return form could be amended to capture this information for the remainder of the project.

11. The Project Steering Group considers whether projects need to provide additional data to calculate the full range of metrics and, if so, to amend the data return form to collect this data.

12. The Project Steering Group considers whether treatment information is required. If so, projects could be asked to provide treatment information relating to cancers diagnosed and reported to date, and the data form amended to collect this data. It is suggested that any amendment to the data collection form enables the type of cancer, staging and treatment to be linked.

13. The Project Steering Group considers whether the VSP project needs to develop and implement a data quality assurance process to identify, correct and provide an audit trail for data corrections and changes.

2 Background

A series of local and national pilots have previously developed, tested and considered service models to address the needs of patients who present with Vague Symptoms (also known as 'non-specific but concerning symptoms') and who do not meet the current criteria for urgent referral to a specialist cancer pathway.

These patients often experience delays reaching a diagnosis, especially as they may be referred to more than one clinical specialty as the diagnostic pathway progresses. The aim of the new Vague Symptoms Pathway (VSP) is to offer expedited access to testing and assessment to establish if further cancer investigations are required. Pathway objectives are to reduce time to diagnosis for patients with malignancy, and to screen out people who do not need to access cancer testing and services.

The Northern Cancer Alliance (NCA) provided funding to enable the piloting of this pathway within the NCA geographic footprint. Four localities (Sunderland, South Tees, South Tyneside and Newcastle) submitted bids for pilot projects. Three of these projects are the subject of this evaluation, with each project at a different stage of maturity at the time of this work. The projects can be outlined as follows:

- Sunderland is an established service which has been running since September 2017 and has over 18 months of operational experience and data;
- South Tees has been running for 10 months since October 2018; and,
- Newcastle launched its pathway in June 2019 and no operational data was available at the time of this evaluation.

All three projects are following guidance and implementing learning from the national ACE Programme and this, along with the evaluation outputs, will feed into any extension of the pathway into other areas, for example, North Cumbria.

HASCE was commissioned by the NCA to evaluate and report on the implementation and emerging results of the three projects outlined above. The agreed approach to this work has been a mixed-methods evaluation to bring the robustness of the quantitative data together with the richness of qualitative work. This combination makes for a fuller narrative of evaluation findings for the commissioner and the projects considered.

2.1 Contextual demographic, socio-economic and cancer incidence information for projects

At the outset, to set the scene, below is a range of contextual demographic, socio-economic, cancer incidence and outcome information for each of the projects. This has been extracted from the bid documentation submitted by the pathways to the NCA. Further specific profile data related to patients registered with each GP practice (GP practice size, age, deprivation, ethnic and rural-urban location) is discussed in Section 4.7.

2.1.1 Sunderland

City Hospitals Sunderland (CHS) is a large acute trust located within the city of Sunderland. During the evaluation the trust merged with South Tyneside Trust. It provides cancer services to the local population of approximately 330,000 people and sub-regional services to a population of up to 850,000, depending on the subspecialty. Service delivery is supported by tertiary and regional services based in Newcastle providing oncology and radiotherapy for more rare cancers such as thyroid or leukaemia.

CHS is the prime secondary care provider for the local population commissioned by Sunderland Clinical Commissioning Group (CCG), which comprises 40 local general practices. The local population is primarily urban or semi-urban and exhibits relative stability without significant mobility. Social deprivation affects a significant element of the population and there is a significant burden of morbidity resulting, in part, from a history of heavy industry. In 2014-15, CHS provided almost 2,000 first treatments, with 48% of these coming from Sunderland CCG residents.

The Radiology Service and Primary Care have previously developed a strong working relationship, which enable them to deliver a combined approach to pathway redesign in 2014, resulting in significant improvement in the local lung cancer pathway.

Some key data relating to the Sunderland CCG locality includes:

- The cancer incidence rate in this locality - 663.1 per 100,000 - is higher than the English average (606.7 per 100,000);
- The cancer mortality rate (338.9 per 100,000) is also higher than the English average (285.4 per 100,000);
- The rate of people under 75 dying of cancer (classified as premature cancer deaths) in Sunderland (175.5 per 100,000) is higher than the English average (141.5 per 100,000);
- One-year cancer survival in NHS Sunderland CCG (69.4%) is similar to the English average (70.2%); and,
- 20.9% of patients in NHS Sunderland CCG are diagnosed with cancer through emergency routes; this is comparable to the English average of 20.1%. However, generally higher numbers of patients diagnosed through emergency routes may indicate late diagnosis and may correlate closely with poor survival.

2.1.2 South Tees

Situated in the North East of England in the Tees Valley sub-region and the Hambleton, Richmondshire and Whitby areas of North Yorkshire, South Tees Hospitals NHS Foundation Trust is the largest hospital trust in the Tees Valley. The trust runs one acute hospital with services delivered over two sites, as well as services in a number of community hospitals. It provides cancer services across seven Local Authority areas and five CCG areas, serving a population of approximately 1.5 million people.

This area exhibits diversity in both geography and population; the densely populated urban centres of Middlesbrough are in stark contrast to remote rural communities in Aysgarth, Reeth and Leyburn. There are levels of high social deprivation and unemployment with consequent impacts on health.

The James Cook University Hospital is situated in the heart of Middlesbrough and is one of Europe's largest and most modern hospitals offering 80+ specialist services from one location. Numerous services support the prevention, diagnosis, treatment and rehabilitation of those affected by cancer on the James Cook Hospital and Friarage Hospital sites.

Some key observations on South Tees:

- Overall, the incidence of cancer is higher than national levels (in England, one in three people in England will develop cancer at some stage in their lives);
- Cancer poses particular challenges to the health of the population of Middlesbrough and Teesside;
- Survival rates from some cancers are among the worst in the country;
- Cancer is a major cause of premature death in North Yorkshire and York;
- Scarborough and Richmondshire both have an increased incidence of cancer and higher mortality than North Yorkshire as a whole;
- North Yorkshire and York has an ageing population who are at increasing risk of cancer; and
- The overall cancer incidence rate increased from 317 per 100,000 in 1993 to 373 per 100,000 in 2009. Despite this, mortality from cancer fell over the same time period from 193.6 per 100,000 during 1993 to 150.0 per 100,000 in 2010.

2.1.3 Newcastle

Newcastle-upon-Tyne is based in the North East of England. There are 33 GP Practices in Newcastle and the total practice population size is 315,905 (as at September 2018). Newcastle and Gateshead (the neighbouring town to Newcastle) are served by Newcastle Gateshead CCG[2].

There are high levels of deprivation within Newcastle City and its surrounding areas, with Newcastle being one of the 20% most deprived areas in England. The health of the people in Newcastle is generally worse than the England average, with life expectancy lower than the England average for both men and women. There are a number of factors contributing to poorer health outcomes for people in Newcastle, including its industrial past, high levels of social deprivation and historically high levels of smoking.

The Newcastle-upon-Tyne Hospitals NHS Foundation Trust (NuTH) provides a tertiary centre for cancer, the Northern Centre for Cancer Care, based in the Freeman Hospital. The majority of patients in Newcastle diagnosed with cancer will receive treatment from NuTH, although there are several other hospitals in the area, which patients could choose to attend, such as Gateshead NHSFT, Northumbria NHSFT and City Hospitals Sunderland NHSFT.

Some key facts on Newcastle:

- The cancer incidence rate in Newcastle in 2014/15 was considerably higher at 609.1 per 100,000 than the England average of 523 per 100,000. Of these cases, only 47.4% were diagnosed following a referral to a 2 Week Wait (2WW) pathway;

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[2] Some demographic data is available at a CCG level only

- In 2016, in the Newcastle Gateshead CCG area, only 52.5% of cancers diagnosed were detected at stage 1 and 2;
- Under 75 years mortality from cancer in Newcastle Gateshead was 157.6 per 100,000, compared to the national average of 121.9 per 100,000 (in 2016);
- One-year survival rates in the CCG area are 71.4% compared to the England rate of 72.3%;
- In 2016/17, 96 per 100,000 were diagnosed with cancer following an emergency presentation, compared to an England average of 88 per 100,000.

3 Evaluation approach

This section will outline the main research questions, the methodological approach to the evaluation, the quantitative analysis of the project data returns, and the qualitative data collection through interviews with primary and secondary care staff involved with developing, implementing and delivering the three VSP projects that form part of this evaluation.

3.1 Research questions

The evaluation was designed to address the following research questions:

1. Is the development and implementation of the participating projects to date on target to meet the NCA objectives?
2. What do data from project returns to date tell us about the performance of the pathways in each location?
3. Are there emerging themes and/or recommendations for the remainder of this project and for future VSP projects?

3.2 Methodological approach

The approach to this evaluation was based on a realist methodology, which involves forming and testing hypotheses on how a programme has been delivered and considers what works for whom and in what circumstances (Pawson, 2013).

Baseline information about each pathway was gathered by the evaluation team via 'scoping' interviews with VSP programme leads and a sample of other leading figures responsible for developing the projects. These scoping interviews, together with an analysis of the complexity of the context(s) in which the intervention takes place using a VICTORE approach (Volitions, Implementation, Contexts, Time, Outcomes, Rivalry, Emerging), were used to develop a Theory of Change (**Error! Reference source not found.**). Scoping interviews also informed the data collection strategy, i.e. key questions, and key personnel to be invited to be interviewed during the subsequent phase of the qualitative work.

Qualitative data was collected in each of the three pilot locations of Newcastle, South Tees and Sunderland. The main empirical component of the qualitative evaluation involved semi-structured interviews with a range of personnel in both primary and secondary care involved with the development and delivery of the VSP. Semi-structured interview guides were designed based on the evaluation team's Theory of Change model (), adapted to individual clinical specialties or professions and the maturity of each pilot area.

The research design aimed to include a representative sample of professionals and clinicians working in a variety of key positions and roles in each pathway area. These included specialties and professions such as: Consultant Gastroenterologist; Strategic Cancer Lead; Macmillan Lead Cancer Nurse; Macmillan GP; Cancer Lead GP; VSP Project Delivery Officer; Cancer Care Co-ordinator; Cancer Services Manager; Cancer Improvement Manager and Consultant Radiologist.

GPs who had used the VSP were targeted for interview based on suggestions by Project Leads. Referral patterns from GP surgeries were also examined to identify and target GP surgeries showing a range of referral patterns:

1. Large practices with a low number of referrals
2. Large practices with a high referral rate
3. Small practices with a high referral rate
4. Practices with higher proportion of older patients but low referral rates
5. Practices with higher proportion of deprived patients but low referral rates
6. Practices with higher rate of VSP referrals rejected or redirected
7. 'Average' (ie medium size with mid-range referral rate) practices for comparison

In total, 24 interviews were conducted for the qualitative component of the evaluation.

Additionally, relevant information was also captured during Vague Symptoms Steering Group meetings (attended by members of the evaluation team) and extracted from Steering Group meeting minutes.

Quantitative data about project activity and outcomes was obtained from quarterly returns provided by projects to NCA. Projects report pathway activity on a quarterly basis, according to an agreed schedule (**Error! Reference source not found.**):

Quarter	Period covered	Deadline for submission
1	Start of pilot to include December 2018	23rd January 2019
2	January to March	24th April 2019
3	April to June	24th July 2019
4	June to August	25th September 2019
5	September to December	2nd January 2020
6	January to March	22nd April 2020

Table 1. Reporting schedule and deadlines for participating projects.

During the period of this evaluation[3], two returns (Quarters 1 and 2) from Sunderland were received and three (Quarters 1, 2 and 3) from South Tees. The first return from Sunderland covered a 13-month period from the start of the pre-cursor project on 15 September 2017 to the end of the first VSP quarter on 31 December 2018. The structure of the pre-cursor project, GP Direct Access to CT, was adopted as the structure of the VSP pilot, thus data collected during this pre-cursor project has been included in the data returns for the VSP pilot. The second return from Sunderland covered the quarter from 1 January – 31 March 2019. South Tee's returns covered the three quarters: 1 October-31 December 2018; 1 January -31 March 2019 and 1 April – 30 June 2019.

The data was provided in a summary format report agreed by the Project Steering Group, based on a truncated version of the national ACE Programme Wave 1 VSP data items and returns. The data used for this report (**Error! Reference source not found.**) includes corrections to the original data returns, a s agreed with Project Leads.

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[3] February – August 2019

3.3 Theory of Change

Piloting vague symptoms (VS) pathways: improved diagnosis of patients presenting with concerning but non-specific symptoms of cancer

Context, e.g.: geography; population health profile; socio-economic determinants of health, etc

Objectives	Inputs, Resources & Costs	Activities/Actions - Implementation	Possible Barriers & Enablers	Outcomes	Impact
1. Increase the number of cancers detected in pilot pathway geographies. 2. Reduce the time to diagnosis for patients presenting with vague symptoms to General Practice (and A&E). 3. Reduce the number of diagnoses resulting from emergency presentation. 4. Improve the experience of patients including reducing the number of stages before a confirmed diagnosis & treatment plan, & the time taken to achieve this. 5. Ensure patients referred for testing by a GP receive a definitive diagnosis of cancer or cancer is excluded, within 28 days of referral.	1. Funding from NCA. 2. Funding, in-kind & 'giving time' resources from primary & secondary partners. 3. Inputs from Vague Symptoms Steering Group. 4. Feedback/inputs from patients. 5. Engagement event costs. 6. Training &/or briefing costs for GPs & secondary care personnel. 7. Marketing & communication costs. 8. Possible additional diagnostic activity costs (e.g. endoscopy incl. consumables; CTs; OP appointments; other). 9. Evaluation team inputs.	Primary care 1. Engagement with GP Practices. 2. Training of staff. 3. Design & test referral systems for GPs (e.g. referral forms; choose & book). Secondary care 4. All relevant personnel engaged & informed. 5. Referral pathway specifics agreed (e.g. develop new referrals forms & patient information; clinic slots aligned to VS pathway; new protocols for vMDT &/or for reviewing diagnostic tests, etc). 6. Internal training arranged. General 7. Existing evidence applied to pathway development. 8. Pathway governance structures agreed to provide effective oversight, reporting & leadership. 9. Data collection processes established. 10. Communication or information strategy in place for patients & primary & secondary care professionals. 11. Information about positive & negative aspects of the pathway continuously fed-back to primary & secondary care personnel.	1. Sufficient resources & capacity in place to deliver pathway including: - possible financial costs to secondary care; - possible increased workload for secondary care & overstretch of existing systems & staff capacity. 2. Implementing pathway within agreed timelines. 3. Effectiveness of governance & leadership (e.g. steering groups; pathway management; reporting & monitoring processes). 4. Levels of engagement & support for pathway by key partners (including patients) as it progresses. 5. The appropriateness of referral criteria & the effectiveness of other operational aspects of pathway. 6. Evaluative learning is effectively applied throughout iterative development of pathway. 7. Effectiveness of communication including knowledge & understanding of VS pathway. 9. Sufficient uptake of pathway. 10. Effectiveness of joint working between primary & secondary care.	1. GPs using VS pathway appropriately & consistently. 2. Benefits of the pathway are understood & supported by patients, & primary & secondary personnel. 3. An increase in early diagnosis of stage I & II cancers in pathway areas. 4. Patients referred for testing by a GP have received a definitive diagnosis of cancer or cancer is excluded, within 28 days of referral. 5. Reduced number of diagnoses resulting from emergency presentation. 6. Reduction in the number of stages patients follow before a confirmed diagnosis & treatment plan, & the time taken to achieve this.	1. Optimised VS pathway(s) successfully adopted in local area. 2. An enhanced patient experience. 3. Equity of access achieved for VS patients comparable to that of specific tumour groups. 4. Improved clinical outcomes achieved for VS patients. 5. Cost-effectiveness over current referral processes for VS patients has been demonstrated.

Evaluation (including wider evidence from national pilots & other sources)

Figure 1. Theory of Change model of the Vague Symptoms Pathway.

4 Findings

This section presents the results of the qualitative and quantitative analysis of interviews with GPs, clinicians, Cancer Care Co-ordinators, Project Leads and other people involved in the development and implementation of VSPs in South Tees, Sunderland and Newcastle CCGs. It also presents the results of the quantitative analysis of project data. The findings are presented as thirteen evaluation themes:

1. Development rationale of project pathways
2. Pathway design
3. Referral criteria
4. Primary and second care feedback on the implementation of the VSP
5. Primary and secondary care feedback on the performance of the VSP
6. Number of referrals and pathway uptake
7. Appropriate use of the pathway
8. Characteristics of patients referred to the VSP
9. Diagnostic test(s)
10. Diagnosis outcomes
11. Time to diagnosis
12. Treatment
13. Data collection by projects

4.1 Development rationale of project pathways

The rationale driving the development of the Vague Symptoms Pathways (VSPs) was found to be similar across the three pilot geographies examined by the evaluation. Experiences of late presentations, patients presenting via the route of Accident and Emergency (A&E) or being 'bounced' around the system were frequently cited in the feedback received from both primary and secondary care personnel alike. As one lead General Practitioner (GP) in South Tees explained, the thinking behind the VSP was a perception that there:

> *"… were people presenting late with cancers that didn't fit into things. And partly it's to try and pick-up things earlier, because people presenting late and presenting as emergencies tend to do worse than people who are picked-up in the early stages".*

Another GP commented that addressing the needs of patients with vague symptoms has previously been:

> *'… quite frustrating and patients can be bounced around different specialties.'*

From a primary care perspective, the establishment of a dedicated VSP has removed the challenge and complexity of GPs attempting to 'align' the symptoms of this patient cohort with existing two-week cancer referral pathways, as a lead GP in South Tees recounts:

> *"I suppose in the past because we haven't had a named specific service for that, we've just had to try and find some speciality to vaguely attach it to. If there's one symptom which you think is slightly more severe, or more likely to be indicative of the reasons behind it, you try and slip it into that specialty".*

These difficulties faced by GPs of trying to align patient symptoms with existing pathways are recognised in secondary care. A secondary care manager in the Sunderland pilot acknowledged that:

> *"… historically I think the GPs would have maybe monitored these [vague symptoms] patients for a little bit or they might have tried to shoehorn their symptoms … to fit, you know, if they thought there was maybe something going on in the abdomen, upper or lower GI area. Maybe they would have tried to shoehorn some of those symptoms to fit the two-week wait GI pathway or maybe it was a lung… was to give the GP the opportunity to access a scan, to exclude cancer when they're just not sure - to be honest with you".*

As well as addressing this 'shoehorning' effect, another critical factor driving the development of the VSP, frequently mentioned by both primary and secondary care clinicians, is providing GPs with speedy access to a CT scan. A GP in South Tees explained the difficulties of accessing CT:

> *"… the things we found difficult [before there was a VSP], I think; it's just the power of a GP to request something like a CT scan, quickly".*

A lead GP in the Sunderland geography also had a similar experience, noting that GPs in a neighbouring CCG had access to diagnostic tests unavailable in their area:

> *"… if you take Durham and a patient comes and tells me that the symptom in question is not resolving and the chest x-ray is fine but I'm not happy, I can refer them to a CT chest, whereas we cannot do that here. … So we can't have access to all the diagnostics for various reasons. Anyway, there was clearly a missing link in the jigsaw there [Lead General Practitioner]".*

A lead GP in the Newcastle pilot explained that the establishment of the VSP would facilitate a more structured referral process, beneficial to both primary care professionals and patients:

> *"I know the [vague symptoms] patients I've seen; that I didn't have a pathway, so historically I can see how my patients would have done better as I didn't have this scan [available] in this system. … I had to then refer urgently … to a Consultant who may or may not have seen them quickly … so essentially we're making this more of a rational process for the patient and for primary care".*

Clearly defined outcomes envisaged for the VSP have been identified in each of the pilot areas. A participant who was involved in the developmental work and implementation of the VSP in Sunderland stated that the clinical focus needed to remain on the essence of the intervention, that is, to ensure that the correct diagnosis of patient symptoms has been achieved regarding any suspected malignancy:

> *"… when we first embarked on this project we were conscious that you do a CT thorax abdomen pelvis, there could be lots of incidental illness, lots of incidental*

> *findings. Then you almost begin to report every single detail. Then you could potentially lose the central question of: has this patient got any malignancy based on what you see? We were very clear right from the beginning".*

The primary outcome in all pathways is the equitable access to cancer diagnosis and treatment for vague symptoms patients comparable with other patient cohorts. A lead primary care clinician in the Newcastle pathway commented that:

> *"…for patients it is hoped that the VSP will lead to equitability of treatment for all patients, in particular those with non-specific or vague symptoms".*

In this regard, the intervention aims to contribute to the outcome of reducing the:

> *"huge delays for patients, missed or delayed diagnoses and therefore worse outcomes' [a Newcastle GP]".*

Improving the patient care and their experience more generally has also been a motivating factor propelling the development of the VSP. A lead General Practitioner in the Sunderland pilot commented that:

> *"…we would also want to reduce patient litigations, patient complaints, patient dissatisfaction and increase their satisfaction levels with quick and early diagnosis".*

In summary, across there is agreement in all three project areas there is the perception of a problem for patients who present with vague symptoms. These can be summarised thus: it can be difficult for GPs to know to which speciality or pathway to refer patients, which can lead to delays, either as patients are monitored patients for longer before referral to see how symptoms develop, or as patients are referred between specialities.

4.2 Pathway design

The pathway design, for example, patient assessment; referral mechanism; responsibility for patient care, together with governance and plans for future development of the VSP differs slightly between each project.

4.2.1 South Tees

The pilot commenced on the 5th November 2018, with three GP surgeries and one comparator GP practice included in the initial roll out. This meant that the project was available to patients in Hambleton, Richmondshire and Whitby CCG.

On presentation, GP 'gut instinct' or 'clinical suspicion' appears to be a key factor informing diagnosis of patient symptoms. Assessment of the patients begins with a first screening of bloods, which is carried out within Primary Care. If a patient's symptoms align with the vague symptoms criteria they are referred to the VSP. Patients are referred to the pathway via 'choose and book'. A new referral form has also been developed for this process.

A key component of this pathway is the dedicated Cancer Care Co-ordinator (CCC), who makes ‘first contact’ with patients referred to the VSP clinic (based in Ambulatory Care at the Friarage Hospital). Initially at the clinic, a full examination of the patient is conducted and their clinical history assessed. Following this initial consultation, the consultant decides the next steps which can include undertaking a second level screening of bloods, a CT scan (Chest, Abdomen and Pelvis), Endoscopy or Haematology (or other) referral. The role of the CCC is to ensure that medical professionals follow up the findings of these tests and patients are kept informed about each stage of their journey along the pathway.

Before a patient is discharged, a virtual Multi-Disciplinary Team (vMDT) process is initiated. This is a key feature of the South Tees pathway model. The CCC emails the vMDT group with a summary of patient results for clinical decision. A Word document or template is circulated which used to capture clinicians’ recommendations for each patient. These include:

- No evidence of cancer and the patient is discharged back to their GP;
- A site specific cancer is identified and the patient is referred to a 62-day pathway;
- Referral of the patient to other specialty.

The CCC maintains contact with the patients throughout, until they are discharged from the pathway. The aim of this is so that patients are kept informed about practical matters and support can be provided to alleviate anxiety and stress.

This pathway has been designed to ensure patients receive a definitive diagnosis of cancer or that cancer is excluded within 28-days of referral.

In summary, the South Tees pathway design aligns with the key design principles of a cancer diagnosis service (model 1) (ACE Programme, 2019a, p. 3).

A Vague Symptoms Project Steering Group has been established to oversee and take forward the development of the VSP. All of the key individuals and organisations from primary and secondary care, along with managerial colleagues, are members of the steering group. This is consistent with the recommendations for successful implementation of these types of pathways (ACE Programme, 2019c, pp. 2; 3; 5):

- Ensure organisational commitment and ownership of the project;
- Maintain inter/intra organisational relationships including the most important relationship between primary and secondary care; and
- The need to communicate with clinical staff and other stakeholders, usually through a steering group platform.

In terms of future development, the intention is to roll out the VSP across the Middlesbrough and South Tees geography. The lack of dedicated resources to support this pathway has required a measured and phased roll out.

The A&E phase of the pilot, to be based at James Cook Hospital, has yet to be rolled out. Development of the A&E component of the VSP is still at the discussion stage in South Tees. This development process may take time, as there are limited resources available to support implementation of this phase. In terms of practical steps, a new team of clinicians will need to be brought together to develop and implement the A&E component. There is also an awareness that A&E personnel do not currently have the capacity to absorb the extra workload of the prospective pathway. This is a particular concern, as James Cook Hospital serves a large conurbation, which could lead to a large number of referrals being generated by this pathway, which could potentially place a strain on the resources of Radiology.

It is evident at this stage that the South Tees pathway is a smaller scale pilot compared with the urban-based pathways at Sunderland, which covers most or a significant proportion of the CCG geographies of these areas. The South Tees practices cover large rural areas and smaller centres, compared with the other city scale pathways. Patients at these practices often stay with the same GP or Practice from 'cradle to grave'.

In addition, it is evident that the South Tees VSP is being rolled out slowly and in a staged manner, with an initial small pilot established that will inform wider iterative development across a broader geographical area. The relatively slow roll out is mainly due to limited resources, as well as a desire to learn as the process develops. In this regard, consultants and clinical staff support the VSP on a 'best efforts' basis, as the pathway is not built into their current job roles and planned workloads. In addition, this staged roll out aims to ensure that the capacity of the pathway is not exceeded, assist with identification of early problems with service delivery and enable monitoring of GP uptake of the pathway.

It is evident that the CCC has a pivotal 'lynchpin' role in the smooth and effective operation of the pathway, both in terms of supporting and managing patients and as an intermediary or facilitator between primary and secondary care. It is envisaged that the CCC will also play a critical role in delivery of core outcomes of the pathway, in particular, 'enhancing patient experience' by providing personal support to each patient.

A communications strategy has been developed by the Pathway team that is designed for both internal and external stakeholders. There is an emphasis on effective communication with patients and among the leading players with operational responsibility for the pathway. Patient experiences will be captured by a patient questionnaire and likewise that of GPs.

4.2.2 Sunderland

Of the three pathways, Sunderland's is the most mature and established, building on a scheme for direct access to CT scans in operation in 2017. Patients were involved in informing the design of this pathway following a presentation to, and feedback from, a meeting of cancer survivors in 2018. Referral or inclusion criteria for the pathway were developed in collaboration with General Practitioners and the CCG (**Error! Reference source not found.**).

The first stage of the pathway involves GPs arranging an initial screening of bloods and urine tests. In cases where abnormalities are identified, patient referrals are made via the ICE system[4] for a CT scan of the Chest, Abdomen and Pelvis with contrast. Internal escalation of positive

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[4] CliniSys ICE (Integrated Clinical Environment) is a suite of interoperable technologies that enables different patient care units to communicate with a wide range of ancillary and clinical departments such as laboratory and radiology. Additionally, web-based services deliver comprehensive messaging capabilities for use in primary, community and secondary care facilities. See: http://www.clinisys.co.uk/gb/en/solutions/electronic-requesting-results-reporting/.

findings suggestive of malignancy is undertaken by the Radiology Department to the relevant subspecialty for Outpatient review and MDT discussion.

The Sunderland VSP aligns with the key design principles for model 2 ‘Y/N cancer diagnostic service’ (ACE Programme, 2019a, p. 4).

A specific feature of the Sunderland pathway is that the reporting process for VSP CT scans are reported by two consultant radiologists (where possible) as a quality assurance and safety-netting measure. Any urgent or unexpected findings are communicated to the GP in line with the Radiology Department’s ‘Standard Operating Procedure for the Notification of Unexpected or Urgent Findings.’ Patients with negative findings are reviewed by their GP and a decision is made for expectant management or referral to the relevant subspecialty on the basis of the screening information and clinical assessment.

Given that ‘vague symptoms patients’ tend to have some imaging performed, it is expected that over its lifetime, the new pathway will not generate a significant increase in imaging requests. Instead, imaging requests will simply arise from a different source. However, there are potential resource implications associated with scheduling examinations, reporting, communication with patients and GPs, onward referrals and subsequent tracking. Until July 2019, this pathway design did not include a CCC and therefore one benefit of this pathway design is that it does not require any additional staff training, saving time and resources. However, recruitment for a CCC started in July 2019, which will increase the cost of this pathway design as well as enhancing the patient experience.

Pathway design has incorporated patient co-development as part of the iterative development of the pathway. A group of patients have committed to commenting on their experiences for this purpose and patient questionnaires are analysed.

Furthermore, GPs also have filled-in evaluation forms about their experiences of the pathway to date.

Initially, the close working relationship between the Radiology Department and CCG meant that the pathway operated without a co-ordinator or navigator role to guide and support the patient through the process. As a result, care of and responsibility for the patient remains within primary care, until the point of referral to a specialty. However, recruitment for a coordinator role commenced in July 2019.

Unlike the other pathways, access to the Sunderland pathway is not restricted to patients within a specific age range and is open to all adults.

4.2.3 Newcastle

The Newcastle VSP is at a formative stage of development and is the least advanced of the three pathways and is to be based on the Oxford SCAN model.

Referral criteria (**Error! Reference source not found.**) are applied to eligible patients i.e. aged 40 y ears and over. At this stage, Newcastle have not added ‘abnormal test results’ to their pathway criteria as it is deemed as being too vague and unclear.

The initial bloods are undertaken by the GP. If abnormalities in the patient are detected and there is a need for onward referral, the GP is responsible for arranging a CT scan.

It is important to note that GPs can currently access CT scans but this is taking place in an 'ad-hoc' matter. As a result, this pathway aims to formalise this existing informal referral process.

The extra funding obtained from the NCA will fund a CCC to be based in the Radiology Department. The role of the CCC will involve acting on the outcomes of abnormal scans and ensuring that patients with suspected cancers are fast tracked onto appropriate tumour pathways. In addition, the results of these CT scans will be communicated to primary care. Specifically, the CCC will be responsible for contacting patients and arranging appointments at hospital and informing primary care, including ensuring that GPs send a referral letter to the hospital containing the patient's full medical information. There has been discussion within the Newcastle team about effective communication with the patient, in order to alleviate the stress of being informed they are on a pathway for suspected cancer. In this regard, the patient is given a letter informing them as to why they are being referred for a CT scan in an effort to pre-empt any concerns and alleviate their anxiety.

If a scan identifies an abnormality that is not a cancer, the patient is referred back to their GP, who will then determine the next steps. In summary, the Newcastle pathway design aligns with the key design principles of a cancer diagnosis service (model 1) (ACE Programme, 2019a, p. 3).

There is a Steering Group or Team within secondary care who are working with hospital departments to obtain feedback about any potential impacts, especially the management of patient flow and demand generated by the pathway. There is another grouping composed of primary care professionals, who are examining the process from their sectoral point of view. Initial feedback suggests that because this work is viewed as sector specific, it should be carried forward in this dual way. A Cancer Services Manager performs a 'co-ordinating' role between the two groups; although it is not clear whether this is a formal role in terms of the governance of the pathway. It is not clear at this stage if these are development task groups and whether new governance structures will be established once the pathway is operational.

The implementation of the full pathway has been delayed until March 2020 to allow every department in Newcastle hospitals an opportunity to provide feedback and allay any concerns within secondary care about issues such as the potential for high numbers of referrals that may overstretch existing capacity.

Consequently, the plan is to roll out the pathway on a practice-by-practice basis so that the number of referrals will slowly increase as the pathway becomes established and is capable of accepting more patients. The 'guesstimate' is that approximately 300 – 500 referrals per year will be generated by this pathway, although this a viewed as a tentative figure.

In summary, the Newcastle approach is consistent with ACE Programme recommendations (ACE Programme, 2019c, pp. 2; 3; 5) for successful implementation of this type of pathway:

- Ensure organisational commitment and test receptiveness to change prior to commencing;
- Ensure key stakeholders have sufficient time to deliver their responsibilities; and
- Invest time in developing a robust implementation strategy and maintaining inter/intra organisational relationships.

The Northern Cancer Alliance patient questionnaire will be utilised to collect patient's feedback and experiences of the pathway.

There is a sense that the Newcastle model is creating a formal diagnostic framework for both patients and practitioners to replace the current ad-hoc referral arrangements. Patients are already being referred for CT Scans by GPs and the objective is to provide these patients with a structured pathway that will lead to speedier diagnoses.

Also built into the Newcastle pathway is the use of an 'advice and guidance' protocol, which is already in place at the CCG. For instance, if a GP has concerns about a patient who does not meet all of the specific symptomatic criteria necessary for escalation, the hospital should be contacted and advice sought about how best to manage their situation. This protocol aims to provide an additional layer of 'safety-netting' for patients. At this stage, it is not clear whether the Newcastle model has an MDT component.

In summary, each project has a slightly different pathway design but these are consistent with the design principles identified in the ACE Programme review of Emerging models and principles of MDC projects (ACE Programme, 2019a, pp. 3-5).

4.3 Referral criteria

Referral criteria for all three pathways are based on the commonly accepted group of 'vague' or 'concerning but not-specific symptoms' (ACE Programme, 2017, p. 1), with varying levels of specificity:

- Unexpected weight loss
- Severe unexplained fatigue
- Onset of persistent nausea and appetite loss
- Emergence of pain/discomfort of unknown ætiology

Projects vary in the use of age limits to determine patient eligibility. The Sunderland VSP is available to all adults (i.e. greater than 18 years). South Tees have set an eligibility age limit of greater than 30 years and Newcastle have targeted their pathway at an older cohort of patients aged 40 years and over (Table 2).

	Sunderland	South Tees	Newcastle
Symptom category	Other symptoms causing GP tend to have a high suspicion of malignancy, (often described as GP's "gut feeling")	GP suspicion / concern	GP gut feeling
Gut feel	Unexplained weight loss >5% within the preceding 3 months	Age 30+ unintentional weight loss (patients that have other symptoms and fulfil 2WW rule criteria for upper and lower GI **must** be referred using current pathways)	Unexpected weight loss > 5%
Weight loss	Recent or progressive pain of unexplained aetiology of more than four weeks duration	Age 30+, Non-specific recent onset abdominal pain/discomfort with no associated change in bowel habit (**must not** fulfil criteria for any other 2WW rule pathway or had previous investigations for chronic abdominal pain)	New atypical pain
Pain	Severe constitutional symptoms e.g. fatigue, nausea, sweats of unknown aetiology of more than 4 weeks duration	Age 30+ persistent nausea/ loss of appetite (do **not** fulfil criteria for 2 WW GI referral)	Persistent nausea and appetite loss
Nausea, fatigue, loss of appetite	Fatigue (as above)	Age 30+ persistent fatigue that is significantly altering a patients quality of life (must **not** have undergone investigations or have been diagnosed with ME)	Severe unexplained fatigue
	Patient is unsuitable for another urgent or two-week wait system pathway based on the GPs assessment of their clinical symptoms		
Exclusion criteria	1. Known contraindication to intravenous contrast media which would include a GFR less than 45 2. Known allergy to contrast media 3. Known risk of contrast induced nephropathy 4. Morbid obesity 5. Age under 18 years		

Table 2. Referral criteria for Sunderland, South Tees and Newcastle VSP projects.

Interviews with VSP project members identified GP 'gut feeling' or clinical suspicion as an important, if not, the critical criterion in the assessment of potential alarm-symptoms experienced by patients. As a secondary care clinician in the South Tees pilot explained:

> *"We carefully thought through our inclusion criteria … the most important criteria is GP suspicion".*

From a primary care perspective, clinical suspicion is also often viewed as the determining factor when deciding to refer a patient. Exploiting these instinctive diagnostic skills is key:

> *"I think a lot of GPs really have quite good levels of suspicion and diagnostic skills. So it's really to try and harness that and to channel that forward, allowing us to still raise alarm bells even if it doesn't meet the direct two-week rule criteria" [A South Tees GP].*

A GP in South Tees outlined how they have made referrals of patients who have presented with vague symptoms:

> *"I think it's where there's no specific indications for a two-week rule referral, or there's no specific signs so that you know exactly which speciality to go for, but you have a gut feeling. Maybe the non-specific symptoms that your patient has might add up to something a little bit more than meets the eye".*

A lead GP in Sunderland explained the range of alarm symptoms that patients present with, which can trigger a high level of clinical suspicion among GPs:

> *"Basically, this pathway aims at identifying people who do not meet the two-week criteria, but where there is a high clinical suspicion of cancer and we objectified that in certain ways where we said the patient should have lost about five percent of their body weight over a three-month period. Constitutional symptoms like myalgia, generalised aches and pains, bone pains, night sweating. All of these non-specific symptoms".*

However, analysis of data on '4.10.5 Presenting symptoms' shows that overall only 11.8% of patients were recorded as having GP 'gut feel' as a presenting symptom, although this figure differed between the two projects. Thus, in South Tees, 26.9% of patients were recorded with GP 'gut feel' as at least one of their presenting symptoms, whereas in Sunderland the corresponding figure was 8.1%.

The majority of patients (61.5% of all patients referred to the VSP in both projects) were recorded with weight loss as one of their presenting symptoms (48.1% in the South Tees VSP, 64.8% in Sunderland VSP).

Feedback on referral criteria from one senior secondary care clinician identified potential ambiguity in applying weight loss as a diagnostic criterion:

> *"I had a bit of an issue [in relation to the referral criteria] because one of the symptoms that goes through the vague symptom pathway is weight loss. And to my mind that's a two-week rule referral".*

It is important to note that the evaluation has not found any challenges or detected only one instance of some wider clinical concern associated with applying this criterion in the three pilot locations. However, from a precautionary standpoint, a process of ongoing reassessment of the efficacy of each of the referral criteria, based on experiential learning, could be applied as each pathway evolves and matures going forward.

In summary, all three projects use appropriate 'vague' symptoms in their referral criteria but have different eligibility criteria with respect to age. Whilst, interview data suggests that 'GP gut feel' is a critical aspect of the decision to refer patients to the VSP, for most patients (61.5%) weight loss is the most frequently recorded symptom. Differences between projects were noted as part of the analysis of the frequency of presenting symptoms (section 4.10.5). Thus, 26.9% of patients in the South Tees project were recorded as having 'GP gut feel' as at least one of their symptoms, whereas in Sunderland this was true for only 8.1% of patients. This may be related to the different age and socio-economic profiles of the patients registered with participating GP surgeries in each of the two projects. However, it may also be that presenting symptoms are not being recorded in full at the point of referral. If this trend continues as the projects continue, it is recommended that further analysis of presenting symptoms in primary care is considered (see Recommendation 8 (5.3 Recommendations) and the section on presenting symptoms (section 4.10.5).

4.4 Primary and secondary care feedback on the implementation of VSP

There have been no significant challenges relating to rolling out the intervention across the three pilot areas. The evaluation found that a key issue of concern which project leads have been cognisant is the need to avoid what could be described 'big bang' approach when implementing the VSP across the entirety of the CCG footprint. Instead, programme leaders particularly in Newcastle and South Tees, opted to roll out the intervention in a deliberate and staged manner on practice-by-practice basis in order to avoid any potential overloading of existing clinical resources and staffing capacities. For instance, a senior primary care clinician in Newcastle stated that only a small number of practices are involved in the early stages of the pilot to prevent a surge of demand in patient numbers that could potentially overwhelm the existing resources of secondary care services:

> *"… we've got to do that carefully because they [secondary care] don't want every practice to start at once … There are going to be two practices to start with and hopefully iron out any problems once that starts to work. Also reassure secondary care that there are not going to be hundreds of people coming this way".*

In Hambleton, Richmondshire and Whitby CCG, the VSP was also successfully rolled out in a series of phases across this geography. A secondary care practitioner explained the thinking behind the phased roll out:

> *"…we've done a very slow burn with this pilot…don't get me wrong, we're covering the entire Hambleton and Whitby patch now, but actually we've done that quite slowly really, just to see how many patients come through the doors*

> *so as not to overburden the systems. Being mindful that this is a pilot. So, actually I think that's worked really well".*

From the feedback received by the evaluation, this phasing of the roll out process appears to have been a successfully approach adopted by the pathway geographies. It has allayed operational capacity concerns among secondary care clinicians regarding the potential of the intervention to overburden existing administrative systems, clinical services and staff capacities. These concerns were primarily focused on the capacity of radiology departments to cope with any significant increase in patient referral numbers, especially as it is acknowledged across all pathway pilot areas that radiology departments and their personnel are working at virtually full capacity (indeed this is a national issue) and therefore there is little slack in the system. A senior secondary care clinician in the Newcastle pilot commented:

> *"I think we've even got issues with capacity for CT scanners and stuff as well. They're being used to the max".*

However, the evaluation found that radiology departments and their clinicians are willing to take on the task within existing capacity and resource constraints. Indeed, it is fair to say that radiology personnel have been receptive and support of the VSP concept:

> *" … there's not been anybody in radiology who has said; no, we're not doing it … we'll find a way to make it work" [Newcastle senior secondary care clinician]."*

This highlights the positive relationship between primary and secondary care personnel and a willing to work together in order to successfully implement the VSP, across all of the pathway geographies.

In addition, project leads also emphasised that this phased process allowed for the identification of any potential early teething troubles with the VSP, enabling any fine tuning to take place before there was a wider expansion across the CCG footprint. A project leader at the Newcastle pilot explained the rationale of this process to the evaluators:

> *"… we need to get the first patients through the pathway to just make sure there's no little wrinkles or anything that needs to change. Then, I do think that they will quite quickly roll out to more practices"*

In this respect, all of the pathways are viewed as an iterative development process by the project teams, with experiential learning continuously incorporated into incremental improvements of the pathway.

4.5 Primary and secondary care feedback on the performance of the VSP

The evaluation sought views of primary and secondary clinicians and managers about their perceptions of the VSP and its performance to date across the three pilot locations.

Overall, the evaluation can report the positive finding that the intervention has been well received in each pathway area among all clinical groups and professions and the concept underpinning the intervention is widely supported. In particular, the pathway is seen as addressing an important gap for those patients who do not easily fit with existing two-week rule pathways and reducing the need for multitude of investigations requested by primary care, as a lead GP in the South Tees explained:

> *"As to what the intervention or pathway is replacing or enhancing, it's enhancing all the two-week rule pathways and it's filling the gaps for people who don't fit into that but they've got the suspicion that they've got something nasty going on. … I suppose the thing it is replacing is lots of the investigations that are being done in General Practice. Because everything is being done in the one place, at the one time".*

The VSP also addresses the referral dilemma experienced by GPs who are a struggling to direct vague symptoms patients towards appropriate clinical pathways, providing General Practice with an additional clinical option:

> *"I just think it seems like it's one of those things that as soon as somebody said they were going to launch it, we kind of thought: 'gosh, that's a good idea, that's really great.' So yes, I'm really happy it's there as part of our clinical arsenal to use". [South Tees General Practitioner].*

It is clear from the evidence found by this evaluation that among General Practitioners the VSP is viewed as a much needed intervention, capable of empowering GPs, especially when they are unsure about making a definitive diagnosis. A lead GP in Sunderland stated that:

> *"… what we also wanted to do was empower GPs with the diagnostic tools and give them a kind of - a tool if you like when they are stuck. Often we are placed as clinicians in the conundrum of; we know something is wrong but we don't know where exactly the problem is. That's one of the key outcomes we would expect, is to have a clear pathway that would almost be prescriptive of what has to be done … when symptoms are vague."*

To date, there has been positive feedback from primary care about the VSP in Sunderland and South Tees where the intervention has been operational for some time. A GP lead in the Sunderland pilot, who is in regular communication with a range of colleagues across their CCG footprint, provided this insight:

> *"… we've had so many GPs compliment us about how helpful they find this to be and how much it helps them and their patients as well."*

Comments like this have been typical of feedback the evaluation team has received. A GP in the South Tees area believed that the introduction of the intervention has been a positive development, which has benefitted their patients:

> *"I think yes, because as good as the templates are for the specific conditions, they don't always cover for every patient presentation. So, I think having something like that [the VSP] within the system makes a lot of sense… some of the things I've had - x-rays - I've been in the dilemma of where do I send this patient? Because the presentation wasn't just fitting. ... I buy into it."*

One lead GP did raise a cautionary note about the intervention, questioning whether the VSP would make a significant overall difference to clinical outcomes for vague symptoms patients as a cohort. This was based on a view that the volume of patients referred along the pathway might be low, due to a lack of clarity over the definition of vague symptoms:

> *"Basically, looking at it from a GP perspective I'm not too sure, I'm not too convinced, actually, that a pathway like that might be high demand. These kinds of patients with vague symptoms. As I say, it's the definition of what vague is. Some GPs don't consider them vague, some people might. My advice was that perhaps the numbers going through this pathway would be quite low. But also, we … are quite lucky because we do have capability to request things like CT. Would they be doing anything different to what we're doing already? I can understand the way of streamlining the approach for the patient, but if someone comes to see me with vague-ish symptoms, I would expect them to come back and see me with the results. That's my own personal opinion on it. I'm not too convinced that a pathway like this would make such a massive difference, but I'm open to the counterargument towards that, really."*

A secondary care professional in South Tees, who regularly engages with General Practice, told evaluators that they received positive comments from GPs about the intervention:

> *"Interestingly, the feedback from GPs is: 'we've got somewhere to send these patients now. We've struggled to know - we've tried to fit them into a two-week rule pathway but sometimes they just don't fit."*

In their responses to the evaluation team, secondary care personnel were equally as complimentary about the VSP as their primary care colleagues. In the first instance, it is clear that secondary care professionals have been supportive and committed to the pathway, exemplified by many clinicians giving their time for free (for a more detailed exposition on this subject, see below). A senior secondary care clinician in Sunderland told evaluators that 'there seems to be a lot of interest in it [VSP] within the hospital.' In the South Tees pilot area, a secondary care clinician commented that the secondary care team with operational responsibility for the VSP had:

> *"… loved being part of the pilot, we've loved doing the pilot. We really do see its benefit ... we're probably biased; we think we've got a really good pathway."*

Whilst noting that there is very limited knowledge of the pathway among secondary care staff generally who do not have regular contact with the VSP team or vague symptoms patients, a secondary care practitioner in South Tees told evaluators that they had received positive feedback from colleagues once they were made aware of the purpose of the pilot:

> *"… when you do speak to people about it they think it's great. And the success stories that we've had so far have been very positive."*

Responses from radiology in all pilot geographies have also been positive towards the intervention, exemplified by a willingness among personnel in radiology departments to undertake the VSP workload, on what has been described as a 'best efforts' basis. A senior secondary care clinician at the Newcastle pilot commented that:

> *"… there's not been anybody in radiology who has said: 'no, we're not doing it. … We'll find a way to make it work."*

No testimony was gathered directly from patients about their journey along the pathway as part of this evaluation. However, primary and secondary care professionals did provide some anecdotal secondary evidence in the form of their perceptions of patient's experiences of the VSP. Significantly, these limited impressions of patient experiences have been positive. For instance, a senior secondary care clinician in South Tees stated that they had received positive comments from those vague symptoms patients who had been referred to the pathway:

> *"You get good feedback from patients because they get seen quickly and sorted out."*

Similarly, primary care clinicians have reported high levels of patient satisfaction. A GP in Sunderland stated that they believed patient experiences to date had been positive:

> *"They [patients] have felt that their complaints or representations have been addressed in the sense that they've had - I mean, a scan is a big deal. I think it's been positive in that sense. They can feel that they've had a follow-up check."*

A GP in South Tees recounted feedback they had received from a patient who had been referred to the VSP:

> *"…she thought it was amazing. Fortunately, she didn't have cancer but she was very, very impressed…"*

Overall, the feedback to date obtained by this evaluation indicates that the vast majority of clinicians and professionals who have operational responsibilities for the intervention are enthusiastic about the pilot. What is more, some medical professionals, especially in radiology, have been proactive in supporting the VSP, often doing so on a goodwill basis. Anecdotal evidence from a clinical perspective also tentatively suggests that patients too have had positive experiences of the intervention and high levels of satisfaction have been reported.

4.5.1 Challenges

In each of the pathway areas, there have inevitably been what might be described as teething issues, virtually all of which are to be expected when rolling out a project of this nature. From the evidence gathered, none of these issues were found to be insurmountable or threatened to undermine the process of implementation and the operational efficacy of the intervention.

A key challenge when attempting to implement the VSP has been the capability of NHS IT systems to be adapted to pathway requirements. This issue has been a common issue of concern in the three VSP pilots. In Newcastle for example, there has been considerable discussion between primary and secondary care about the IT system and cross-sectoral communication more generally, given the technical limitations imposed by existing processes, as a senior secondary care clinician explains:

> *"…it's [about] how GPs and secondary care communicate with each other through their IT systems. And how we [secondary care] provide robust feedback*

> *[to primary care] and then follow-up information when it comes to booking specific slots within the secondary care system."*

The delay in Newcastle in implementing the VSP was attributed to ensuring that the IT referral system could be configured to the requirements of the pathway and would be functional in operational circumstances. One of the main practical implementation issues relating to the IT system that has provoked significant internal discussions is the need to ensure patients can be effectively navigated along the pathway:

> *"The problem we had at the last minute - the hospitals were unhappy about their internal systems. If a CT scan was found to have a cancer, how were we going to ensure that patient got to the right place? They were aware that they had different mechanisms for different tumour groups." [Lead General Practitioner]*

More specifically, as seen from a secondary care perspective, the delay in implementing the pathway in Newcastle was:

> *"… because it's working out the IT and communication system between primary and secondary care. Because the GPs have a certain way of booking patients into certain slots and certain requests and things. To do this, the pathway we needed to set up something slightly different, so that they weren't double-booking slots, and that they were using a specific format for the request … how that is set up and what the limitations of that are. But then also about choose and book and that system… [and] if we refer somebody onwards in the Trust, how we then get a two-week referral to match it up to our cancer target data and make sure the patient is still being passed from a cancer diagnosis. That's been the main bulk of the delay." [Senior secondary care clinician]*

In order to 'stress test' the capabilities of the new referral system in Newcastle, a number of dummy runs or tester appointments have been made:

> *"… they [secondary care] were uncomfortable with that because they thought things might fall down, which is fair enough. So each of the tumour groups had long conversations and they are going to have dummy appointments on the computer which the nurse or the Coordinator can book the slot, and the GP can add the letter to that place." [A Lead GP]*

Systemically, it would appear that there is a knowledge gap between different specialties of the medical profession about how each side use the ICE (Integrated Clinical Environment) system:

> *"A lot of us don't know enough about what the other person does, to know how they would use it to make it work at our end. Do you see what I mean? … the GPs … they know the front-end of ICE. Our radiologists will know the requesting end of ICE, but we don't really understand what each other are doing." [Senior secondary care clinician].*

These issues relating to operability have been the main focus of attention, which have required some:

> *"… modifications for ICE so that certain things can be put in and we can capture that these patients are on a vague symptoms pathway - because there doesn't seem to be even a box to put that in, particularly…" [Senior secondary care clinician]*

The functionality of the IT system was also an issue identified in the South Tees locality. Whilst noting there had not been any major operational difficulties with VSP there had been technical issues related to implementation of the vMDT process of the pathway. A secondary care practitioner explained:

> *"We struggled in the first instance with the virtual MDT component of it, but that was more about process. How do we do it? Working in the NHS our IT systems aren't particularly as we would want it… So probably that's the only thing that we've struggled with, that concept."*

This IT issue relating to the vMDT was addressed by some basic but effective improvisation by the South Tees project team:

> *"We've resorted to a good old-fashioned Word document on a shared drive, which actually works very, very well. There wasn't really a lot of information out there we could pinch. So we sort of made it up… and actually, probably it does fit what we need at the moment."[Secondary care practitioner].*

The feedback suggests that this streamlined Word based system is working well, in terms of the decision-making process and allowing for a quick turnaround in the reporting of results.

As mentioned in the earlier sections of this report, at the developmental stage, there was some initial concern among project leaders in all pathway areas that the intervention could lead to a surge in patient volumes, which possibly could cause an overstretch of resources, especially in radiology departments. These concerns have resulted in short operational delays, particularly in terms of having sufficient staff capacity in place, as a secondary care practitioner in the South Tees pilot explains:

> *"It's not been without its teething problems and that's just been from a manpower perspective rather than anything else. But we think we are probably there now in a lot of respects, but that's taken some time to get off the ground…"*

One important operational issue to emerge from the evaluation is that the VSP, to some extent, is reliant on the 'goodwill' of hospital personnel, as a secondary care practitioner explains:

> *"So we run quite a bit on the goodwill of the ambulatory care team who step in. Because the clinics run on their department, so they often step in and help out. Which moving forward, we need to look at and improve."*

Furthermore, it is often the case that radiology departments and the clinical staff are supporting the VSP on a 'best efforts' basis, as the demands of the pathways are technically not built into their current job descriptions and planned workloads. A project leader in South Tees explained:

> *"The pathway here works really well. A lot of the consultants support it on a best efforts basis… they don't have any formal job planning for it and we know this is a down side to it."*

Relying on goodwill is potentially problematic as there is acknowledgement across the pathway areas that increases in throughputs of patients could place strain on the capacity and resources of the system to cope. The potential for overstretch is recognised by personnel in both primary and secondary care. One secondary care practitioner in South Tees commented that the:

> *"Numbers [of patients] are small though at the moment. I think we have to be really mindful that radiology is a really precious resource … In reality, whether that would continue as the numbers increase, I don't know".*

Sustainability of projects was an issue identified in MDC pilot projects (ACE Programme 2019 c, p. 4) and it is clear that sustainability could be an issue affecting the successful implementation of existing and new projects. The evaluation has not detected any overburdening of existing resources because of excessive patient volumes inundating radiology departments across the pathway areas. Nevertheless, the possibility of overstretch is clearly an issue, which pathway leaders must remain cognisant, particularly as awareness of the intervention in primary care grows and the potential for an increase in patient referrals through the system.

The evaluation also identified some other challenges facing VSP project teams. In the South Tees pathway, there had been a relatively low response rate from GPs about their experiences of using the intervention to date. Evaluators were informed:

> *"We're struggling - we've not had much from GP Practices. The feedback from them has been slow, but we can appreciate they're probably not best placed to spend the time filling in a questionnaire, as much as we would appreciate it…"[Secondary care practitioner]*

This is a topic that may require further work by VSP project teams to ensure that the views of General Practice are effectively captured and fed into ongoing pathway development.

In Sunderland, the need for more effective patient communication has been identified as an area that would benefit from further attention, in terms explaining the purpose of the pathway and nature of the diagnostic tests patients will receive. Consistency in conveying this message to patients is viewed as particularly important, as a senior secondary care clinician explained to evaluators:

> *"One area around that we need to do more work on. I wouldn't say it was a disaster but I think it could be markedly improved on, is the patient communication, about what we communicate to patients about what tests they're having had done, to make sure that's consistent. I think although the GPs are telling them some information. I can't be sure it's actually consistent who is being told what…"*

This pathway area has recognised the need to improve communication with patients, and the evaluation team understand that further developmental work is underway to address this issue. A secondary care manager at Sunderland outlined the Trust's agenda to increase the involvement of patients in the future design of cancer pathways:

> *"I'm really looking forward to trying to look at the patient side of things and the co-design work. I think we need to be including patients, involving patients in any redesign work that we do around cancer pathways. It's a very new entity, our organisations, at the moment, but I'm hoping that at a point in time, it's just the norm that we involve patients in this type of work."*

These findings suggest that patient communication practices and their inputs into cancer pathway design more generally, are streams of work which all VSP project teams may wish to explore going forward.

More time for the projects to mature will allow firmer conclusions to be drawn on the efficacy of the VSP and the specific benefits the intervention delivers.

In the longest running pilots, the responses received revealed a number of benefits of having this intervention available to General Practice. In the Sunderland and South Tees areas, which have been operational since last year, the prevailing mood among clinicians is positive about progress to date and the future trajectory of the VSP. As one lead GP in Sunderland summed up:

> *"From a direction of travel point of view I think we are fairly happy with the way it's going."*

In both Sunderland and South Tees, the VSP appears to be operating relatively efficiently. For example, the speed and efficiency of the testing and reporting process undertaken by the radiology team in South Tees, comparable with other cancer pathways, was highlighted by a senior secondary care clinician:

> *"I think the radiology seems to be working very well and they seem to get their scans either the same day or the next day, and then reported by the same radiologists. I think that's quite impressive really. They are almost getting a quicker pathway than the two-week wait pathway."*

In the Sunderland pathway, a senior secondary care manager expressed positive views about the performance to the VSP to date:

> *"Efficiency? I would say it was quite efficient in terms of doing a CT. I think the conversion rate is quite good as well, how many cancers we pick-up".*

Despite some initial concerns among project leads and clinicians about the potential of the VSP to lead to an over-stretch in resources, this does not appear to have transpired. The various pathways have been able to operate within the resources allocated, as a result of careful advance planning. A secondary care practitioner in South Tees explained:

> *"At the moment there isn't (strain on existing systems), because I think we planned it quite carefully and we've been very tight with numbers. The triaging helps to make sure that we get the right people in the right place. I think that would be a very different answer if the numbers had come through more quickly, but they've come in a very sort of sensible way. We have on average about two or three a week, which is a manageable workload…"*

In the Sunderland pilot, a lead GP stated that the VSP had performed well in relation to detection rates, compared with other interventions:

> *"The pick-up rates from my understanding, it's going very well. In fact it is the single biggest intervention with such high pick-up rates, from what I can see. This is not a detailed analysis or anything, this is just a raw look at the figures, obviously. From a pure numbers point of view it looks very promising."*

Similarly, in South Tees the intervention had been successful in contributing to the detection of cancers, as a secondary care practitioner explained to the evaluation team:

> *"I think we just believe it's such a good project. And it's actually been really valuable and we've obviously found some cancers in there, which is not great for the patients, but in reality is what we wanted to do."*

It was immediately evident from the feedback received that the position of CCC is critical to the effective operation of the VSP. Both primary and secondary care personnel recognised the importance of the CCC role. A secondary care practitioner informed the evaluation team:

> *"I have to say, without our Cancer Care Coordinator in this role, we could not have done this pilot, it's as simple as that. She's highly, highly efficient. She has a complete grip on the entire patient pathway; who's in, who's out, what the patients need, what the patient's don't. Yes, we truly could not have done it without the Cancer Care Coordinator. And anybody who tries to do it without one, I feel sorry for them… It's been absolutely pivotal and we had a coordinator in post the day the pilot started and that was absolutely paramount to the pilot. The fact that she's been there right from day one has made the whole process a lot simpler… And she's expedited appointments. She's made sure people have come. She's got them here, if they can't get into the hospital by organising transport, making sure they don't DNA. Just keeping that pathway flowing. There's probably nothing she actually physically doesn't do. Including making the tea for patients…"*

Project data to date tends to support the importance of the CCC role in avoiding patients failing to attend appointments for assessments and/or diagnostic tests (commonly referred to as Did Not Attends - DNAs). Thus, the South Tees VSP, which has had a CCC in post from the start of the project, has a 1.9% DNA rate. The Sunderland VSP, which at the time of this report has not had a CCC in post, has a 5.7% DNA rate (recruitment for a CCC commenced in July 2019).

As the response of the interviewee above highlights, the CCC requires a broad range of skills and personal attributes to perform this multifaceted role. Interestingly, in one pathway location the evaluation team were informed that the person recruited to the CCC position came from an administrative background and the individual's interpersonal skills in relation to dealing with patients and working along alongside clinicians were deemed a critical attribute essential to this specialist role. A secondary care practitioner set out the qualities required for the Coordinator position:

> *"We went out for more of an administrator. They had to have either something like business administration or a health and social care qualification at NVQ level. We asked for them to have some knowledge of patient pathways, some knowledge of the NHS and actually preferably some previous contact with*

> *patients. They didn't necessarily have to be cancer patients, but from a vulnerable patient group…"*

The importance of this role to the effective operation of the intervention has also been recognised in Sunderland, where the pathway currently does not have this specialist position in place. As a result, Sunderland is conducting a recruitment process for the Cancer Care Co-ordinator role, in order to enhance the operational performance of the VSP in this location.

There is some evidence from our interviews to indicate that the VSP has reduced the so-called 'bounce effect' undergone by vague symptoms patients who require a number of referrals to different clinical specialties/sub-specialties before their condition is diagnosed. Based on their experience of using the intervention, a lead GP in Sunderland stated that:

> *"It has saved a number of referrals. Normally a patient would be - prior to this pathway - I would refer them to a general medical consultant but increasingly that is a dying trade, but cardiologists, gastroenterologists, endocrinologists - the concept of a general medical consultant is almost non-existent now. So you end up with a lot of different consultants before they are diagnosed…"*

Overall, the qualitative findings of this evaluation indicate that the VSP has contributed to a number of positive outcomes for patients and has provided GPs with an additional weapon in their 'clinical arsenal' to more speedily address the needs of patients who present with vague symptoms.

4.6 Number of referrals and pathway uptake

A total of 226 patients have been referred to a VSP, during the period of this evaluation[5]. Data for the Sunderland project covers the eighteen month period between 15 September 2017 and 31 March 2019, with 210 patients being referred to the pilot 'check and book' service/VSP by 40 GP surgeries. The pilot project, where direct access to CT was given for thorax and abdominal symptoms, was a precursor to the VSP project that was subsequently subsumed into the NCA project as the Sunderland VSP. Since no changes were made to the structure, the data from the previous operation of the CT access project has been included by Sunderland as part of their VSP project data.

Data for South Tees CCG covers the nine months between 1 October 2018 and 30 June 2019. 52 patients were referred to the VSP from 22 GP surgeries, although not all 22 surgeries were involved from the beginning of the project.

In relation to referral numbers, there were no reports from interviewees of any significant overstretch of resources in the pilot areas that have been operational for the longest period time. In this regard, both Sunderland and South Tees have found patient volumes to be manageable, as a secondary care practitioner in South Tees explained:

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[5] The evaluation was conducted between February – August 2019.

> *"At the moment there isn't [any strain on resources], because I think we planned it quite carefully and we've been very tight with numbers. The triaging helps to make sure that we get the right people in the right place. I think that would be a very different answer if the numbers had come through more quickly, but they've come in a very sort of sensible way. We have on average about two or three a week, which is a manageable workload."*

Similar feedback was received from Sunderland, where patient numbers have remained relatively constant throughout the duration of the pathway and the volumes to date have not exceeded original estimates forecast by VSP planners:

> *"Well, I think the numbers were about what we thought they might be. Since starting in earnest in January 2018, the numbers have been steady and they haven't gone up a lot. I think probably our expansion to South Tyneside will increase it, because obviously it's a larger trust now… so I think that will expand a little bit…" [Senior Secondary Care Clinician].*

These results are consistent with the findings of the ACE evaluation of MDC pilot projects (ACE Programme, 2019c, p. 3), which found that despite concerns about meeting demand for additional diagnostic capacity, such as radiology or endoscopy, this had not been an issue for projects.

However, it is important to note that in at least one pathway location there is an occasional reliance on 'goodwill' from other clinical colleagues to assist with the management of some patients. A secondary care practitioner told evaluators:

> *"I would say our main issue at the moment is; it's manageable for myself, from the perspectives of the clinics. Today, for example, we have a specialist oncology nurse who is here to clerk the patient in and take their blood. Then the consultant will see them when the blood test results are in and the CT has been reported. However, this morning the oncology nurse also covered [another hospital] site for acute oncology and she had two poorly patients who she also had to see…"*

Again, this was consistent with the results of the ACE evaluation of MDC pilot projects, which found that all pilots experienced some pressure relating to securing MDC clinician capacity (ACE Programme, 2019c, p.2).

4.7 VSP uptake by GP practices

Data reporting the uptake of the VSP by GP practices is not presented in this evaluation report, as the rollout of uptake in South Tees has been managed specifically to enable implementation to be monitored and to manage resource demand. However, it is recommended that uptake by GP practices is monitored during the remainder of the project (and reported on in any future reports put together by the programme team), to identify whether further promotion of the VSP is required to achieve appropriate uptake. Appropriate uptake levels may be evaluated in comparison to the guidance for the implementation of RDCs (NHS, 2019, p. 25):

"Cancer Alliances should ensure their RDC(s) provide sufficient capacity so, by the end of the first year, 20% of cancer patients with non-specific symptoms in their area are diagnosed via an RDC and 50% of GPs are actively referring into RDCs."

These diagnosis and uptake rates have been calculated based on high-level modelling for potential population coverage for RDCs. This estimates that within any Cancer Alliance area, approximately 22% of people currently diagnosed with cancer by any route are diagnosed based on vague (or non-specific) symptoms. Based on the 8% conversion rate reported in the ACE MDC Programme (Ace Programme, 2019b, p. 13), the RDC Implementation guidance estimates that to diagnose 1 person with cancer, 12.5 patients need to be seen.

5.3 Recommendations 1: The NCA monitors uptake of the VSP by GP practices for the remainder of the project to identify whether further promotional activity needs to take place and to enable uptake rates to be captured by the programme or project leads.

4.8 Profile of patients and participating GP surgeries

Profile data related to patients registered with each GP practice may identify trends that merit further investigation, for example, differences in access to the VSP. It may also provide contextual information to differential performance and outcome data for different projects. Therefore, summary data on GP practice size, age and deprivation profiles, ethnic diversity and rural-urban location is presented below.

4.8.1 GP practice size

Nearly half (49%) of GP practices participating in the NCA VSP pilot project to date are medium in size (5,000-9,999 patients). A third (32%) are small (less than 5,000 patients) with 17% being large (10,000 – 14,999 patients) and 2% having the largest practice lists in the project (more than 15,000 patients) (Figure 2).

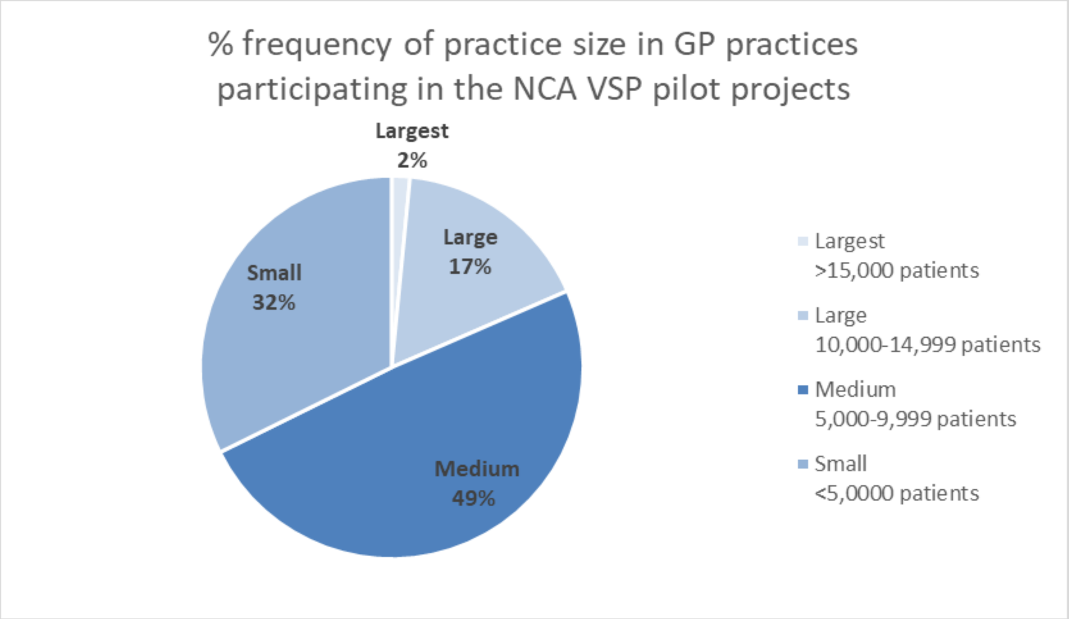

Figure 2. Proportion of GP practice sizes participating in the NCA VSP pilot projects.

Over half (55%) of VSP referrals are made by medium size GP practices (Figure 3). Proportionately, large GP practices make twice as many VSP referrals as small GP practices, even though small GP practices are twice as frequently occurring. The evaluation team is not able to establish an explanation for this.

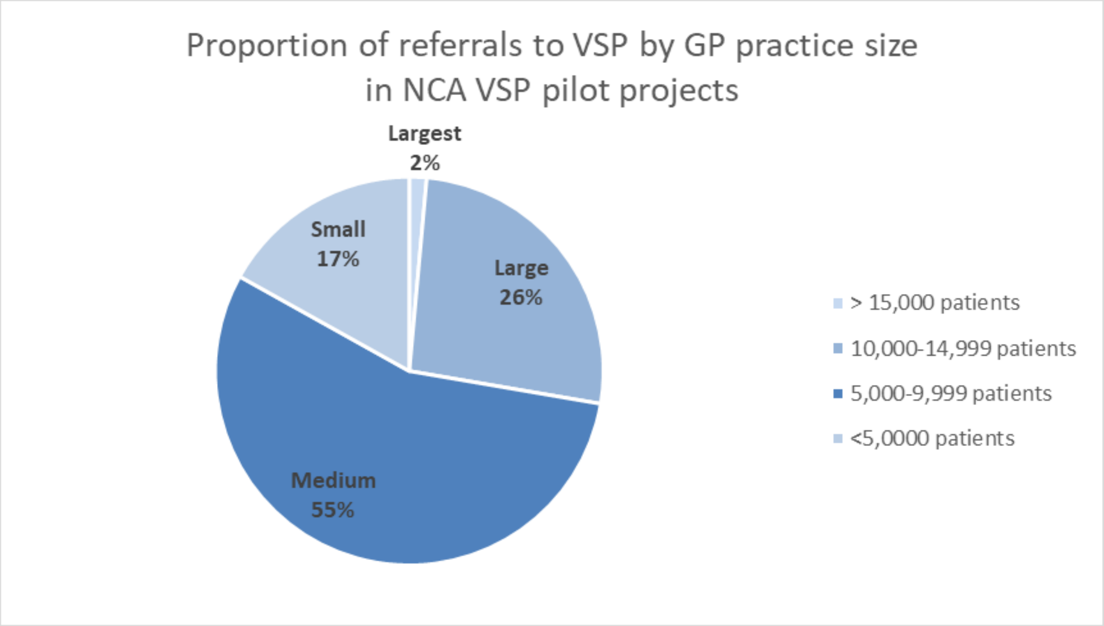

Figure 3. Proportion of VSP referrals by GP practice size.

In South Tees, over half (54%) of participating GP practices are medium sized (Figure 4), but account for 65% of VSP referrals in South Tees (Figure 5). 36% of participating GP practices are small and yet account for only 19% of referrals to the South Tees VSP.

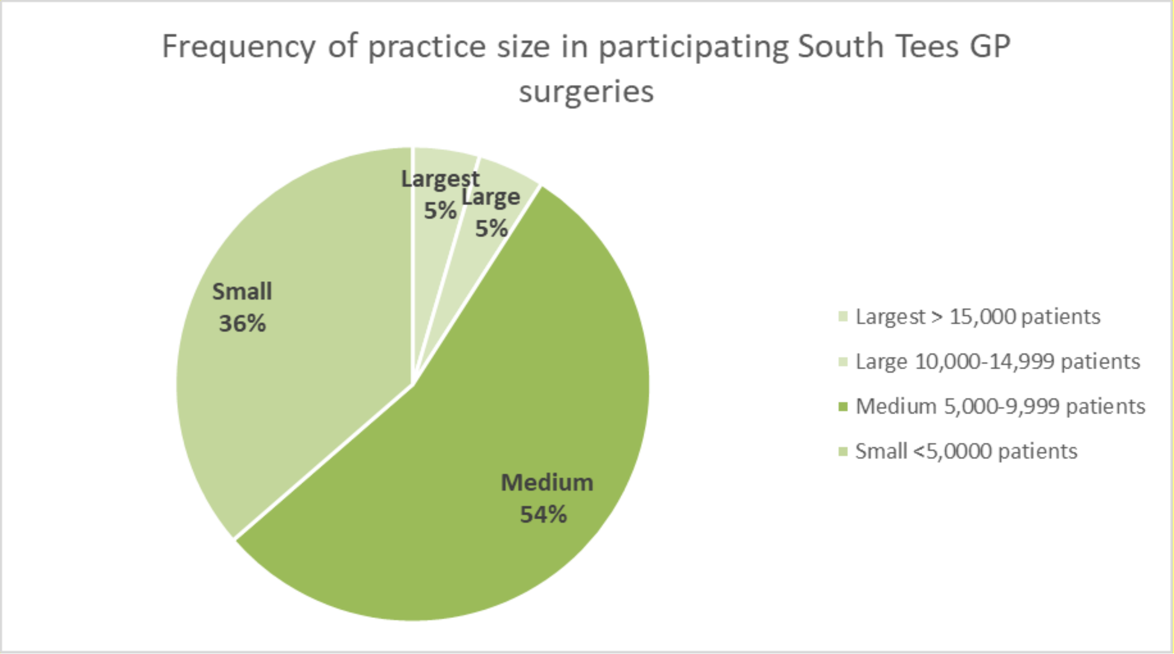

Figure 4. Proportion of GP practice sizes participating in the South Tees VSP project.

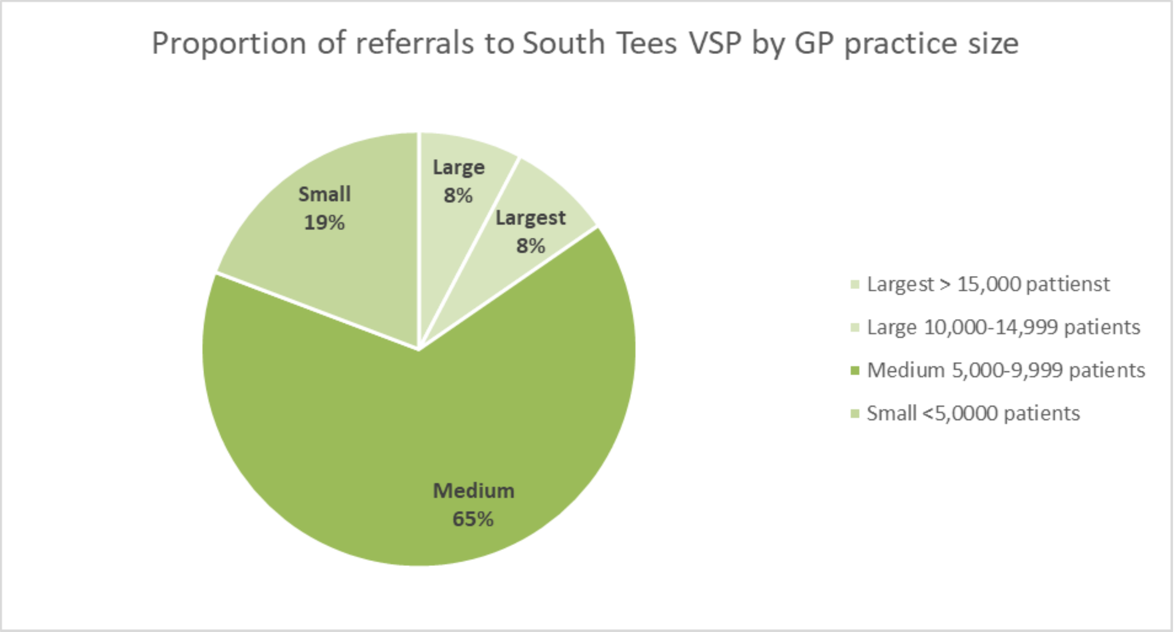

Figure 5. Proportion of VSP referrals by GP practice size in South Tees.

47% of participating GP practices in the Sunderland VSP are medium sized (Figure 6) and are responsible for a similar proportion (51%) of VSP referrals (Figure 7). However, 30% of GP practices are small yet account for only 15% of VSP referrals. Large GP practices (23%) account for 33% of VSP referrals.

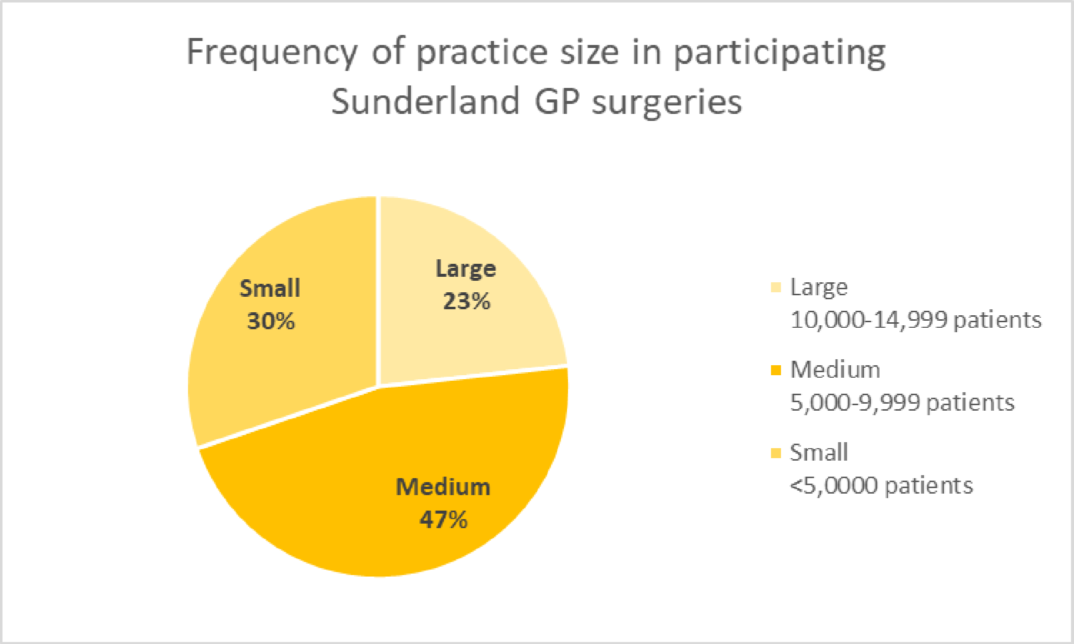

Figure 6. Proportion of GP practice sizes participating in the Sunderland VSP project.

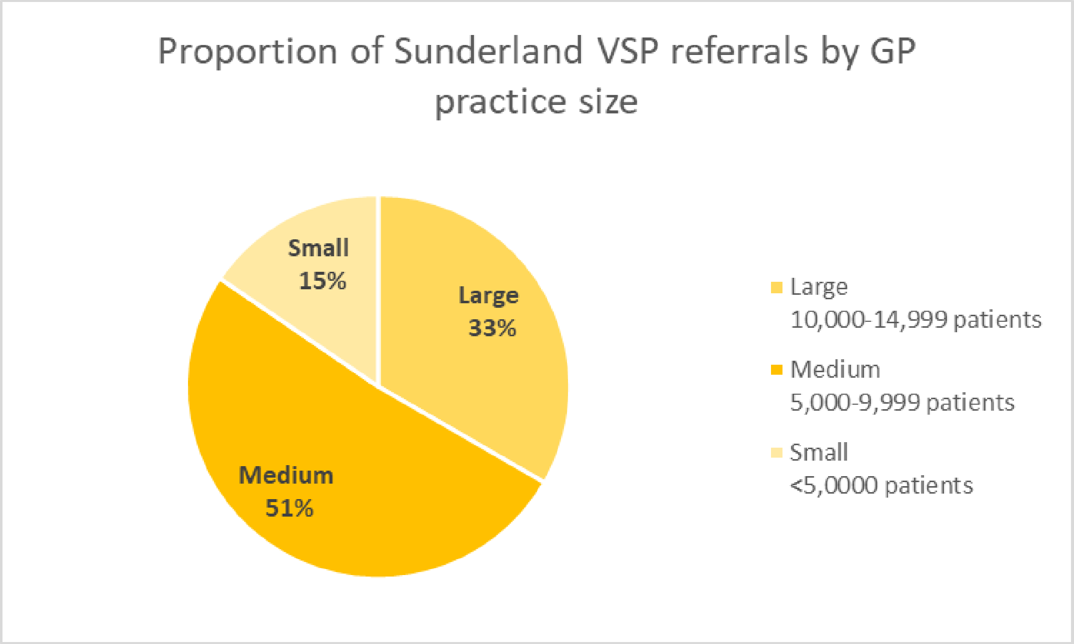

Figure 7. Proportion of VSP referrals by GP practice size in Sunderland VSP.

These results suggest an effect of small and large practice size on rate of referrals. Thus, small GP practices tend to make up to 50% fewer VSP referrals, proportionate to how often they occur in the project. Similarly, large practices tend to make nearly twice as many VSP referrals, proportionate to their occurrence frequency. This trend is consistent across both projects, despite the differences between GP practices in the two projects (discussed further below but relating to the age, deprivation, ethnic and rural-urban profiles of GP practices in the two projects to date). Therefore, it is recommended that the trend continue to be monitored throughout the rest of the project. If the trend persists, further exploration may provide insights to operational aspects of the pathway to maintain equitable access.

4.8.2 Relative deprivation

An estimated measure of the relative deprivation[6] (based on the Index Multiple Deprivation, IMD) of areas covered by each participating GP practice was obtained from the PHE National General Practice Profile website.

A majority (67%) of participating GP practices were in relatively deprived areas (deprivation deciles 1-4). A fifth were in mid-deprivation level areas and 14% were in less deprived areas (deprivation deciles 6-9) (Figure 8).

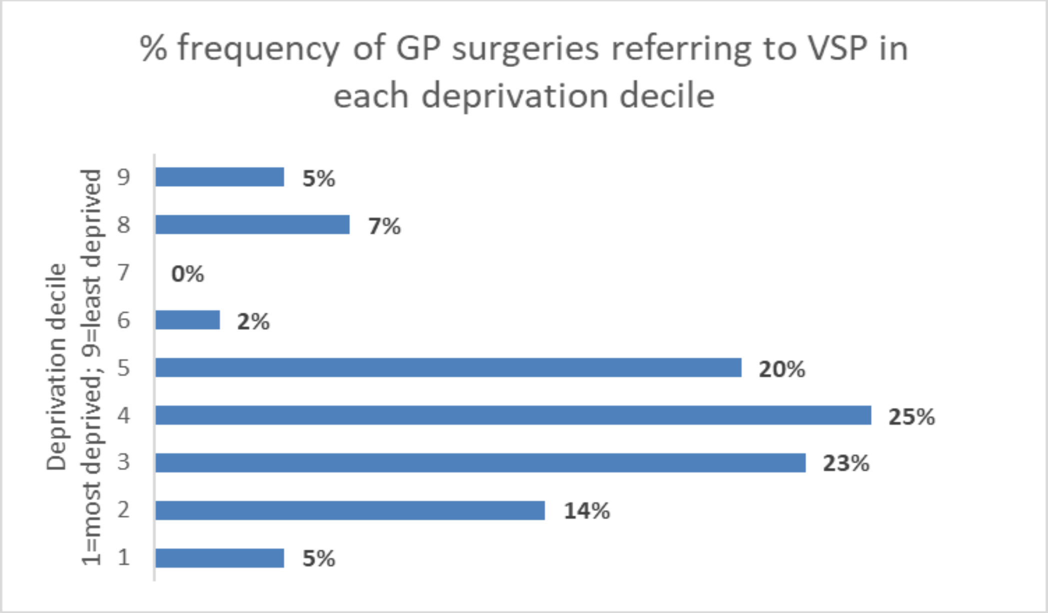

Figure 8. Percentage frequency distribution of participating GP practices by deprivation decile.

However, the results for each of two operational projects were quite different. The South Tees project had deliberately chosen to start the project in rural, less densely populated areas which were characterised by older (often retired) and more affluent residents. Thus, 91% of participating GP practices in the South Tees VSP were in the least deprived areas (deciles 6-9), with only 5% in mid-deprivation areas (decile 5) and 5% in lower deprivation deciles (decile 4) (Figure 9). There were no GP practices in the lowest three deprivation deciles (1-3).

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[6] The deprivation decile for each GP practice represents the population-weighted average over the IMD scores of the Lower Super Output Areas where the practice population lives using 2016 populations. Deprivation scores cover a broad range of issues and refers to unmet needs caused by a lack of resources of all kinds, not just financial. Deprivation scores are not measures of affluence; all of the indicators used in the index are designed to identify aspects of deprivation, not affluence. Therefore, the area ranked as the least deprived is not necessarily the most affluent.

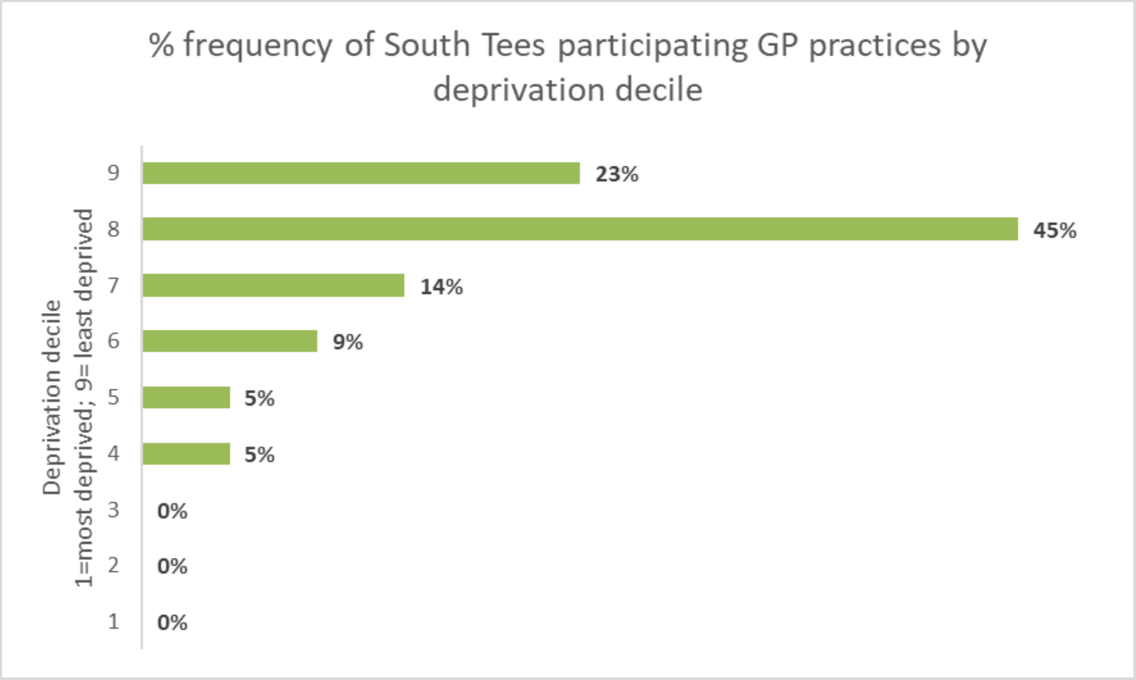

Figure 9. Percentage frequency distribution of participating South Tees GP practices by deprivation decile.

Conversely, 96% of participating GP practices in the Sunderland project were in more deprived areas (deciles 1-5) (Figure 10).

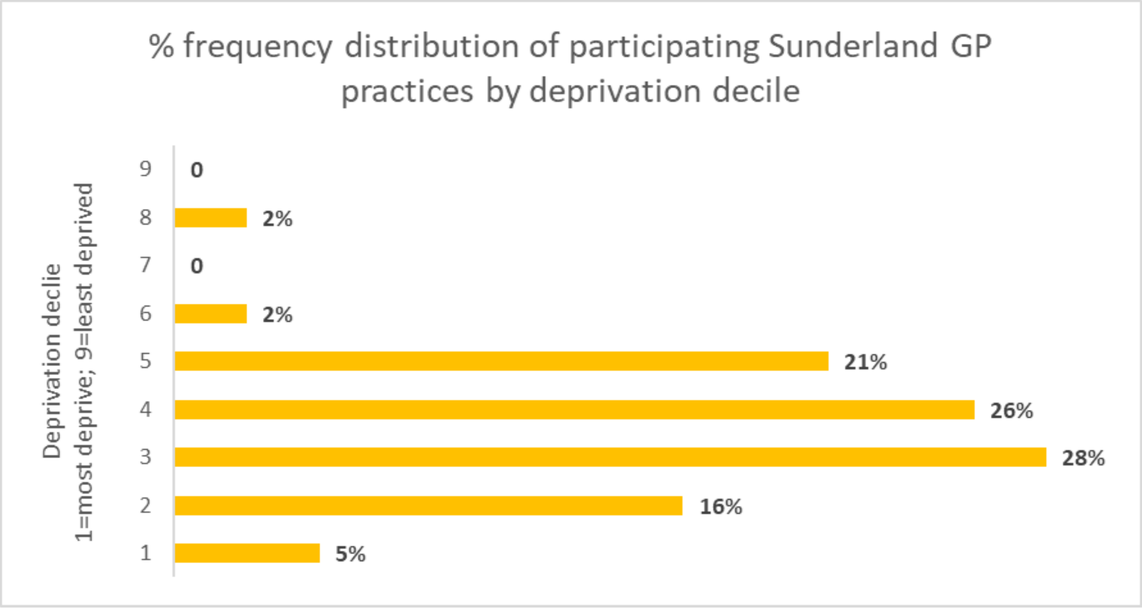

Figure 10. Percentage frequency distribution of participating Sunderland GP practices by deprivation decile.

These trends are likely to change as the projects progress, and particularly as the South Tees project is rolled out to more urban areas. Thus, it is recommended trends relating to deprivation profiles in participating projects continue to be monitored in relation to equitable access and to provide contextual information to differences in outcomes in different areas.

4.8.3 Ethnic diversity of participating GP practice registered patients

Estimates of the ethnicity[7] of patients registered with participating GP practices was obtained from PHE National General Practice Profile website, an outline of this follows.

The most frequently occurring (estimated) non-white ethnic group in participating Sunderland GP surgeries was 'Other non-white' (88% of participating surgeries), together with 'Asian (70% of participating surgeries) (

Table 3).

	Asian	Other non-white	Mixed	Black
% of participating GP surgeries recording patients in each non-white ethnic category	70%	88%	2%	7%

Table 3. Percentage of participating Sunderland GP surgeries with estimates of non-white ethnic groups (source: PHE National General Practice Profile).

The most frequently occurring (estimated) non-white ethnic group in participating South Tees GP surgeries was 'Other non-white' (86% of participating surgeries), together with 'Asian (32% of participating surgeries) (

Table 4).

	Asian	Other non-white	Mixed	Black
% of participating GP surgeries recording patients in each non-white ethnic category	32%	86%	9%	5%

Table 4. Percentage of participating South Tees GP surgeries with estimates of non-white ethnic groups (source: PHE National General Practice Profile).

4.8.4 Age profile of participating GP practice registered patients

At this point in the project, half (51%) of participating GP practices in South Tees have patient age profiles where a quarter to one third of patients are over 65 years of age (Figure 11). This reflects the implementation strategy of the project to target rural, less populated areas which in the South Tees area are characterised by high numbers of older (often retired) and more affluent populations.

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[7] Estimated proportion of non-white ethnic groups in the practice population (weighted average over the contributing LSOAs). Based on data drawn from the 2011 Census using ethnicity categories: White; Mixed/Multiple ethnic groups; Asian/Asian British; Black/African/Caribbean/Black British; Other ethnic group. Where an ethnic group's proportion is < 1% it is added to (other) non-white ethnic groups.

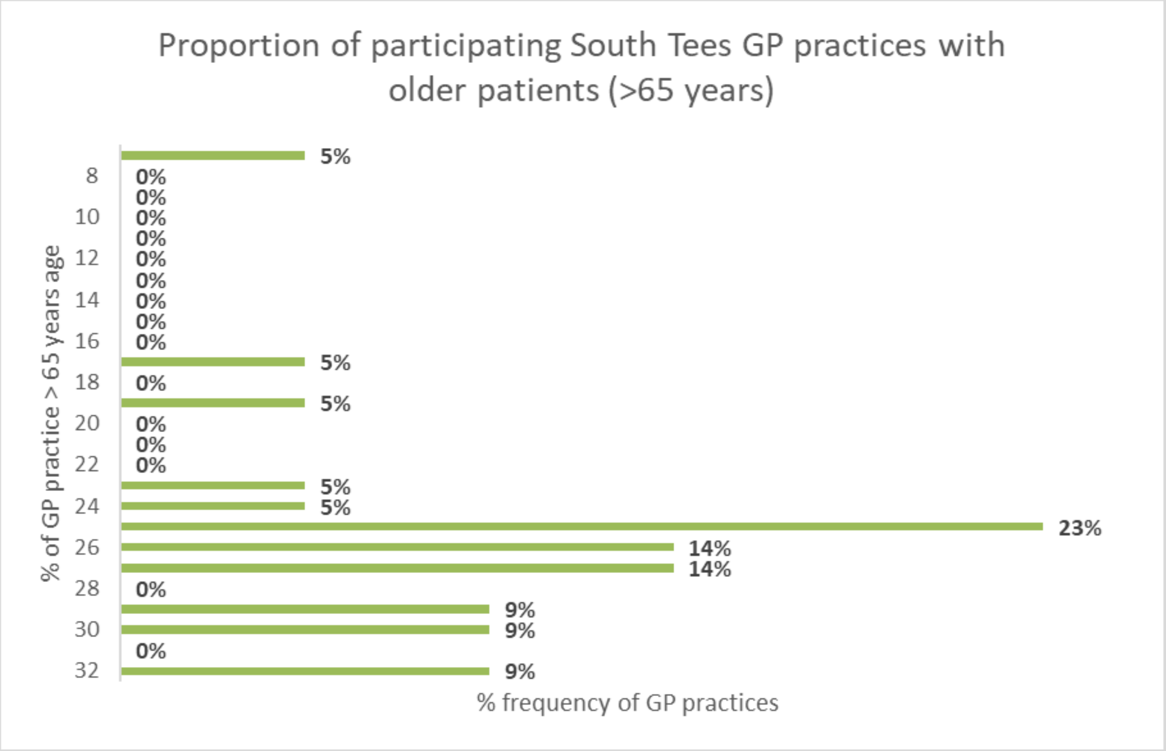

Figure 11. Proportion of older patients (>65 years) amongst South Tees GP practices.

Over half (57%) of participating GP practices in Sunderland have patient age profiles, where the proportion of older patients (> 65 years) in the practice list is lower (between 16-20%) (Figure 12).

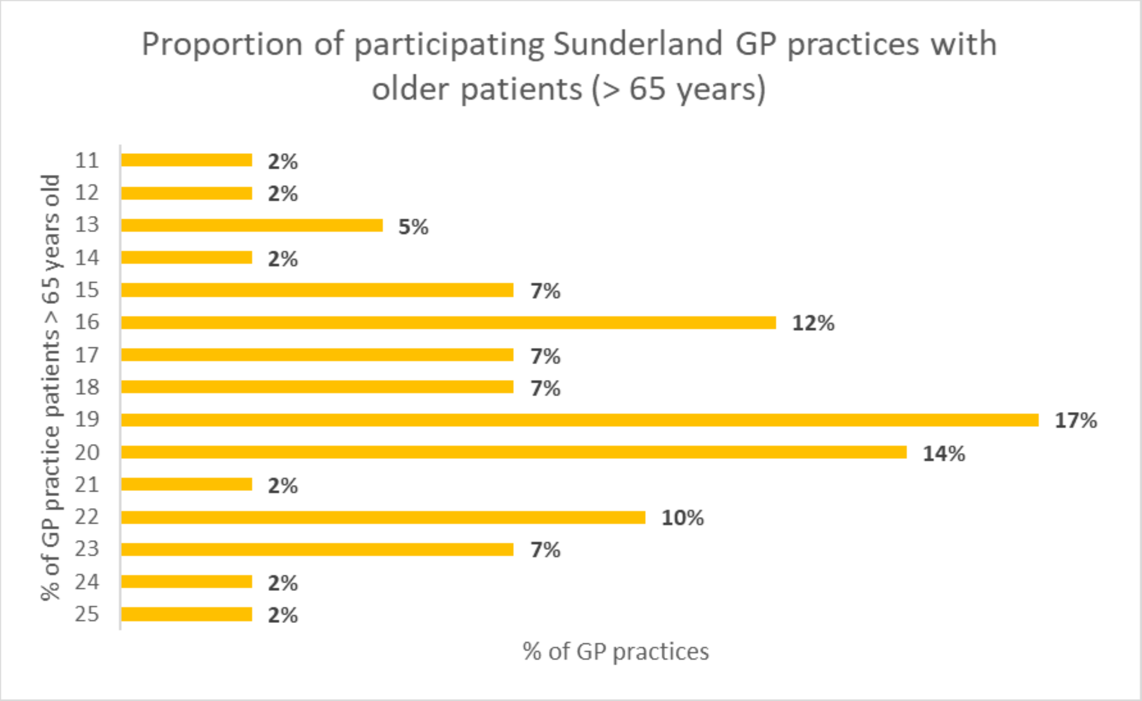

Figure 12. Proportion of older patients (>65 years) amongst Sunderland GP practices.

These trends are likely to change as the projects progress, and particularly as the South Tees project is rolled out to more urban areas. Thus, it is recommended trends relating to age profiles in participating projects continue to be monitored to provide contextual information to differences in outcomes in different areas.

4.8.5 Rural-urban differences between projects

Data on the rural-urban location of participating GP practices has not been presented in this report. As described above in 4.2.1 South Tees Pathway Design, the rollout of the South Tees pathway has initially targeted rural GP practices and the Friarage Hospital, which serves a rural population of 122,000 people in its 1,000 square miles area. At the time of this report (August 2019), more urban areas and the areas served by the James Cook Hospital in Middlesbrough, one of Europe's largest and most modern, had not yet commenced. Thus, until all GP practices across all rural and urban areas in South Tees are participating, this data would be incomplete and not helpful.

However, people living in rural areas are 5% less likely to survive cancer compared to people in urban areas, even when key confounders such as socio-economic status are taken into account (Carriere et al., 2018, p. 225). For example, one study in North East Scotland found that rural patients were diagnosed and treated for their cancer more quickly than people who lived in urban areas of the same territory, yet rural dwellers still died earlier (Turner et al., 2017, p. 444).

Therefore, it is recommended that data on the rural-urban character of participating GP practices is and differentials between performance and outcome data are monitored by the programme team.

Recommendation 2: It would be useful for the programme commissioners to continue monitoring a number of metrics, to include: trends relating to GP practice size and proportion of VSP referrals; trends relating to GP practice size, age, deprivation profiles, ethnic diversity, geographic profile, are monitored with regard to equitable access or to provide information on performance and outcomes against different variables.

4.9 Appropriate use of the pathway

Project teams in all pathways areas are aware of the potential for inappropriate patient referrals by GPs to the VSP. A lead GP in Sunderland cautioned:

> *"What we don't want is people using it irrelevantly just because they think that there's something wrong, you know? But if there has been too many scans and whether there have been too many scans; because now we know that the service is available or they are doing too many scans just to be on the safe side. We have people almost erring on the side of caution."*

There is awareness in all pilot areas of the need to monitor inappropriate referrals and to react to this if the number of such referrals become too high. In the two more mature pilots areas, interviewees did highlighted a number of inappropriate referrals. In one pathway area, a secondary care practitioner explained why they thought inappropriate referrals were occurring:

> *"I would say it's probably down to them not understanding what we're here for. For example, one of the GP Practices that hasn't engaged as yet, sent one for*

> *breast pain; no associated weight loss, no abdominal pain, no previous history, nothing. If [the GP] was concerned about breast cancer then it obviously should have just gone straight to breast. So there's been the odd ones like that. We've seen a couple of patients who we probably shouldn't have but did, just erring on the side of caution."*

Although, a higher rate of inappropriate referrals may be expected during earlier phases of the VSP, as GPs become familiar with the referral criteria, qualitative feedback suggests there are no concerns that primary care is using the intervention inappropriately.

To date, the rate of referral rejections in the South Tees project has been 15.4% (two rejections in Q1 (one of these also recorded a new non-cancer diagnosis and was included in that category in the project return; one in Q2 and seven in Q3). No referrals in the Sunderland project have been declined. The IT system used in Sunderland for the 'check and book' service for GPs to request a scan, limits GPs to 50 characters. Thus, unlike typical referrals, which consist of a letter from the GP, together with a patient history, VSP referrals in the Sunderland project may not provide sufficient information to enable secondary care clinicians to reject inappropriate referrals.

Incorrect use of the pathway is not necessarily unexpected, as GPs get to know of and use the pathway. Furthermore, since the pathway is being rolled out in a phased approach in South Tees, this period of acclimation might be expected to last until the pathway is fully embedded across the project territory. However, it is recommended that referral rejection rates are monitored throughout the project in order to identify potential operational issues that need addressing.

Recommendation 3: Referral rejection rates are monitored throughout the project to identify whether repeat/revision of guidance on referral criteria or other action is needed.

It is also recommended that consideration of how pathway configurations where there is minimal referral information/ no clinic assessment can evaluate and monitor inappropriate referral rates. It is worth noting that the specification guidance for the implementation of Rapid Diagnostic Centres (RDCs) (NHS, 2019) requires all referrals to capture relevant information about the patient, in line with the minimum dataset (section 5.3.3) and for all referrals to be reviewed to ensure all referral information is present and that RDC is the most appropriate pathway for the patient (section 5.4.1). The guidance also requires that where GP 'gut feeling' is a reason for referral, this needs to be clearly described. Therefore, referrals forms will need to allow space for this to be included.

Recommendation 4: VSP configurations where minimal referral information is available and/or no clinic assessment is performed, consider how they can how they can obtain sufficient referral and patient information in order to evaluate referrals and monitor inappropriate referral rates.

In summary, where referrals are reviewed, a rejection rate of 15.4% has been recorded to date. There is no significant evidence that referrals are being made inappropriately, although there is no evidence that projects are specifically monitoring rejection rates. Therefore, it is recommended that referral rejection rates are monitored and that projects with little referral information/no clinic assessment consider how inappropriate referrals can be monitored.

4.10 Characteristics of patients referred to the VSP

Data from both operating pathways about six characteristics of patients referred to the VSP are summarised in this section. These characteristics are:

1. Gender
2. Age
3. Co-morbidity
4. Performance status
5. Presenting symptoms
6. Duration of symptoms prior to presentation

4.10.1 Gender

Of the 226 patients referred to the VSP to date, over half (55%) were female and 45% were male (Figure 13). No other gender categories were recorded. This is consistent with the gender proportion reported in the MDC aggregate project data (ACE Programme, 2019b, p. 13).

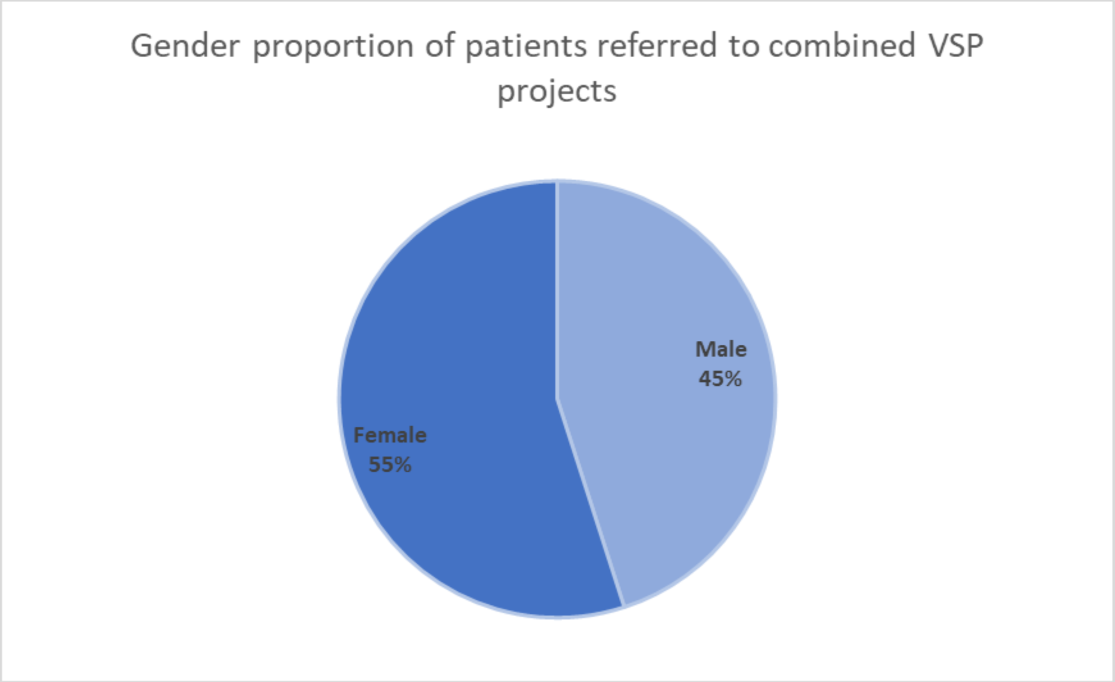

Figure 13. Gender proportion of patients referred to both South Tees and Sunderland VSPs.

The patient gender proportion in South Tees (Figure 14) was very similar to that in Sunderland (Figure 15), with 56% females and 55% females, and 44% and 45% males, respectively.

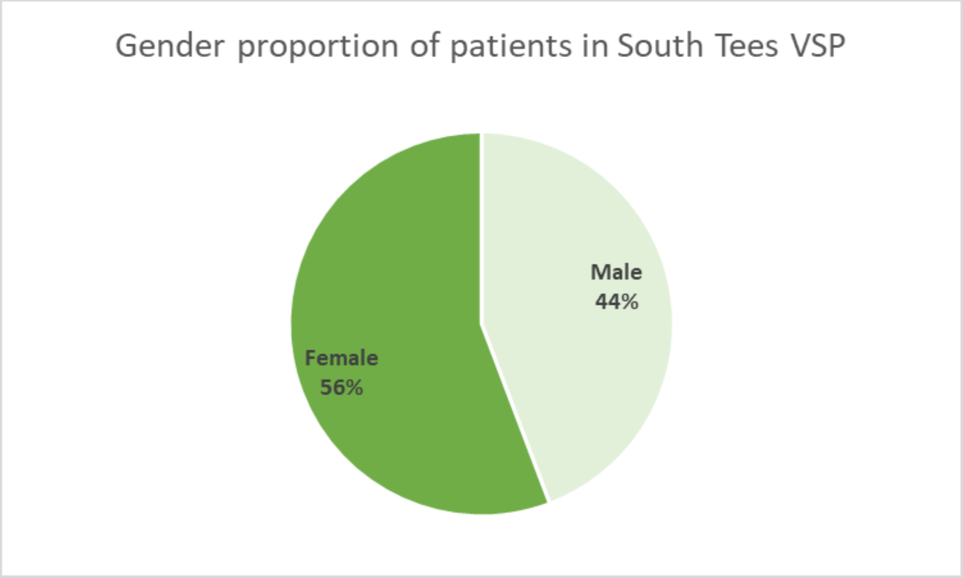

Figure 14. Gender proportion of patients referred to the South Tees VSP.

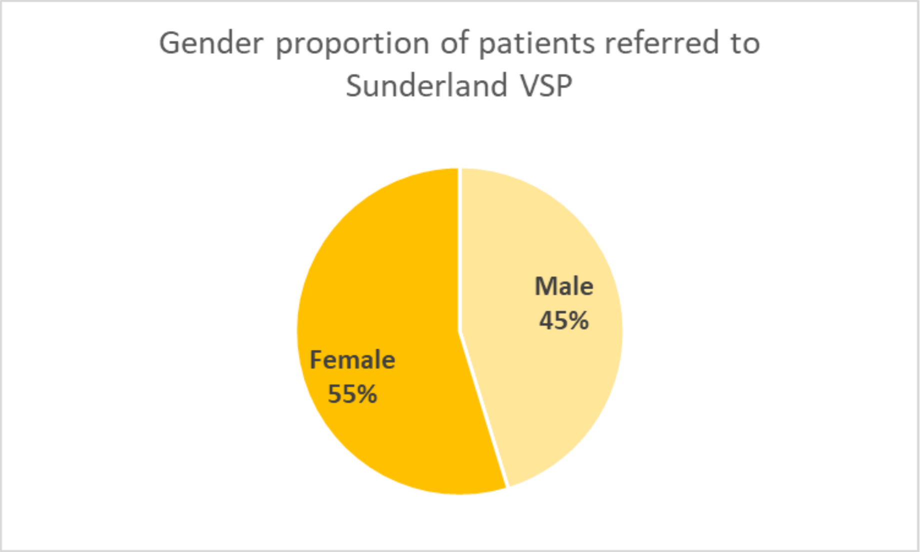

Figure 15. Gender proportion of patients referred to the Sunderland VSP

4.10.2 Age

Over half (52%) of all patients referred to the combined VSP projects were aged 70 or over (Figure 16). There was an age referral criterion of >30 years for the South Tees VSP, whereas the age criterion for the Sunderland VSP was >18 years.

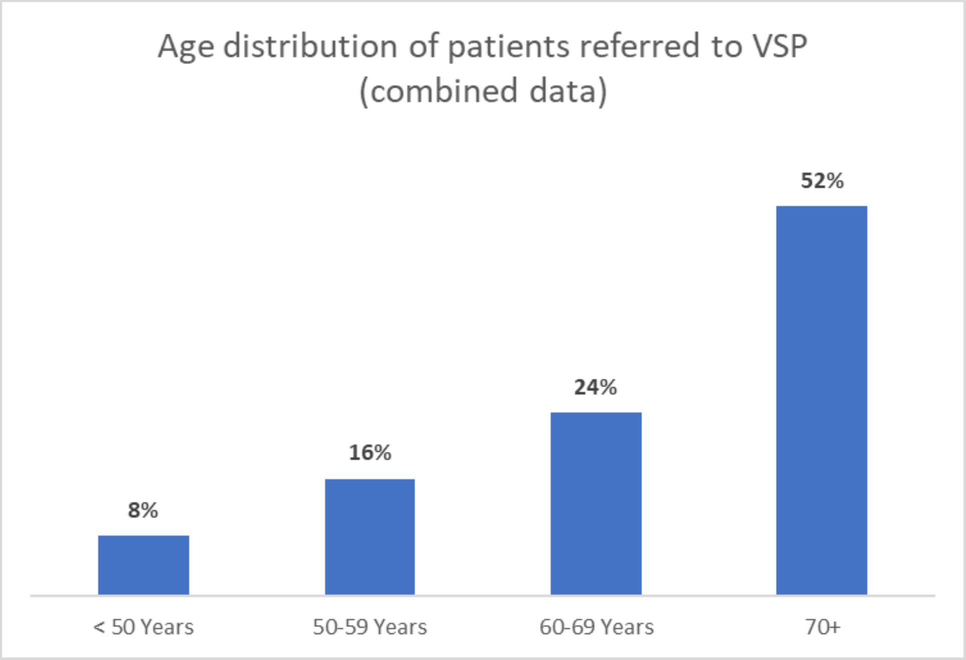

Figure 16. Age distribution of patients referred to both South Tees and Sunderland VSP.

The age distribution for South Tees (Figure 17) has nearly twice as many patients under 50 years of age (12% for South Tees cf. 7% Sunderland) (Figure 18), despite having a greater than 30 years age criterion and the socio-economic profile of South Tees patients being generally older, rural and less deprived.

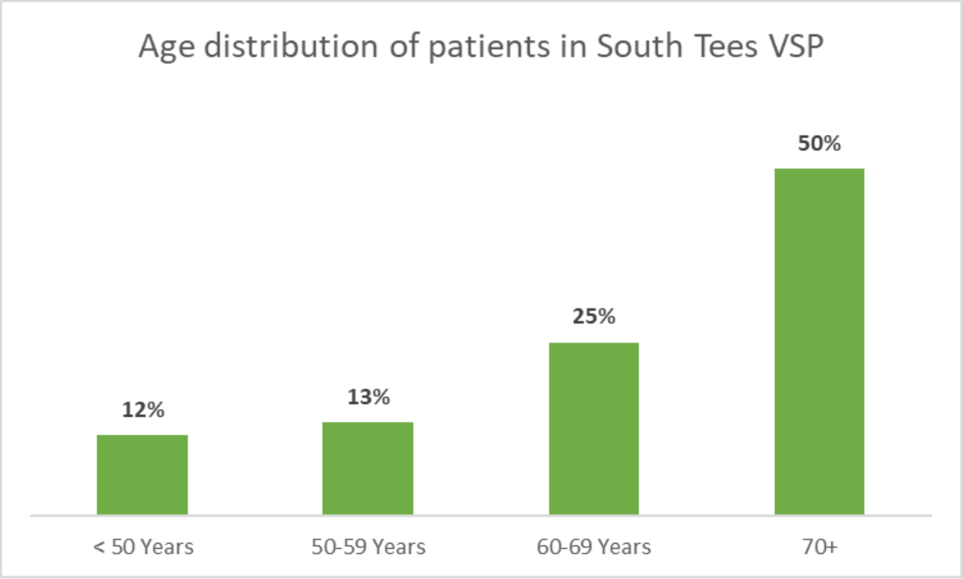

Figure 17. Age distribution of patients referred to the South Tees VSP.

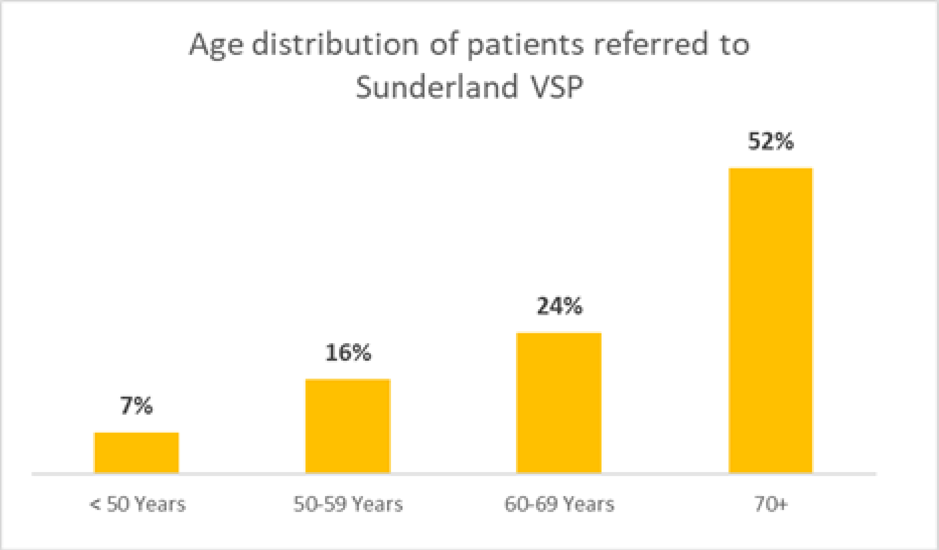

Figure 18. Age distribution of patients referred to the Sunderland VSP.

However, the total number of patients for South Tees to date is much lower than that for Sunderland[8], together with project duration and number of participating GP surgeries and this difference may change/disappear as the project continues. Nevertheless, this is a somewhat unexpected difference, since one might expect a greater number of patients <50 years in the Sunderland VSP, since they do not have a >30 years age criteria and the age profile of Sunderland GP practices is younger than that in South Tees. Therefore, it is recommended that this difference in patient age distribution frequency is monitored throughout the rest of the project, to enable investigation of underlying causes if the trend continues.

Recommendation 5: The age distribution, and particularly the frequency of patients <50 years of age, is monitored and investigated if the current unexpected trend continues.

4.10.3 Co-morbidity

Previous pilot studies of VSPs reported that patients presenting with vague symptoms to their GP (and particularly those with weight loss and fatigue) were often from older age groups, who therefore also tended to present with comorbidities (ACE Programme, 2017, p. 8). This has implications for both the expected outcomes and staging profile of cancers diagnosed as a result of referral to the VSP. For example, the death of patients referred to VSP may be associated with their co-morbid conditions and the staging of cancers diagnosed for acutely ill patients is likely to be at a later stage, due to masking of symptoms by existing co-morbid conditions. Therefore, if

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[8] 6 patients < 50 years were referred to VSP in South Tees over nine months cf. to 15 patients <50 years referred to VSP in Sunderland over eighteen months

patients referred to the VSP show higher levels of co-morbidity this is unlikely to lead to improvements in diagnosis at earlier stages.

There is currently no co-morbidity data available for the Sunderland VSP, since there is no clinic assessment and only very limited information in the Sunderland patient referral form. Moreover, since patients remain the responsibility of primary care, until and unless abnormalities are found and they are referred to the appropriate specialist or pathway, patient information is located in primary care systems and may not be immediately available to secondary care.

However, data is available for most patients referred to the South Tees VSP (45 of 52 patients including patients with no co-morbidities and 5 patients for whom co-morbidities are not known). This data shows that 40% of patients referred to the South Tees VSP had mild co-morbidity (1-2 co-morbid conditions) and 35% had moderate co-morbidity (3-4 conditions) (Figure 19). This is consistent with data from the MDC programme that reported 43% mild co-morbidity and 27% moderate and severe co-morbidity (ACE Programme, 2019b).

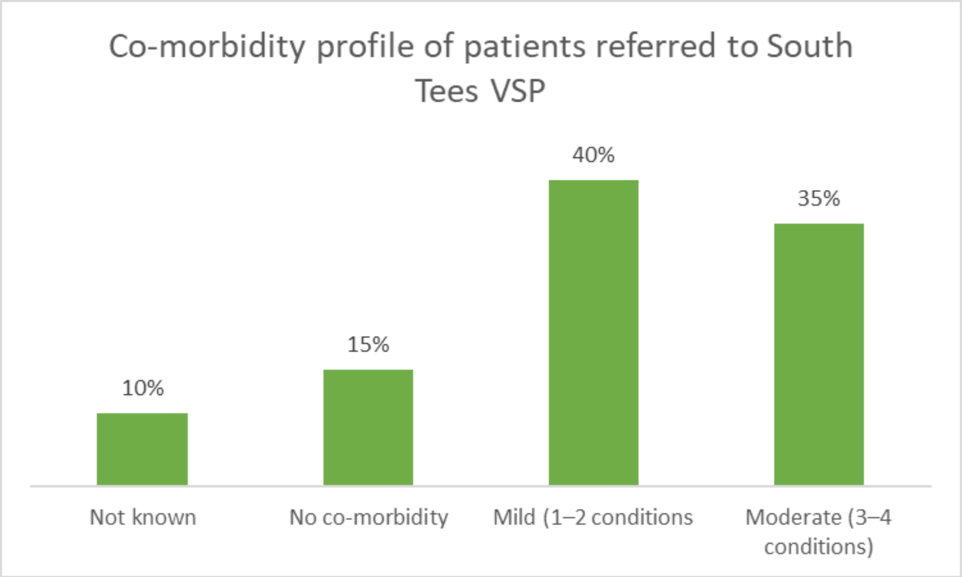

Figure 19. Co-morbidity profile of patients referred to the South Tees VSP.

The South Tees returns include data on the type of co-morbid condition(s), although the return only requests information on the top three co-morbidities. The three most frequently occurring co-morbid conditions were hypertension (10%), followed by diabetes (9%) - two Type I and six Type II diabetes (including two where type not specified but assumed to be Type II) and hypothyroidism (6%). The percentage frequency of occurrence for each co-morbid condition recorded as a percentage of all recorded co-morbid conditions is shown in Table 5.

% frequency of occurrence	Co-morbid condition(s) (patients may have more than one)
10%	Hypertension
9%	Diabetes 6 x Type II (including 2 cases where type not specified); 2 x Type 1
6%	Hypothyroidism (including sub-clinical)
5%	Previous breast cancer
5%	Coronary (Ischaemic) Heart Disease
5%	Chronic obstructive pulmonary disease (COPD)
3%	Atrial fibrillation
3%	Diverticulitis
3%	Ex- or current smoker
2%	Anaemia
2%	(Congestive) heart Failure
2%	Chronic Kidney Disease Stage G3
2%	Pneumonia
1%	Addison’s disease
1%	Anxiety
1%	Aortic stenosis
1%	Back pain
1%	Cerebrovascular accident
1%	Chest infection
1%	Cholecystitis
1%	Chronic kidney disease
1%	Chronic sinusitis
1%	Colitis
1%	Constant nausea
1%	Depression
1%	Ear pain
1%	Gastric ulcers
1%	Gout
1%	Haemochromatosis
1%	Hip replacement
1%	Hysterectomy
1%	Immune thrombocytopenia purpura
1%	Laminectomy
1%	Melanoma
1%	Monoclonal gammopathy of unknown significance (MGUS)
1%	Myocardial infarction
1%	Osteoarthritis of knee
1%	Osteopenia
1%	Osteoporosis
1%	Papilloma

1%	Polymyalgia rheumatica
1%	Previous pulmonary embolus
1%	Renal failure
1%	Rheumatoid arthritis
1%	Sciatica
1%	Seborrheic keratosis
1%	Syncope
1%	Tachycardia
1%	Vascular dementia
1%	Weight loss
100%	

Table 5. Percentage frequency occurrence of recorded co-morbid conditions in patients referred to South Tees VSP (patients may have more than one).

Further information on co-morbidities for patients referred to the South Tees VSP, together with associated diagnosis outcomes, grouped into cancer and non-cancer diagnoses is provided in **Error! Reference source not found.**).

Recommendation 6: The Project Steering Group considers whether co-morbidity data for all patients on the VSP is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

4.10.4 Performance status

Performance status also has a highly significant effect on patient outcomes (more so than patient's age at diagnosis) (e.g. West and Jin, 2015) and inclusion of this data in the analysis of patient treatment options and outcomes may add important contextual information to VSP performance data. The implications of poorer patient performance status (which may also be associated with co-morbidities) is that this may limit patient treatment options and affect outcomes. Thus, even if earlier and faster diagnosis occurs, this may not be reflected in outcome data. It is worth noting that treatment options for patients with better performance status at diagnosis can include more aggressive treatments with higher rates of success (and indeed side effects), thus this is a somewhat nuanced aspect of VSP outcomes. Performance status is routinely recorded as part of patient assessment and treatment decision-making in secondary care, although it is not necessarily assessed or recorded as part of primary care data.

No performance data is currently available on the performance status of patients referred to the Sunderland VSP. This is because performance status is assessed once patients are referred from primary care into secondary care i.e. only patients for whom the CT scans and blood tests show an abnormality and who are referred to a speciality or 2WW pathway. Performance status is currently available for one patient to date in South Tees VSP.

Recommendation 7: The Project Steering Group considers whether performance status data is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

4.10.5 Presenting symptoms

Currently, data on how many and which symptoms each patient presented with at the point of referral is available from South Tees. This shows that nearly half (42%) of patients presented with one symptom, over a third (35%) presented with two, with 17% presenting with three symptoms and 6% presenting with four symptoms (Figure 20).

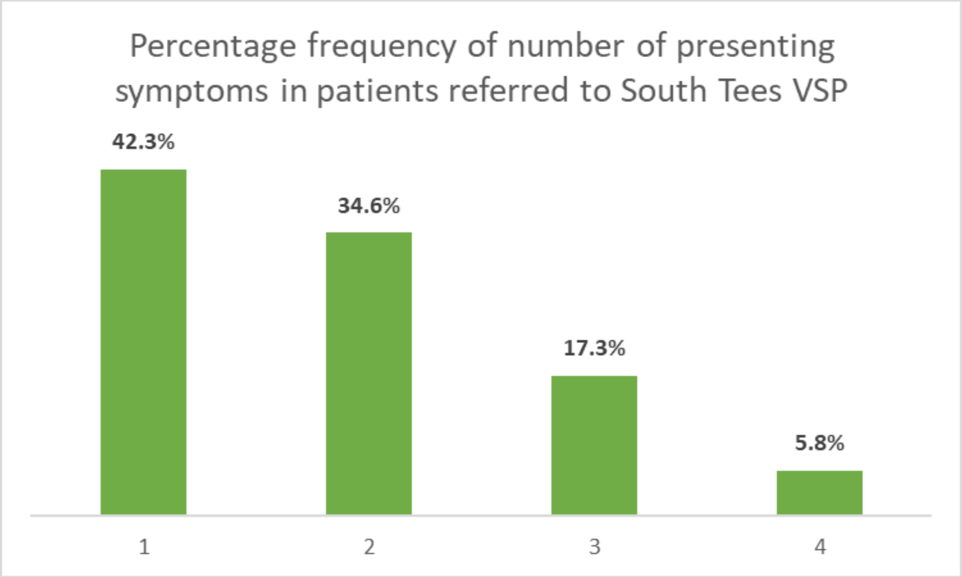

Figure 20. Number of presenting symptoms at referral for patients referred to the South Tees VSP.

For those patients diagnosed with either a cancer or non-cancer condition, nearly half (46%) presented with 2 symptoms, a further third (31%) with 1 symptom, 8% with 3 symptoms and 15% with 4 symptoms (Figure 21. Percentage frequency of number of symptoms in referrals to the South Tees VSP that were subsequently diagnosed with either a cancer or non-cancer condition.

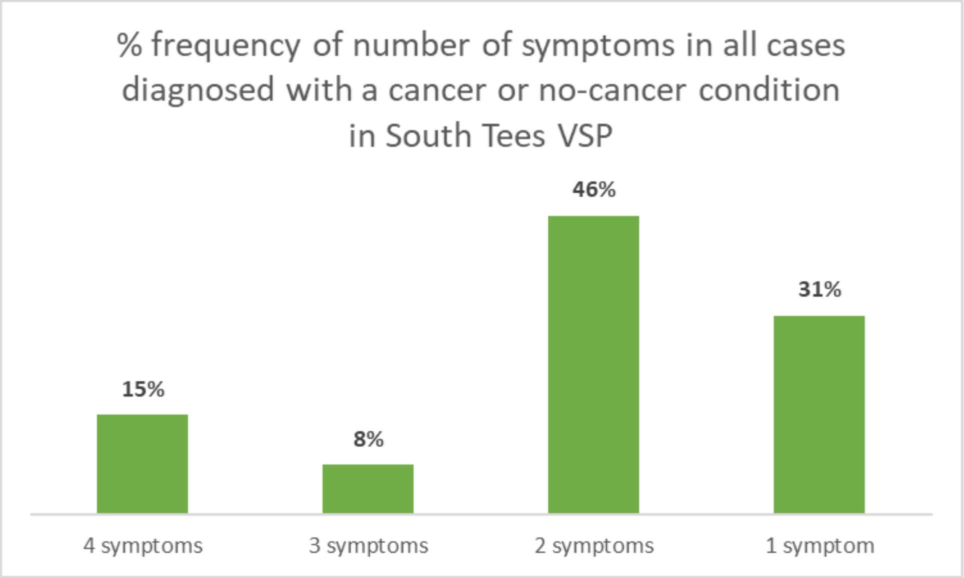

Figure 21. Percentage frequency of number of symptoms in referrals to the South Tees VSP that were subsequently diagnosed with either a cancer or non-cancer condition.

Furthermore, whilst absolute numbers of cancer diagnoses are still very low and therefore subject to distortion, results to date show that of patients diagnosed with cancer as a result of referral to the South Tees VSP, over half (60%) presented with 2 symptoms and a fifth (20%) presented with either one symptom or three symptoms) (Figure 22).

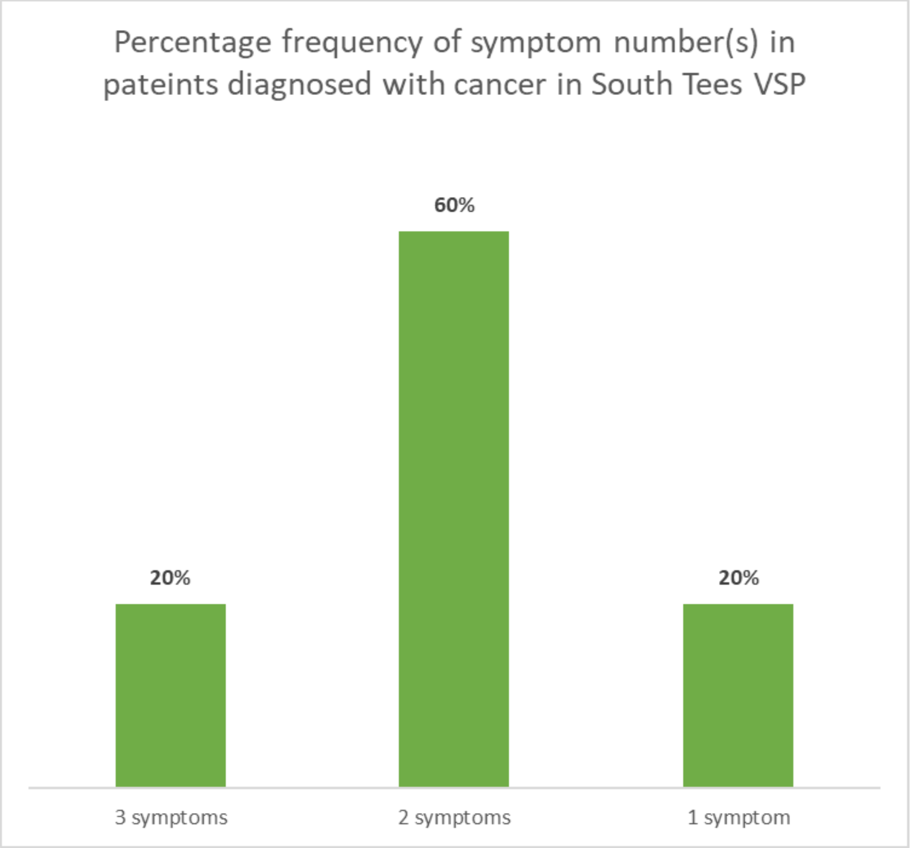

Figure 22. Percentage frequency of number of symptoms amongst patients diagnosed with cancer in the South Tees VSP.

Likewise, numbers may be too low and subject to distortion to identify trends but currently 38% of patients subsequently diagnosed with a non-cancer condition presented with only 1 symptom, a further 38% with 2 symptoms and 25% with 4 symptoms (Figure 23).

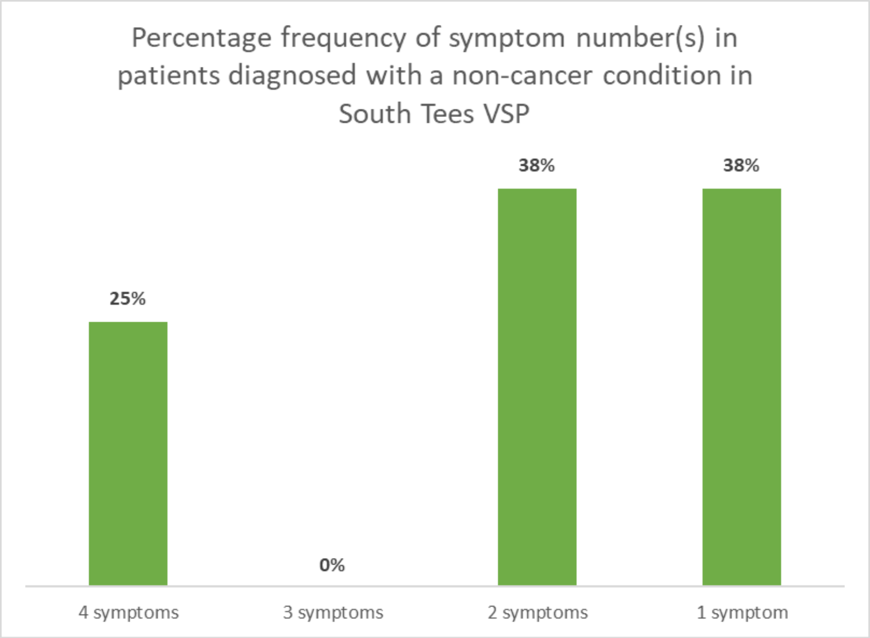

Figure 23. Percentage frequency of symptom number(s) in patients diagnosed with a non-cancer condition in South Tees VSP.

Significantly, more patients (61.5%) presented with weight loss as at least one of their symptoms, than any other symptom (Figure 24). One fifth of patients presented with fatigue (20.6%) and/or abdominal pain (19.1%), 14.5% with nausea/appetite loss, 12.2% with a respiratory problem (patients could have more than one symptom, therefore percentage frequencies sum to more than 100%). According to data collected to date, only 11.8% of patients presented at referral with GP ‘gut’ feeling as a symptom, despite this being a requisite in South Tees’ original referral criteria and being identified as the most critical factor in interviews with project members and GPs.

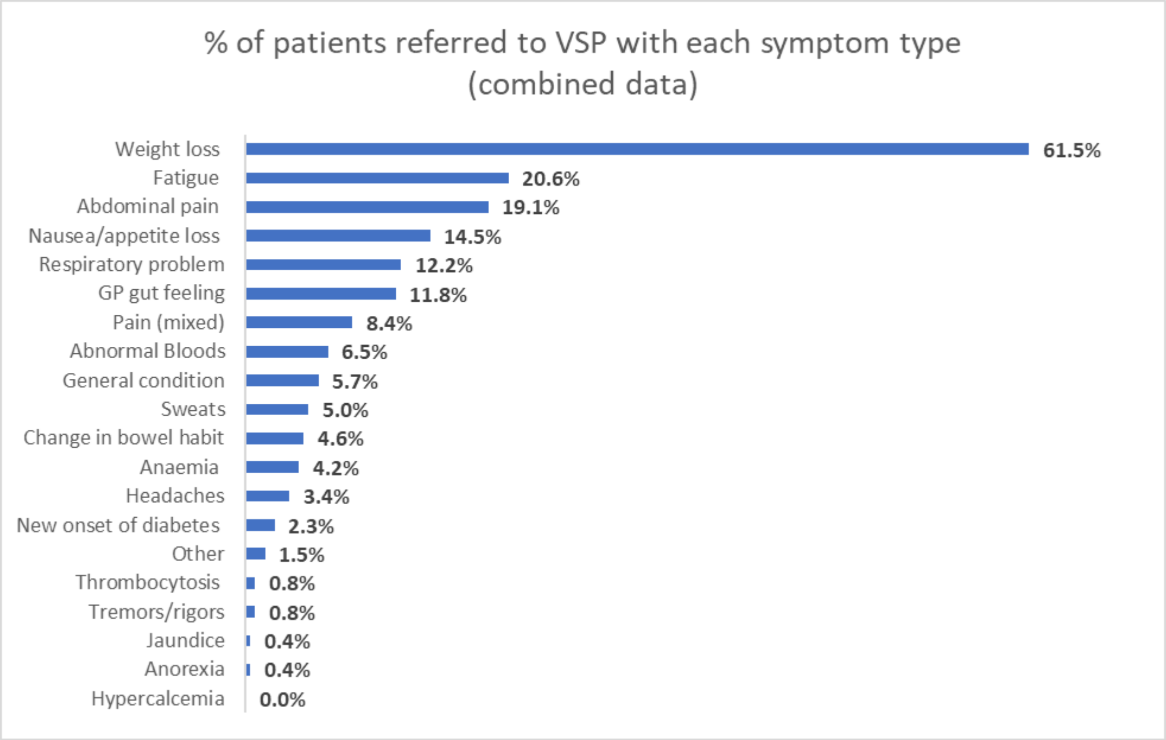

Figure 24. Percentage frequency of presenting symptom type at referral amongst patients referred to the combined VSP projects. Patients may have more than one symptom, chart shows prevalence of any one symptom in all patients.

However, at this point in the project, there is some difference between patients in the two projects. Thus, for Sunderland patients, more patients (64.8%) present with weight loss as the, or one of, their symptoms, than any other symptom (Figure 25).

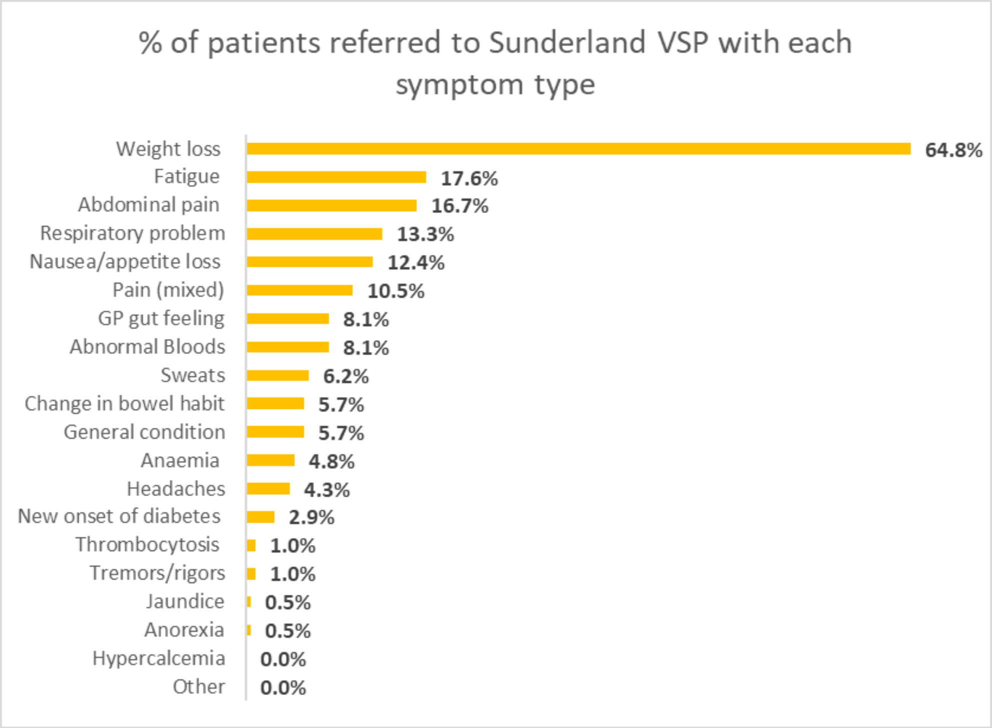

Figure 25. Percentage frequency of presenting symptom type at referral amongst patients referred to the Sunderland VSP.

In South Tees, weight loss is still the dominant symptom for most patients (48.1%) but more patients present with fatigue (32.7%), abdominal pain (28.8%) and GP gut feeling (26.9%) than in Sunderland (Figure 26).

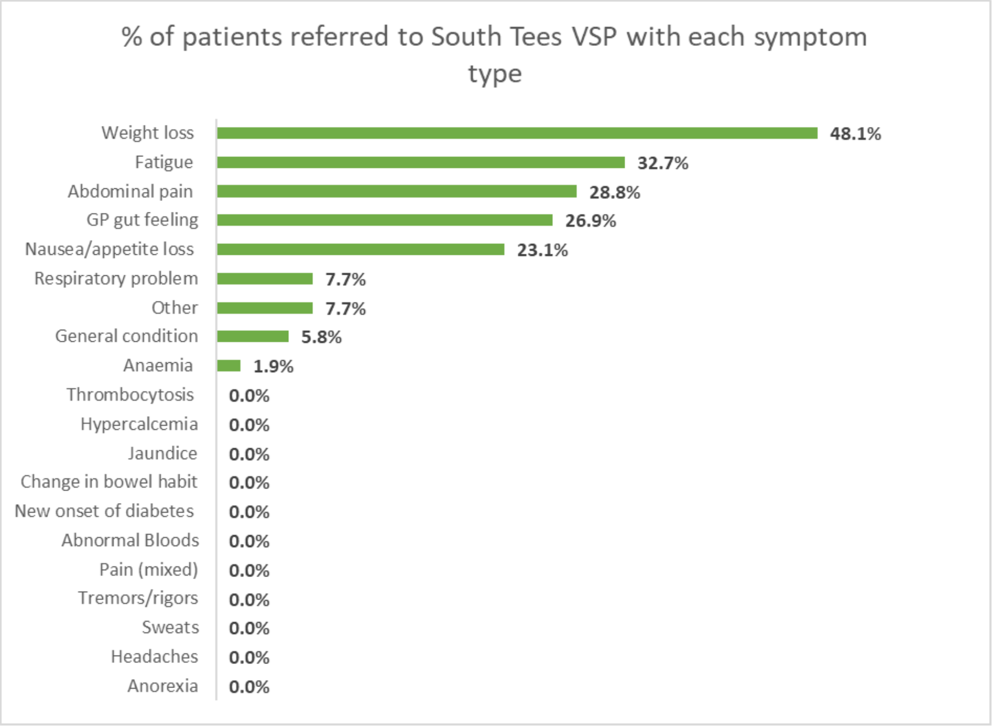

Figure 26. Percentage frequency of presenting symptom type at referral amongst patients referred to the South Tees VSP.

It is noticeable that GP gut feeling is a symptom for 26.9% of patients in South Tees, whereas only 8.1% of patients in Sunderland are recorded as having GP gut feeling as a referral symptom. The profile of patients registered with participating GP surgeries in the South Tees project tends to be older, rural and less socially deprived than those in participating GP surgeries in the Sunderland project (see Section 4.6 4.7 VSP uptake by GP practices for further details). If this trend continues, it may be worth further investigation, and with reference to the body of research on the factors affecting GP suspicion of cancer. For example, one study found that GPs first impressions about cancer risk are influenced by patient age, gender and ethnicity as well their prior experience and knowledge of cancer epidemiology but that GPs were significantly more likely to suspect cancer in older patients, irrespective of gender and ethnicity (Adam et al., 2017, p. 9). This study focused only on first impressions (using fast-thinking cognitive processes) and GPs take other information and use reflective, slow-thinking processes to make reasoned decisions about diagnostic possibilities (e.g. see Foot *et al*, 2011, p. 11 for a model of diagnostic strategies in primary care). However, it does highlight the potential range of influences on the processes and information that constitute GP 'gut' feel and how these might affect referral rates in different areas (on top of factors influencing cancer rates in different areas).

These trends may change as the project continues and more data is gathered, but it is recommended that the percentage frequency of patients with specific symptoms continues to be monitored for projects separately, as well as together, and that further investigation of significant variations, for example, percentage frequency of patients with GP gut feel as a presenting symptom, is considered.

Recommendation 8: The project(s) continue to monitor and investigate trends and variations in the percentage of patients presenting with each symptom type (and particularly GP gut feel) and reports this data on an individual project level as well as combined data for all VSPs.

Data showing presenting symptoms with subsequent cancer and non-cancer outcomes is available from South Tees records (Table 6).

Diagnosis outcome	Number of presenting symptoms	Symptoms	Diagnosis
Cancer	3	Abdominal pain, weight loss, fatigue	C61 Malignant neoplasm of prostate
	2	Abdominal pain, weight loss	C45.1 Peritoneal mesothelioma
	2	Fatigue, general condition	C22.0 Liver cell carcinoma, 9680/3 Diffuse large B-cell lymphoma (DLBCL)
	2	Weight loss, fatigue	C85.90 Non Hodgkin Lymphoma
	1	Weight loss	C78.00 Lung Cancer
Non-cancer	1	Fatigue	Z13.280 Osteoporosis
	2	GP gut feel, general condition	M35.3 Polymyalgia rheumatica
	2	Weight loss, GP gut feel	M35.3 Polymyalgia rheumatica
	1	Abdominal pain	J47.9 Bronchiectasis
	4	Fatigue, GP gut feeling, general condition, Other (sinus tachycardia)	K86.2 Pancreatic cysts
	4	Weight loss, nausea / appetite loss, fatigue, other (erythema nodosum)	D82.3 Glandular fever
	2	Fatigue, GP gut feel	J06.9 Viral upper respiratory tract infection
	1	GP gut feel	A49.9 Bacterial infection, unspecified

Table 6. Presenting symptoms and subsequent cancer and non-cancer diagnoses in the South Tees VSP.

4.10.6 Duration of symptoms prior to presentation

To date, nearly half (43%) of patients referred to the VSP reported that they had been experiencing their symptoms for between 3 and 6 months (Figure 27). This is consistent with most frequent duration of 3-6 months reported by 56% of patients in the combined MDC, although the percentage in the MDC pilot is somewhat higher. However, figure for this project may change as the projects continue.

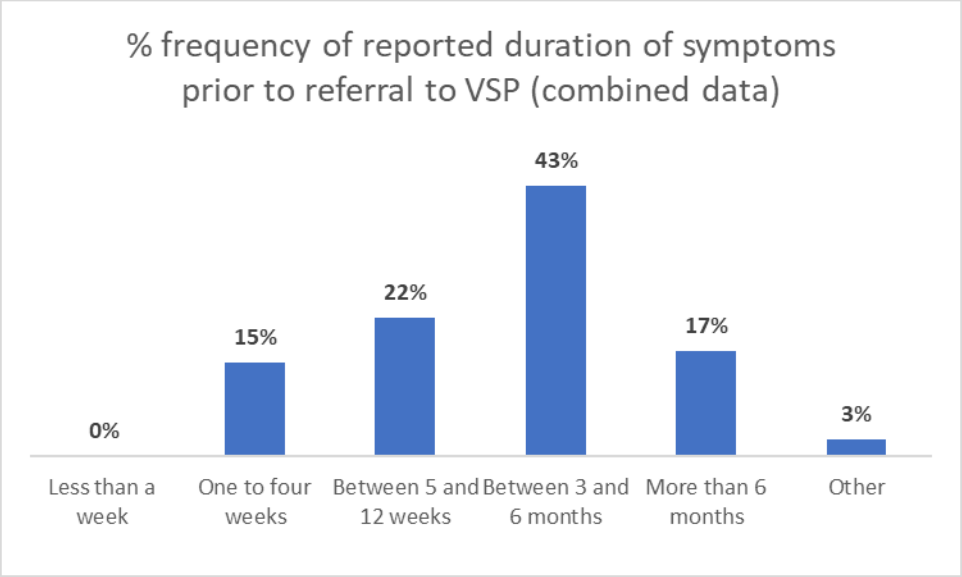

Figure 27. Percentage frequency of reported duration of symptoms prior to referral to VSP for both South Tees and Sunderland projects.

There is currently a difference between the South Tees and Sunderland projects (Figure 28) and (Figure 29) respectively. Thus, the largest proportion (33%) of patients so far in the South Tees VSP report having their symptoms for between 5 and 12 weeks, whereas in Sunderland over half (57%) of patients report experiencing their symptoms for longer (between 3 and 6 months) before contacting the GP regarding them.

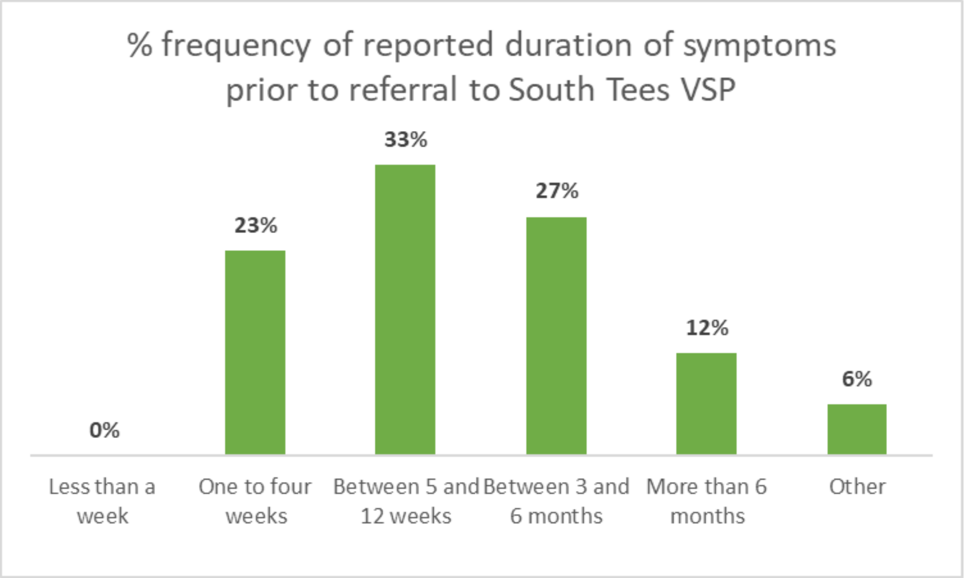

Figure 28. Percentage frequency of reported duration of symptoms prior to referral to South Tees VSP.

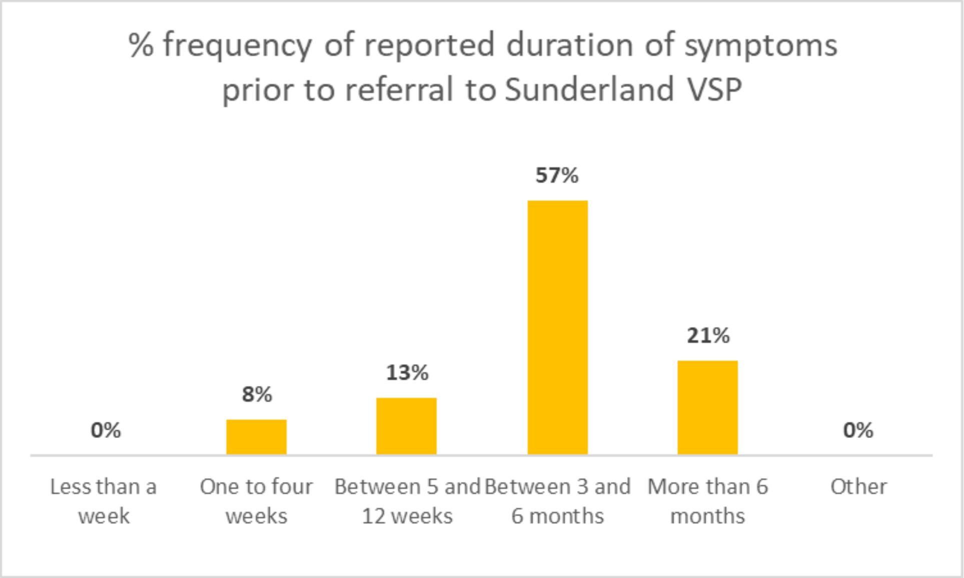

Figure 29. Percentage frequency of reported duration of symptoms prior to referral to Sunderland VSP.

This suggest that patients in South Tees, who tend to be older, less socio-economically deprived than those in Sunderland tend to consult their GP (or be able to consult their GP) more quickly than patients in Sunderland. If this trend continues throughout the project, this may be an area for further research to explore underlying causes.

4.9 Diagnostic tests

Most patients (88.5%) to date have had a CT scan of the chest, abdomen and pelvis (Figure 30) (patients can have more than one type of diagnostic test therefore percentage frequencies sum to more than 100%).

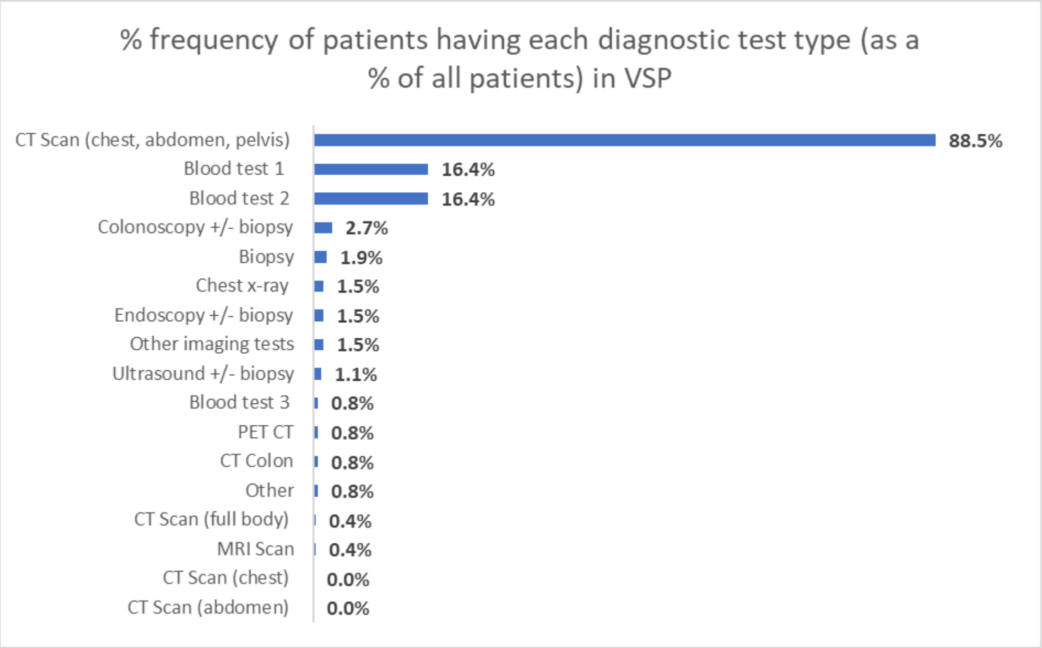

Figure 30. Percentage of all patients (excluding DNAs) who had each type of diagnostic test (combined VSP data).

However, it is probably more informative to consider data from the two projects separately, given the effect of pathway design on the types of diagnostic tests performed.

The pathway design of Sunderland VSP means that all patients who are referred receive initial screening blood and urine tests, requested and reviewed within primary care. Currently, the project does not have access to diagnostic tests performed in primary care and therefore these are not recorded in data returns. Where any abnormal or concerning results are identified by the GP, patients are referred for a CT scan that includes the chest, abdomen and pelvis via a 'check and book' service. All referrals are accepted by the Radiology Department, therefore, 100% of patients referred to radiology have already had blood and urine tests performed and have been referred for a CT scan of the chest, abdomen and pelvis. However, there were eight DNAs during the period of the project to date. Therefore, 202 patients referred to the Sunderland VSP had 202 diagnostic tests, giving an average of one diagnostic test per patients (excluding DNAs) which was a CT scan of the chest, abdomen and pelvis.

The design of the South Tees VSP means that assessment of patients begins with a first screening of bloods, carried out in primary care. Patients with abnormal results and whose symptoms meet VSP criteria are then assessed in a VSP clinic (located in Ambulatory Care) where a full examination of the patient is undertaken and their clinical history assessed. Following this initial consultation, a consultant decides the next steps which can include undertaking a second level screening of bloods, a CT scan (Chest, Abdomen and Pelvis), Endoscopy or Haematology (or other) referral.

Data relating to the proportion of patients receiving each type of test (Figure 31) was extracted from South Tees' data returns. This shows that most (83%) patients receive blood tests 1 and 2 and over half (58%) receive a CT scan which covers the chest, abdomen and pelvis. 13% of patients received a colonoscopy (with or without a biopsy). 10% a biopsy, and 8% a chest x-ray, endoscopy (with or without biopsy) and/or other imaging tests. 6% of patients received an ultrasound (with or without biopsy), 4% a PET CT scan, colon CT scan, blood test 3 and/or Other tests (no details available for what these were). 2% of patients underwent an MRI scan(s) and/or biopsy.

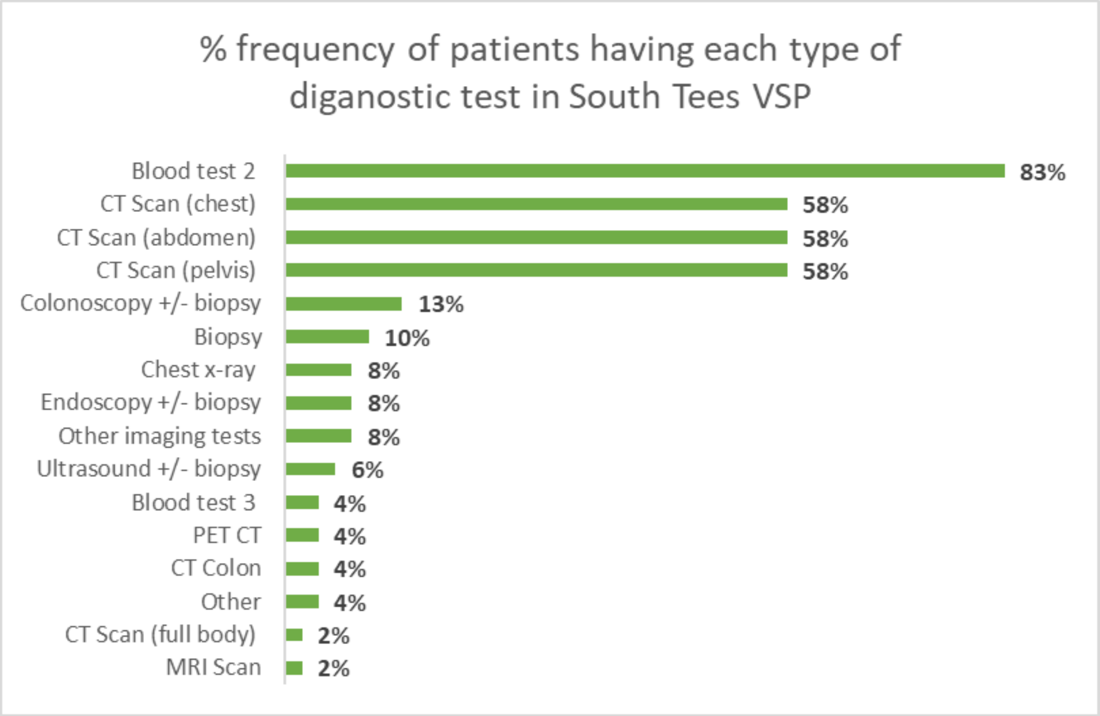

Figure 31. Proportion of patients receiving each type of test in the South Tees VSP (patients may receive more than one type of test, therefore frequencies sum to >100%).

In total, 213 diagnostic tests have been carried out for 52 patients to date, giving an average number of 4.1 diagnostic tests per patient. (There was one DNA in South Tees but the patient subsequently attended for diagnostic tests therefore all patients are included in this metric for South Tees).

Comparative data from previous MDC projects (ACE Programme, 2019d) suggests that more tests per patient are performed on the South Tees VSP and fewer in the Sunderland VSP (Table 7) but this is also affected by differences in pathway design.

	Leeds	Airedale	Oldham	Wythenshawe	BRUHT	S Tees	Sunderland
Average number of diagnostic tests per patient	1.5	2.35	1.8	2	1.6	4.1	1
n=	35	61	38	46	31	52	202

Table 7. Comparative data on frequency of diagnostic test type and average number of tests per patient (source for comparative data ACE Programme, 2019c).

The data on diagnostic tests is presented here for information but it is anticipated this data will be used in the cost-effectiveness evaluation of the VSP, when this is performed. It is expected that guidance on the methodology for cost-effectiveness evaluation will be available from the ACE team in 2019/2020 (ACE Programme, 2019d, p. 7).

4.10 Diagnosis outcomes

The conversion Rate (CR), which is the proportion of VSP referrals resulting in a cancer diagnosis, for the project to date is 10.3% (combined data). This is consistent with of the range of individual MDC project levels CRs of 4-11% and higher than the 8% CR at MDC programme (ACE Programme, 2019b, p. 13) (Figure 32).

A fifth of patients (21.4%) were diagnosed with a new non-cancer condition, which is lower than the rate reported for the MDC programme where one third of cases were diagnosed with a non-cancer condition (ACE Programme, 2019b, p. 14).

Over half (55.3%) of patients were discharged as 'all test normal' and 9.2% pf patients were either still undergoing ongoing tests or were still on the pathway. 3.4% of referrals were rejected and 0.4% diagnosed a recurrence of cancer.

The VSP combined project CR of 10.3% exceeds the CR for all 2WW pathways for the five years 2013/14 - 2017/18 in Sunderland CCG (7.4 %;) Hambledon, Richmond and North Yorkshire CCG (9.8%) (all of the participating GP surgeries in the South Tees project to date are part of this CCG) and England (8%) (2WW Referrals, Cancer Services, PHE).

Some of the participating surgeries in Sunderland are part of the Durham Dales, Easington and Sedgefield CCG, which has a CR for all 2WW pathways of 8.6% for the five years 2013/14 -2017/18.

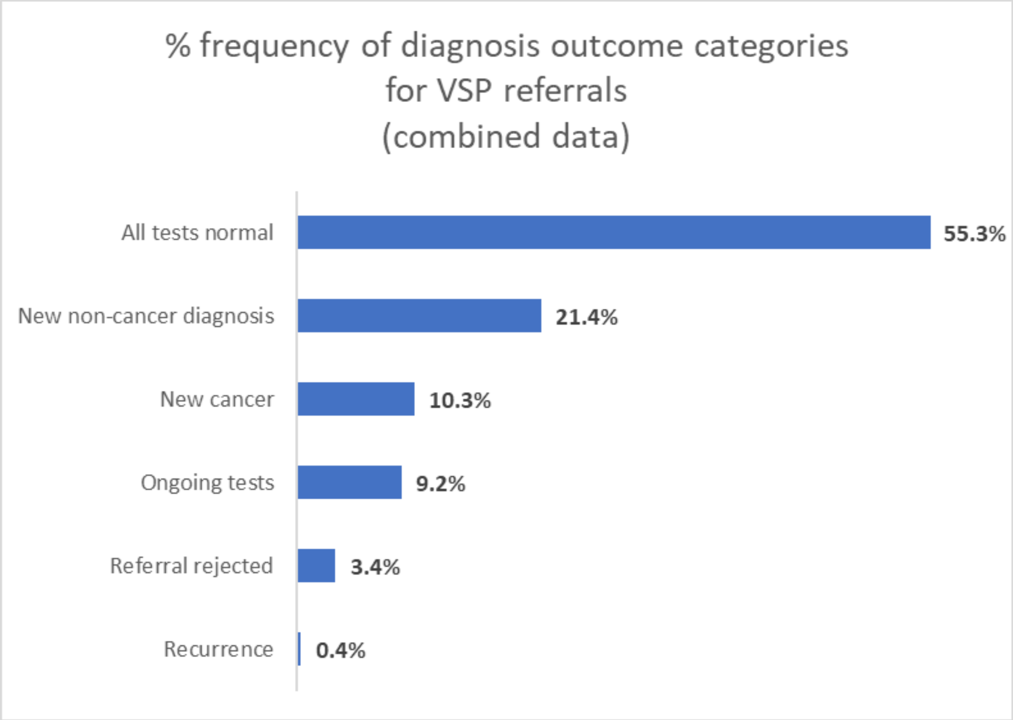

Figure 32. Diagnosis outcomes for patients referred to VSP (combined data).

The conversion rate for South Tees VSP to date is 9.6%. However, a substantial (30.8%) group of patients are either receiving ongoing tests (or still on the pathway for some other unspecified reason) (Figure 33). At this point in the project, there is a comparatively low proportion (19.2%) of patients discharged with 'all tests normal' (compared to 64.3% in the Sunderland VSP but as more of the patients still undergoing ongoing tests/still on the pathway are diagnosed, these figures may change. The diagnosis rate for new non-cancer conditions is also comparatively lower (23.1%) compared to the MDC findings (one third of cases) (ACE Programme, 2019b, p. 14) but consistent with that observed to date in the Sunderland VSP (21.1%). Referrals that were rejected

(17.3%) included information about the reasons for rejection for three of the rejections (met criteria for Upper GI 2WW pathway).

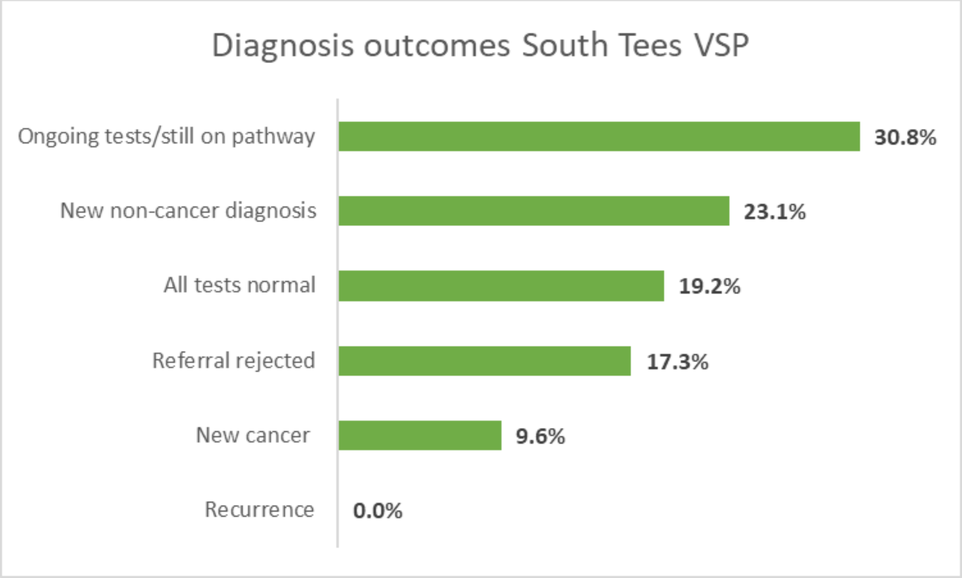

Figure 33. Diagnosis outcomes for South Tees VSP.

The conversion rate for Sunderland VSP is 10.5%, which is at the top end of the range of CRs reported in the MDC programme (4-11%) (ACE Programme, 2019b, p. 13) (Figure 34). Just over a fifth of patients (21%) were diagnosed with a new non-cancer condition, which is lower than the rate reported for the MDC programme where one third of cases were diagnosed with a non-cancer condition (ACE Programme, 2019a, p. 14). A substantial majority of patients referred to the Sunderland VSP (64.3%) were discharged after all tests came back normal. Only 3.8% of patients are still undergoing ongoing tests or still on the pathway for some unspecified reason. Cancer recurrence was recorded for 0.5% of patients.

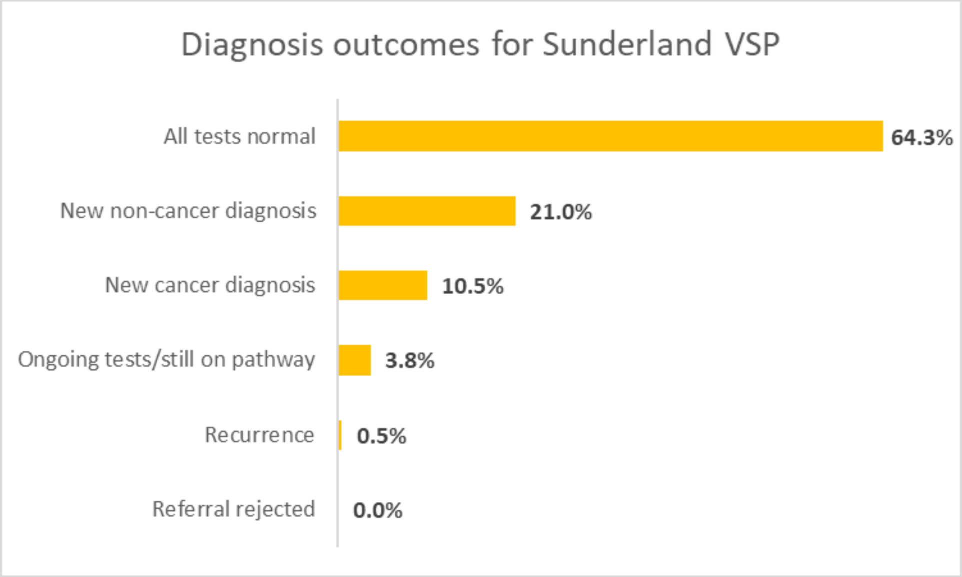

Figure 34. Diagnosis outcomes for Sunderland VSP.

In order to assess the sensitivity of the pathway, it is suggested that the project considers whether the calculation of the Detection Rate (DR) (the proportion of cancers treated which were VSP referrals) when cancer rates for the surgeries involved and for the periods concerned are available. This is consistent with the advice for the implementation of RDCs (NHS, 2019, p. 25), which advises that:

> *"Cancer Alliances should ensure their RDC(s) provide sufficient capacity so, by the end of the first year, 20% of cancer patients with non-specific symptoms in their area are diagnosed via an RDC".*

Recommendation 9: The Project Steering Group considers whether the Detection Rate of the pathway should be monitored and if they wish to disseminate that information further.

4.11 Types of cancer diagnosed

Of the 27 new cancers diagnosed to date as a result of referral to VSP, 14.3% were lung cancer, 10.7 % were haematological cancer and 9% were prostate, colorectal or pancreatic cancer (Figure 35). 3.6% of other types of cancers was recorded: hepatocellular, angiosarcoma, gallbladder, renal, stomach, breast, oesophageal, bladder, liver cell carcinoma, Non-Hodgkin's Lymphoma, lung cancer and peritoneal mesothelioma. One case of recurrent cancer (residual CLL) was also recorded. ICD10 codes were recorded for all but five cancers in the Quarter 2 return from Sunderland (one of these was recorded as lung cancer and has been included in C34,however, these codes will need verifying and possibly correcting when final data returns are submitted).

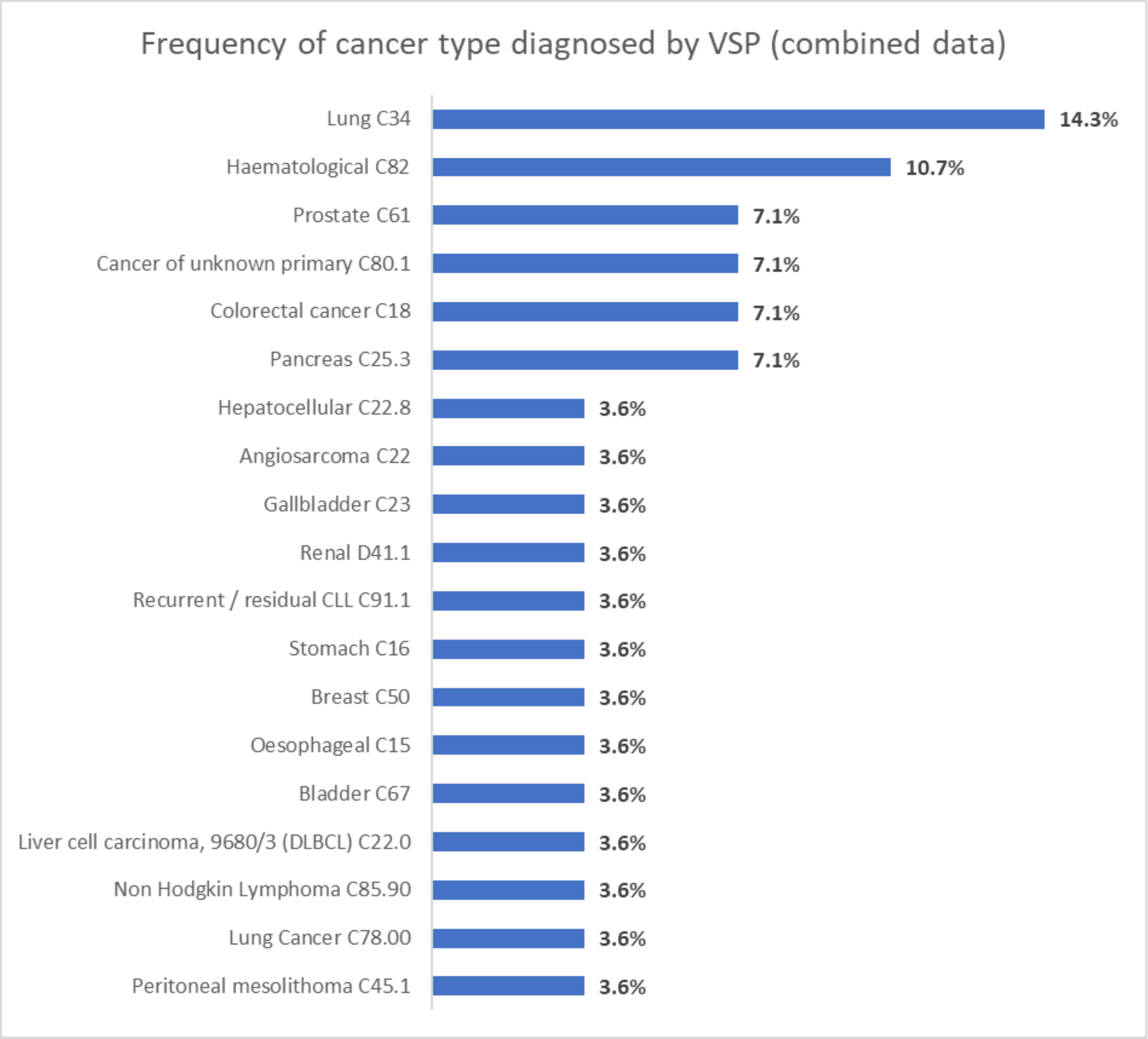

Figure 35. Frequency of cancer types diagnosed by VSP (combined data).

4.11.1 Common, rare and less common cancers diagnosed

The four cancers with the highest incidence rate (breast, colorectal, lung and prostate) are generally known as the ‘common’ or Big Four cancers. ‘Less common’ cancers are those with an incidence greater than 6 per 100,000 population and ‘rare’ cancers are those with an incidence of less than 6 per 100,000 population (PHE and Cancer 52, 2015, p. 7).

Of the cancers diagnosed by the VSP to date (combined data), 53.6% were Less Common and 14.4% were Rare, which is the category of cancers often diagnosed at a late stage e.g. pancreatic or stomach cancer (ACE Programme, 2019b, p.13). Together, this means that 68% of cancers diagnosed by the VSP projects to date have been Less Common or Rare cancers, which is somewhat higher than the 56% of Less Common or Rare cancers diagnosed by the MDC programme (ACE Programme, 2019b, p. 13).

Data relating to the national and local incidence of the types of cancers found as a result of referral to the VSP (Table 8) provides context to the frequencies of cancers diagnosed to date in the VSP projects.

Cancer frequency category	Cancer group or site name	ICD10 code	European Age-Standardised (AS) Incidence Rates per 100,000 Population, England, 2016 (persons unless gender stated in cancer group name) (Cancer Research, 2019)	Incident rate per 100,000 population Sunderland CCG 2014	Incident rate per 100,000 population South Tees CCG 2014	Incident rate per 100,000 population Hambleton, Richmond and Whitby CCG 2014
Common*	Prostate (male)	C61	173.7	142.31		180.55
	Breast (female)	C50	167.9	189.11		178.15
	Lung	C33-34	76.1	118.23		58.58
	Bowel	C18-20	68.7	79.63		70.56
Less common**	Haematological: Non-Hodgkin's Lymphoma	C82-C86	23.5			
	Pancreas	C25	16.7			
	Bladder	C67	16.7			
	Oesophageal	C15	14.9			
	Cancer of unknown primary	C77-C80	14.4			
	Stomach	C16	10.5			
	Hepatocellular	C22	9.7			
Rare***	Mesothelioma	C45	4.5			
	Gallbladder	C23	1.8			
	Recurrent / residual Chronic Lymphocytic Leukemia	C91.1	1.7			
	Soft tissue sarcoma (including Angiosarcoma)	C22				
	Renal	D41.1				
	Neoplasm - Secondary malignant neoplasm of unspecified lung	C78.00				

Table 8. National and local incidence rates for types of cancers diagnosed during the VSP project.

4.12 Staging of cancers diagnosed

A major objective for VSP projects is to improve the diagnosis of cancers at earlier stages of cancer and improve treatment options and outcomes and patient experiences (ACE Programme, 2017, p. 1). The symptoms of some cancers, for example, melanoma, breast, mean they are easier to suspect than others and these cancers are therefore more likely to be diagnosed earlier and more quickly (ACE Programme, 2017, p. ii). Harder to suspect cancers such as myeloma, pancreatic, stomach, and lung cancers typically present with vague symptoms and are thus less likely to be suspected, take longer to diagnose, be diagnosed at a later stage and have poorer outcomes and patient experiences (ACE Programme, 2017, p. ii). For example, 67% of people with vague symptoms typically present with late stage cancers compared to 45% of people with site-specific symptoms (NHS, 2019, p. 9).

Of cancers diagnosed to date by the VSP to date, 82% have staging information (cf. to 79% of cancers diagnosed in the MDC programme (ACE Programme, 2019b, p. 15). To date, all staging information is from the Sunderland project. Five cancers have been diagnosed by the South Tees project, all occurring in the most recent quarter (April-June 2019) and staging information is not yet available for this quarter.

Where staging data was available, 35% of cancers were diagnosed at Stage 1, 9% at Stage 2, 9% at Stage 3 and 48% at Stage 4 (Table 9). Overall, 44% of cancers were diagnosed at early stage (stages 1 or 2), compared to 26% in the MDC programme (ACE Programme, 2019b, p. 15).

Stage	TNM stage grouping (final pre-treatment)	Final haematological staging	Total frequency (rounded)
Stage 1	30.43%	4.35%	35%
Stage 2	8.7%	0%	9%
sub-total	39.13	4.35%	44%
Stage 3	8.7%	0%	9%
Stage 4	39.13	8.7%	48%
Total			100%

Table 9. Staging of cancers diagnosed in the VSP to date (currently staging data available only for Sunderland VSP).

It is not possible to determine from the summary data returns, to which cancers the staging information relates. It is recommended that the Project Steering Group considers whether this data can, and should be, extracted from project records for previous reporting periods and also that the data return form is amended to enable capture of this information for future reporting periods.

Recommendation 10: The Project Steering Group considers whether staging information linked to the type of cancer should, and can be, provided by projects. If so, projects should be asked for staging information, linked to type of cancers for previous data returns. Furthermore, the data return form could be amended to capture this information for the remainder of the project.

4.13 Non-cancer diagnoses

The combined project data shows that 20.6% of patients referred to the VSP were diagnosed with a non-cancer condition (Table 10).

	Sunderland	South Tees	Total
Number of non-cancer diagnoses	44	10	54
Number of patients	210	52	262
% non-cancer diagnoses	20.9%	19.2%	20.6%

Table 10. Percentage of patients referred to the VSP diagnosed with a new non-cancer condition.

This is somewhat lower than the programme level rate for the MDC project for the same pathway (non-specific but concerning symptoms); where over a third of cases resulted in a non-cancer condition diagnosis (ACE Programme, 2019b, p. 14).

The relative proportion of non-cancer condition categories is shown in Table 11, with further details of non-cancer condition types and frequencies provided in **Error! Reference source not found.**. Diseases of the digestive system were diagnosed in 31.4% (39% in the MDC project, ACE Programme, 2019b, p. 14) of non-cancer diagnoses and diseases of the respiratory system in 19.6% of non-cancer diagnoses. These two categories accounted for over half of all non-cancer diagnoses.

ICD disease category and code	**% Frequency**
Diseases of the digestive system K00-K95	31.4%
Diseases of the respiratory system J00-J99	19.6%
Neoplasms C00-D49	9.8%
Diseases of the genito-urinary system N00-N99	9.8%
Certain infectious and other parasitic diseases A00-B99	7.8%
Diseases of the circulatory system I00-I99	7.8%
Endocrine, nutritional and metabolic diseases E00-E89	3.9%
Injury, poisoning and certain other consequences of external causes S00-T88	3.9%
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism D50-D89	2.0%
Diseases of the musculoskeletal system and connective tissue M00-M99	2.0%
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified R00-R99	2.0%
Total	**100.0%**

Table 11. Relative percentage frequency of non-cancer conditions diagnosed by the VSP (combined data).

4.14 Time to diagnosis

Currently, two data items relating to time to diagnosis are captured in the summary data returns from projects:

1. Median number of days to first diagnostic test (also known as Doctor Interval) (Table 12).

	Sunderland			South Tees		
	Q1	Q2	Q3	Q1	Q2	Q3
Median number of days to first diagnostic test	13	14	-	2.5	7	7

Table 12. Median days from referral to first diagnostic test.

Additional data on time to diagnosis is currently available from South Tees detailed project records as follows (shown with comparative data from MDC programme level results (ACE Programme, 2019b, p. 15) (Table 13).

	South Tees Median (range) days n=number of cases	MDC Median (range) days n=number of cases
GP referral to first seen	7 (0-19)	8 (0-84)
GP referral to cancer diagnosis (Cancer diagnosis interval)	24 (13-59)	19 (0-199)
GP referral to New non-cancer diagnosis	31 (8-51)	
GP referral to All tests normal	11 (9-28)	
GP referral to any diagnosis (Diagnostic interval)	24 (8-51)	
Any referral to treatment	No data on treatment yet available	57 (6-269)

Table 13. Time to diagnosis metrics for South Tees (with comparative data from MDC programme level results (ACE Programme, 2019b).

Thus, the South Tees VSP currently has a shorter referral interval (7 days) than the MDC programme (8 days) and a much smaller range. The median cancer diagnostic interval (GP referral to cancer diagnosis) in South Tees is longer (24 days cf. to 19 days) but the range is much smaller.

There are some data items not currently collected in the summary data return including:

- Date of referral to VSP
- Date of first seen in secondary care
- Date of clinical diagnosis
- Date of start of treatment

Recommendation 11: The Project Steering Group considers whether projects need to provide additional data to calculate the full range of metrics and, if so, to amend the data return form to collect this data.

2. Number of Diagnoses communicated within 28 Days

The Faster Diagnosis Standard (FDS) has been developed in response to Cancer Taskforce recommendations and "will ensure that all patients who are referred for the investigation of suspected cancer find out, within 28 days, if they do or do not have a cancer diagnosis" (https://www.england.nhs.uk/cancer/early-diagnosis/#faster). Trusts are due to start being measured against the FDS from April 2020.

Currently, Sunderland data shows that 22 of their 67 diagnoses meet the FDS standard (32.8% compliance). South Tees FDS data in submitted returns needs correcting but the project reports 71% compliance with the FDS standard, as at 9 August 2019.

4.15 Treatment

The data return form does not currently ask for any data relating to treatment and therefore no data on treatment has yet been submitted by projects.

Recommendation 12: The Project Steering Group considers whether treatment information is required. If so, projects could be asked to provide treatment information relating to cancers diagnosed and reported to date, and the data return form amended to collect this data. It is suggested that any amendment to the data collection form enables the type of cancer, staging and treatment to be linked.

4.16 Data collection

Some missing/unavailable data items and minor data entry errors were identified in quarterly returns during the period of this evaluation. Discussions with the project teams and NCA quickly corrected small data entry errors (which could nevertheless have had significant distorting effects due to the small numbers involved, for example, numbers of cancers diagnosed. However, there is currently no data quality assurance process to identify, correct and audit data corrections or changes and this may be something the project needs to develop and implement for the remainder of the project.

Recommendation 13: The Project Steering Group considers whether the VSP project needs to develop and implement a data quality assurance process to identify, correct and provide an audit trail for data corrections and changes.

5 Discussion, conclusion and recommendations

The data gathered, collated and analysed in pursuit of this evaluation and report highlights a range of programme and project successes, as has been detailed above. Some of these are summarised below.

Nevertheless, the possibility of overstretch is clearly an issue, which pathway leaders must remain cognisant, particularly as awareness of the intervention in primary care grows and the potential for an increase in patient referrals through the system.

5.1 The three pathways

5.1.1 Implementation

The evaluation evidences that clinicians and professionals involved in the implementation of the projects are enthusiastic about the pathways and the ongoing potential of the pathways. Furthermore, the data sets out the pro-active approach being taken by many involved in the programme. There was some initial fear that the pathway creation could overload key areas of activities, particularly radiology; it appears that this concern has not been realised, however, pathway leaders should remain cognisant of that risk as patient referrals increase.

5.1.2 Performance

The intervention has been well received and the underpinning concept widely acknowledged and supported. It is considered that the pathway successfully addresses a gap for particular patients who would not fit with the two-week rule. Additionally, it is believed that the pathway also reduces the need for, and the provision of, multiple investigations. Importantly, staff interviewed as part of the evaluation shared anecdotal observations strongly suggesting that some patients are benefitting from the pathways and are finding the experiences positive.

5.1.3 Pathways in Action

The pathways, from going live, had seen over 200 referrals at the time of this evaluation. Evidence shows that the pathways are being utilised in the way intended, with very low rates of rejections. The patients, as would be anticipated, represent a range of ages, range of symptoms and number of symptoms, although it is interesting to note that nearly half of all patients referred were done so on the basis of one symptom. Importantly, from those referrals:

- It is evidenced that across the three pathways, the proportion of VSP referrals resulting in a cancer diagnosis – the Conversation Rate (CR) – is 10.3%;
- 21.4% of patients were diagnosed with a new non-cancer condition; and,
- Over half of patients received 'normal' test results and were discharged.

Of the cancers detected and diagnosed at the time of this work:

- Over 14% were lung;
- Over 10% haematological;
- 9% were prostate, colorectal or pancreatic; and,
- A range of other cancers detected each in one individual patient.

The cancers diagnosed by the VSP often fall into the category of Less Common and Rare – 68%, which is higher than the same category outcome from the MDC programme (Ace Programme, 2019b, p.13).

The staging of cancer diagnosis is important for patient outcomes. Evidence collated and analysed here illustrates that 35% were diagnosed at Stage 1 and 48% at Stage 4.

5.2 Concluding observations

The overarching aim of this Northern Cancer Alliance programme responds to a perceived problem for patients presenting at GPs with vague symptoms, creating a situation whereby GPs could struggle to identify an appropriate response and pathway. The aim of the pathways set up via this programme is to offer expedited access to testing and assessment for the patients with vague symptoms. Pathway objectives include reducing the time to diagnosis for patients and quickly screening out referred patients who do not need access to cancer treatment.

The evidence presented above illustrates that the overall aim of the programme is being met – clearly, the pathways present a highly appropriate and effective option to GPs when faced with a patient with vague symptoms. It is also evidenced via the quantitative and qualitative data that expedited access is generally being achieved, with those who are staffing the pathways and associated activities feeling very positive about their effect and potential. Importantly, that expedited access is reducing the time to diagnosis for patients, thus enabling more rapid care, for cancer, or identifying another condition. That speed of diagnosis will also support treatment plans being enacted more quickly and, potentially, at an earlier stage in their cancer for some patients. It is also worthy of note that for a good proportion of patients referred, the rapidity of the system allows them to get the ‘all-clear’ quickly. There remain some outliers in outcome figures – in particular, the Sunderland data having only 32.8% compliance with the FDS standard. It may be that as the pathways continue to be refined and rolled out, and data reporting is more finely tuned, this compliance will rise.

Overall, the evaluation team feel that the pathways considered here, at their individual stages, are successful, that the programme has been well implemented and is delivering against its core aims. However, in all programmes, particularly those that are piloting new approaches, lessons can be learned and, with this mind, below are a series of recommendations for the programme and pathways leaders to consider.

5.3 Recommendations

Recommendation 1:

The NCA monitors uptake of the VSP by GP practices for the remainder of the project to identify whether further promotional activity needs to take place and to enable uptake rates to be captured by the programme or project leads.

Recommendation 2:

It would be useful for the programme commissioners to continue monitoring a number of metrics, to include: trends relating to GP practice size and proportion of VSP referrals; trends relating to GP practice size, age, deprivation profiles, ethnic diversity, geographic profile, are monitored with regard to equitable access or to provide information on performance and outcomes against different variables.

Recommendation 3:

Referral rejection rates are monitored throughout the project to identify whether repeat/revision of guidance on referral criteria or other action is needed.

Recommendation 4:

VSP configurations where minimal referral information is available and/or no clinic assessment is performed, consider how they can how they can obtain sufficient referral and patient information in order to evaluate referrals and monitor inappropriate referral rates.

Recommendation 5:

The age distribution, and particularly the frequency of patients < 50 years of age, is monitored and investigated if the current unexpected trend continues.

Recommendation 6:

The Project Steering Group considers whether co-morbidity data for all patients on the VSP is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

Recommendation 7:

The Project Steering Group considers whether performance status data is essential for interpreting project results and, if so, discuss with projects whether and how this data can be accessed and extracted.

Recommendation 8:

The project(s) continue to monitor and investigate trends and variations in the percentage of patients presenting with each symptom type (and particularly GP gut feel) and reports this data on an individual project level as well as combined data for all VSPs.

Recommendation 9:

The Project Steering Group considers whether the Detection Rate of the pathway should be monitored and if they wish to disseminate that information further.

Recommendation 10:

The Project Steering Group considers whether staging information linked to type of cancer should, and can be, provided by projects. If so, projects should be asked for staging information, linked to type of cancers for previous data returns. Furthermore, the data return form could be amended to capture this information for the remainder of the project.

Recommendation 11:

The Project Steering Group considers whether projects need to provide additional data to calculate the full range of metrics and, if so, to amend the data return form to collect this data.

Recommendation 12:

The Project Steering Group considers whether treatment information is required. If so, projects could be asked to provide treatment information relating to cancers diagnosed and reported to date, and the data form amended to collect this data. It is suggested that any amendment to the data collection form enables the type of cancer, staging and treatment to be linked.

Recommendation 13:

The Project Steering Group considers whether the VSP project needs to develop and implement a data quality assurance process to identify, correct and provide an audit trail for data corrections and changes.

6 Acknowledgements

We should like to thank all the interviewees who took part in this evaluation project for their time and contributions, together with project staff who provided data, both of which form the basis for this evaluation. All contributions are greatly valued.

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Appendix 1 Patient Consultation

Vague Symptoms Pathway Pilot Project – Patient Involvement Activities

Provided by Jo Mackintosh, Macmillan Engagement and Co Design Project Manager

There is growing recognition of the value that involving people in health services can bring including improving patient safety, the patient experience and health outcomes (NHS England: 2017). However, it is essential that involvement activities are shown to be meaningful, have impact and are not tokenistic or regarded as a "nice to" activity. For this to happen, involvement needs to be fully embedded within NHS services and organisation's and regarded as "usual business".

National policy documents such as Achieving World Class Cancer Outcomes (2015), the NHS Constitution (2015) and NHS Long Term Plan (2019) also recognise the importance of involving people in designing and delivering the changes necessary to drive forward improvements in cancer services. The Northern Cancer Alliance views patients, carers and members of the wider community as equal partners. It is committed to involving people at all levels of its work plan and demonstrating the value that involvement can bring.

The patient involvement methodology adopted for the vague symptom's pathway involved consulting with patients to measure their experience of care. The primary aim of this measurement was to understand which aspects of the pathway provided a positive patient experience and to identify where improvements could be made to further enhance the patient experience.

Experiential data was collected from patients via a paper survey given to at the end of the pathway. The survey was developed by members of the individual project teams, the Cancer Alliance project manager and involvement lead. Survey questions were informed by the NHS Framework for Patient Experience (2011) and the identification of key patient "touchpoints" from across the pathway. Mapping of patient "touchpoints" spanned from the patient's initial visit to the GP to the end of the pathway. Questions covered the following aspects of the patient experience:

Primary Care:

1. Access to care – patients are referred on to the vague symptom's pathway in a timely manner.

2. Information, education and communication – patients understand the purpose of the tests requested by their GP.

3. Information, education and communication – patients understand the results of the tests requested by their GP.

4. Information, education and communication – patients understand the purpose of a referral on to the vague symptom's pathway.

5. Emotional support – the questions patients ask their GP are answered in a way they understand.

Secondary Care:

1. Information, education and communication – patients understand the purpose of the tests requested by hospital staff.
2. Information, education and communication – patients understand the results of the tests requested by hospital staff.
3. Emotional support – the questions patients ask hospital staff are answered in a way they understand.
4. Coordination and integration of care – patients experience continuity of care when referred from the vague symptoms to a tumour specific pathway, back to their GP or other health care services.

Overall:

1. Respect for patient-centred values, preferences, and expressed needs – patients feel involved in the decisions made at each stage of their care.

Qualitative and quantitative data was collected from patients at two of the vague symptom pathway pilot sites (Sunderland and South Tees). Data collection was overseen by members of the project team at each of the sites. Each pilot site was provided with a standardised Excel spreadsheet data analysis tool. This tool produced quantitative results on a monthly basis and provided a repository for qualitative data. Quantitative data analysis provided pilot sites with the opportunity to track their performance over time in both primary and secondary care settings. Data from both pilot sites was fed back to the vague symptoms pilot steering group.

References

NHS England (2017), Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England.