Inequalities in breast cancer care

Quantifying the inequalities across the breast cancer pathway and their impact on health outcomes in Scotland

This research was initiated and funded by Pfizer. The analysis has been carried out collaboratively between Lane Clark and Peacock (LCP) and Pfizer with input from Shine Cancer Support.

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Purpose and disclaimer

Pfizer, Shine Cancer Support and LCP have produced this report to describe the inequalities in the breast cancer care pathway for women in Scotland and quantify the benefit of reducing these inequalities at diagnosis.

In collaboration with LCP, and using information gathered from publicly available sources that are believed to be reliable, reasonable efforts have been taken to ensure that the subsequent analysis and derived data and referenced as 'Data on File', are accurate. The data and information in the analysed data set (cited in the reference pack as "Data on File") , are intended for use by persons possessing technical skill and knowledge in epidemiology, surveillance and data management. While every effort is made to ensure the analysed data quality, the data is provided "as is" by LCP.

Assumptions were required as part of the modelling where there was limited data availability. The methodology for the analysis along with the assumptions used is set out in detail in the Technical Appendix from page 20. All references for the data and literature used in this report are set out on page 30.

Some analysis was not possible due to data availability, such as analysis of male breast cancer due to limited publication of male breast cancer statistics. We have therefore restricted the analysis to female breast cancer, further detail on data limitations is discussed later in this report.

We have aimed to use the most up-to-date data available. Where data was only available in the year 2020 this has not been used due to the Covid19 pandemic occurring primarily in this year, resulting in disruption to aspects of cancer care. Most of this analysis uses data from 2021 and cancer waiting times are based on 2022 data.

Due to this, and the assumptions used, the results set out in this report will vary if more up-to-date data is available or different assumptions are used. As more recent data is available these results can be compared to understand how inequalities in Scotland have varied over time.

Glossary

Term	Definition
Health boards	There are 14 health boards in NHS Scotland. They aim to improve the population's health and deliver frontline healthcare services[1].
Health inequalities	Health inequalities are unfair and avoidable differences in health, health outcomes or access to care, between different groups of people[2]. They are influenced by a combination of socioeconomic and environmental factors that affect people's lives such as income, education, or geography[2].
SIMD	An abbreviation of "Scottish Index of Multiple Deprivation": The official measure of deprivation in Scotland. The index ranks every small area in Scotland from least to most deprived. The domains used to determine deprivation include income, employment, education, health, crime, housing and access to services.[3]
Stage of cancer	Four stages are used to describe cancer. The staging will affect treatment and long-term outcomes. Broadly the four stages are:
	•Stage I: The cancer is small and has not spread •Stage II: The cancer has grown or had spread to local tissues •Stage III: The cancer is larger or may have spread regionally to the lymph nodes •Stage IV (Metastatic): The cancer has spread to different tissues or organs in the body
Early-stage cancer	Cancer diagnosed as Stage I or II
Late-stage cancer	Cancer diagnosed as Stage III or IV
Metastatic cancer	Cancer that has spread from its original location to other distant parts of the body
PALYs	An abbreviation of "Potential Additional Life Years": An estimate of the years a person would have lived if they had not died prematurely (in this report this is measured as the years a person would have lived if they were diagnosed at an earlier stage of cancer)

Executive summary

Reducing health inequalities is a key priority for Public Health Scotland[4] and government[5]. This analysis used publicly available NHS data to describe the existing inequalities and model the potential impact of eliminating these in the breast cancer care pathway for women in Scotland. The model uses data published by Public Health Scotland, information from published literature and includes several assumptions. This report demonstrates some of the biggest inequalities in breast cancer care and identifies realistic actionable next steps for policy makers and NHS leaders.

Key Findings

Women living in the most deprived communities have significant inequalities across the diagnosis pathway and are more likely to have late-stage cancer at diagnosis[6].

The data published does not include ethnicity as routine and there is only national level data for the referral pathway[7], no breakdown by deprivation, health board or ethnicity is published thus limiting the understanding of what could be driving inequalities in cancer care in Scotland.

In addition to differences in stage of breast cancer there are large differences observed in cancer treatment waiting time performance[8] between areas of Scotland (by health board) and depending on the rurality of the area.

Recommendations

1

Public health Scotland should **publish and improve access to more of the data which the NHS already collects** about health inequalities in breast cancer. Where possible lags in data availability should be reduced. This will help to shine a light on existing inequalities and help their stakeholders support the NHS to address inequalities.

2

NHS leaders should make best use of their **local data to identify and tackle inequalities in breast cancer diagnosis and treatment.** Data will help local leaders identify the key drivers of health inequalities in their area and identify areas to learn from such as alliances with similar characteristics that have successfully reduced inequalities.

3

Support from multiple stakeholders including patient groups, NHS leaders, healthcare professionals and pharmaceutical companies **using the broader data available and local insights will allow the NHS and stakeholders to have the greatest possible impact** in identifying solutions to improving survival in patients through pathway improvement.

Contents

Tackling health inequalities is a priority for Public Health Scotland[4] and the government[5]

Key Aims

Health inequalities in Scotland have been highlighted for decades. Scotland has had the lowest life expectancy of the UK nations since the 1950's[9] and inequalities in life expectancy have been widening between the most and the least deprived communities.

Since devolution over 20 years ago the powers of the Scottish government have increased and many of the powers that can influence health are held by the Scottish government. Despite this the Health, Social Care and Sport Committee inquiry into health inequalities in 2022 found there was no overarching national health inequalities policy in Scotland and health inequalities were widening[10.]

There is no overarching national health inequalities policy in Scotland, as highlighted in the Health, Social Care and Sport Committee's inquiry into health inequalities[10]. However, health inequalities are a focus of different bodies across Scotland[4,5].

Public Health Scotland aims to "put reducing inequalities at the heart of all we do" as part of the 2022-2025 strategy[4].

The Cancer Strategy for Scotland 2023-2033 includes a specific ambition of "Tackling Inequalities"[5]. The strategy highlights different factors which can affect cancer risk such as sex, age, ethnicity and geography (particularly rural and island communities)[5].

Other ambitions within the strategy highlight the need for early and faster diagnosis and timely access to treatment[4].

Tackling health inequalities can have wider economic benefits to society, beyond removing inequity in the population. Studies have indicated health inequalities lead to higher healthcare costs and losses to welfare, productivity, growth and development[12].

Men and women in the most deprived communities have a healthy life expectancy more than 25 years lower than those in the least deprived communities[11].

This project aimed to understand inequalities across the whole breast cancer care pathway

Breast cancer accounts for 15% of newly diagnosed cancers and is the most common cancer in the UK[13]. In Scotland breast cancer accounts for a third of all cancers in women[14].

Health inequalities are important both from a policy perspective and as barriers to wider societal improvements. There are known inequalities within breast cancer. Sociodemographic factors such as age, ethnicity, socioeconomic status, and geography affect patient's access to breast cancer screening, timely diagnosis, and effective treatment options in the UK, resulting in avoidable disparities in survival among different demographic groups[15,16].

The Cancer Strategy includes optimising screening uptake as a potential solution to earlier diagnosis in cancer[5]. The strategy recognises however this is not the only solution to improving early diagnosis in populations and includes understanding diagnostics and harnessing data.

This project aimed to take a holistic approach to understanding health inequalities across the whole pathway to identify potential drivers of inequality and solutions required to reduce these inequalities.

This report focuses on female only breast cancer due to limited data available for male patients. Additional data gaps, data challenges and data limitations are discussed later in this report.

We examined four key steps in diagnosis and treatment of breast cancer

We aimed to describe existing health inequalities and the potential impact of reducing such inequalities using NHS data and published literature (described in detail in the Technical Appendix) across four stages in the breast cancer care pathway:

Screening:
Women aged 50-70 in Scotland are invited to breast cancer screening every three years[17]

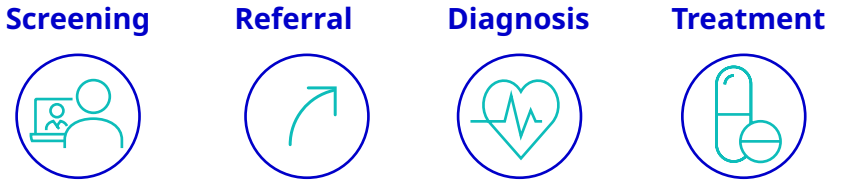
Referral:
Scottish government guidance states any patient aged over 30 with a breast or axillary lump should be considered for an urgent suspected cancer referral[18]

Diagnosis:
The Scottish Cancer Strategy aims to reach 76% of cancers diagnosed at stage I or II in 2033[5]

Treatment:
Cancer waiting time targets based on achieving treatment within 31 days of decision to treat and 62-days to treatment from urgent suspicion of cancer referral[19]

We also developed a model to estimate the additional years of life that could potentially be saved by removing inequalities in stage at diagnosis. This pathway element was used due to readily available data on survival and stage at diagnosis.

We looked at two major social determinants of health available in Scottish health data: geography (health boards) and socioeconomic deprivation (as measured by SIMD quintiles).



This report is designed to shine a light on the biggest inequalities in breast cancer and identify realistic actionable next steps for policy makers and NHS leaders.

Abbreviations: SIMD, Scottish Index of Multiple Deprivation

A third of breast cancer patients are diagnosed via screening[7]

Literature findings: Screening in Scotland

Women aged 50-70 in Scotland are invited to breast cancer screening every three years[17]. Drivers of low uptake include deprivation[20], ethnicity[21], mental illness[22] and learning disability diagnoses[23].

In Scotland, low uptake has been observed in more deprived areas[24]. Between 2018-2021 attendance at screening appointments was 61.2% in the most deprived 20% compared to 80.8% in the least deprived group[24].

Of the 14 health boards only one health board did not meet the acceptable uptake standard of 70% (68.5%) over the three years[24]. This health board did meet the standard when measured across 2020-21 (73.8%)[24].

Our analysis of NHS data

Our analysis aimed to quantify the percentage of patients diagnosed by screening. Public Health Scotland publishes monthly counts of the number of patients eligible for 31 or 62-day targets by the source of referral, including screening[7]. This data is measured nationally and does not include further breakdown by deprivation or geography[7] limiting the data analysis possible for this pathway element.

Our analysis of Public Health Scotland source of referral for 31-day eligible patients over 2021 indicated a third of patients are screen-detected[7].

- 33% of patients were diagnosed via screening[7] nationally.
- This is similar to that observed in the England Route to Diagnosis 2018 study where 34% of patients were diagnosed via screening[25].

Breast Cancer Now called for timely access to screening performance data which included data on breast cancer inequalities[26]. Public Health Scotland should publish more detailed uptake and diagnosis data using the data it currently collects to detail differences by deprivation and ethnicity.

Referral data is only available on a national level limiting understanding of inequalities across Scotland[7]

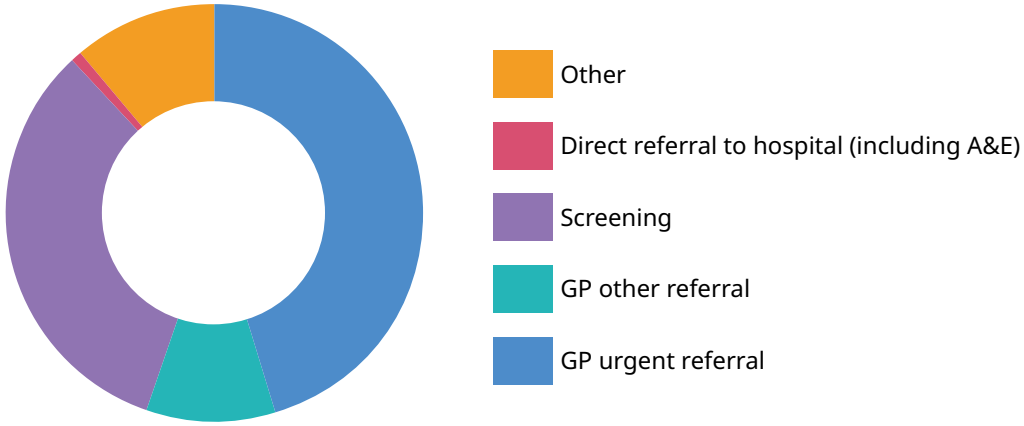
Analysis of Public Health Scotland referral data

Public health Scotland publish the source of referral for patients eligible for the 31-day waiting time target. This data is only published on a national level limiting understanding of drivers of inequality in referral.

Our analysis of Public Health Scotland source of referral over 2021 was limited by the lack of granular data[7]:

- 46% of patients were diagnosed via urgent GP referral[7].
- Data was only reported on a national level[7]. Publishing data by geography, deprivation and ethnicity could help identify inequalities to target.
- The 'Other' category includes incidental findings across emergency and other secondary care[27]
- Data which included the number of diagnoses from emergency care specifically could help identify populations struggling to access care in a primary setting. This is aligned with ambitions set out in the Cancer strategy[5].

Percentage of patients diagnosed source of referral (2021)[7]



Public Health Scotland should publish more granular data on source of referral by a range of characteristics. This data is currently collected and publishing it publicly will help help target interventions for earlier and faster diagnosis.

Note on terms[27]: GP urgent referral: patients urgently referred with a suspicion of cancer by a primary care clinician (GP or GDP). GP other referral: routine or urgent referrals non-specific to cancer by a primary care clinician (GP or GDP). Screening: patients referred through a National Cancer Screening Programme. Direct referral to hospital (including A&E): patients who attend A&E/direct referrals to hospital where the signs and symptoms are consistent with the cancer diagnosed as per the Scottish Referral Guidelines.

A higher percentage of women living in more deprived communities are diagnosed with late-stage cancer[6]

Literature findings: Staging

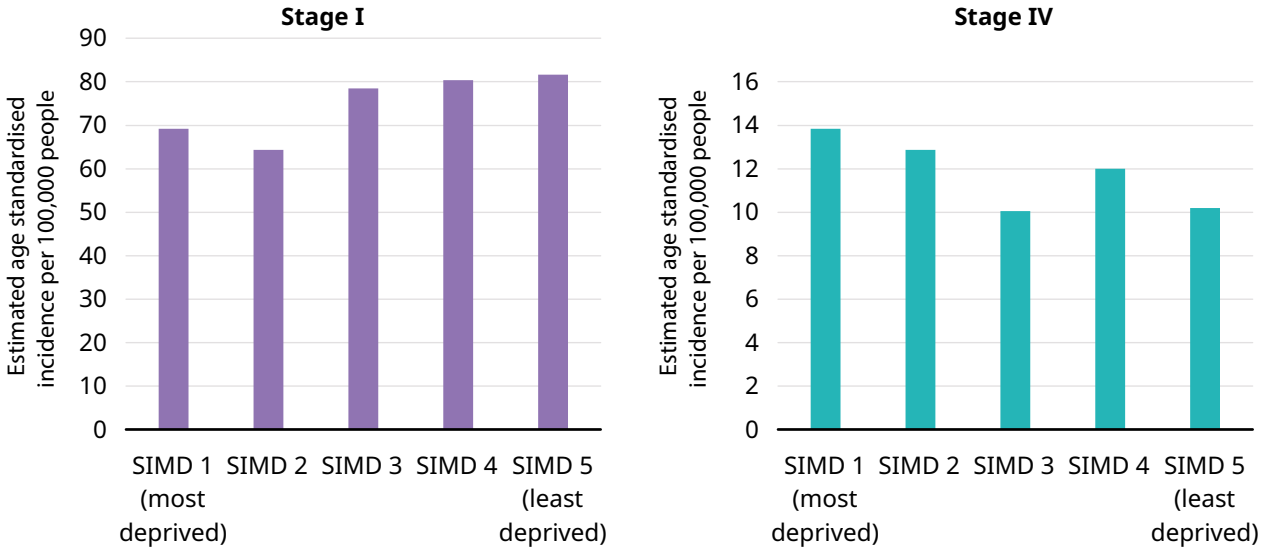
Women living in more deprived communities have higher risk of late-stage cancer at diagnosis in Scotland[5]. Patients with later stage cancer at diagnosis have been shown to have poorer survival outcomes[28].

Our analysis of Public Health Scotland diagnosis data

Late-stage breast cancer was highest for those living in the most deprived communities in 2021* in Scotland[6].

- Overall, the incidence of breast cancer is higher in people in less deprived communities[29].
- This pattern was observed for patients with stage I cancer but reversed for stage IV cancer, for which women in the most deprived communities have the highest incidence[6].
- England has a similar pattern for deprivation as set out in our England report. The variation by ethnicity was published by NHS England but is not available in Scotland.

Estimated Stage I and Stage IV breast cancer incidence according by deprivation (2021)[6,†]



Public health Scotland should aim to publish ethnicity data by stage to understand other inequalities that may exist in the pathway. NHS Scotland should use patient-level data to understand where in the pathway is leading to certain groups of women to be diagnosed later, in order to set up initiatives to target those areas for improved outcomes.

Abbreviations: SIMD, Scottish Index of Multiple Deprivation. †Estimated incidence at each stage based on the age-standardised incidence for each deprivation group[30] multiplied by the proportion of patients diagnosed in Stage I and IV (excluding unknown stages)[6]

*This is the most up-to-date standardised staging data available at the time of analysis.

Removing diagnostic inequalities could result in hundreds of potential additional life years per year nationally[30]

Modelling PALYs

Our modelling indicates that removing differences in stage at diagnosis (such as improving early diagnosis) for the most deprived communities could lead to the biggest improvements in survival[30]

Removing deprivation inequalities could results in nearly 800 PALYs per year overall[30]. Those in the most deprived community could have an increase of 5 months of life per patient[30].

The English analysis demonstrated higher PALYs for black women. This analysis was not possible for Scotland limiting the depth of understanding.

PALYs can be used to identify where initiatives are most needed and monitor progress of such initiatives.

Potential additional life years if diagnostic inequalities are removed by deprivation (SIMD)[30]

Modelling Methodology

- We estimated the number of PALYs if all deprivation groups had the same stage at diagnosis distribution as the least deprived group[6].

Modelling Assumptions

- Due to data limitations, we used assumptions to model the number of cases in each deprivation category ("sub-populations") and estimated survival:
- Due to a lack of granular survival data for Scotland, we estimated the mean survival in years by age and stage by extrapolating NHS England survival data[31] (due to data limitations with Scotland survival data) as detailed on page 26-27. The survival assumptions do not vary between sub-populations.
- We estimated the number of cases in each sub-population group by age and stage.
- We have assumed the age distribution to follow a normal distribution and match the age distribution of cases observed for Scotland as a whole[30]. (See Appendix). This assumes the same distribution across sub-populations which is unlikely in practice.
- For this model we estimated the proportion of patients diagnosed at each stage by deprivation[6] (See Appendix)

Abbreviations: SIMD, Scottish Index of Multiple Deprivation; PALYs, Potential Additional Life Years

There are also inequalities in treatment after diagnosis

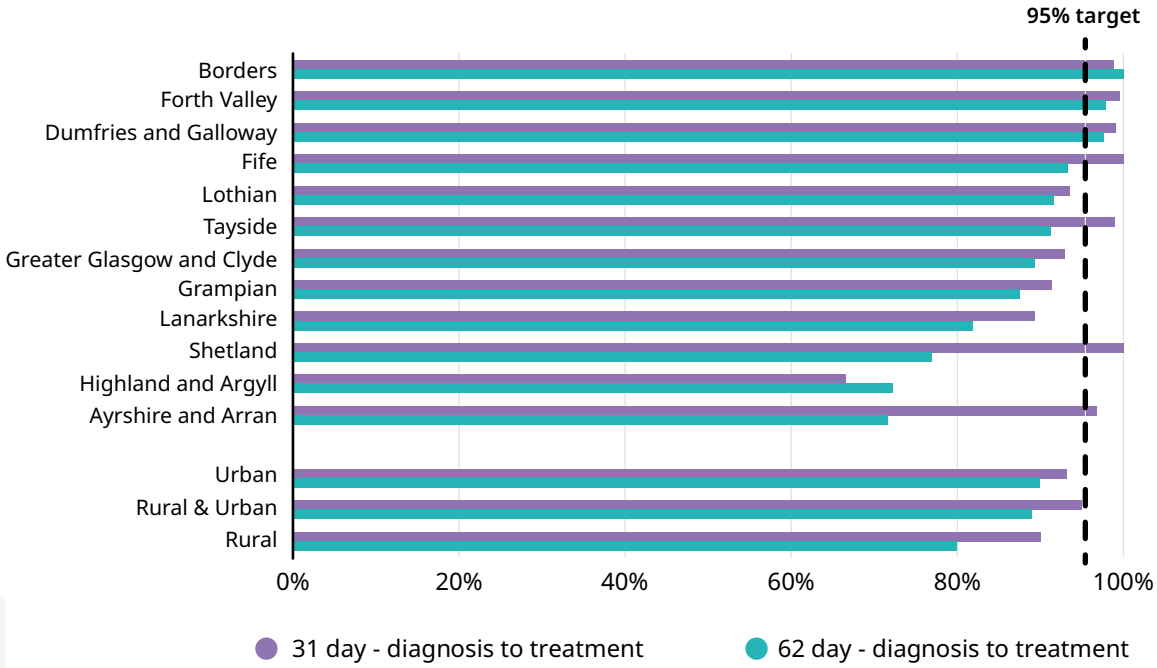
Our analysis of Public Health Scotland cancer waiting time data

No treatment time data is published by deprivation or ethnicity in Scotland

- The official cancer waiting time targets are based on achieving treatment within 31 days of decision to treat and 62-days from urgent referral to first treatment[19].
- In Scotland, the 62-day standard is to treat 95% of eligible patients within 62-days of first referral[19].
- Three health boards met the 62-day target over 2022[8].
- Overall rural health boards met the target less than others (80% compared to ~90%)[8].
- Two health boards had no data due to no patients being eligible for the target in 2022. Both health boards are based in the islands limiting interpretation of the impact of mainland vs. island access to treatment[8].

Publishing waiting time data by geography and deprivation, ethnicity or other demographic characteristics could help health boards and policymakers target and implement interventions to improve treatment times.

Percentage of patients meeting the 31- and 62-day target by health board (2022)[8]



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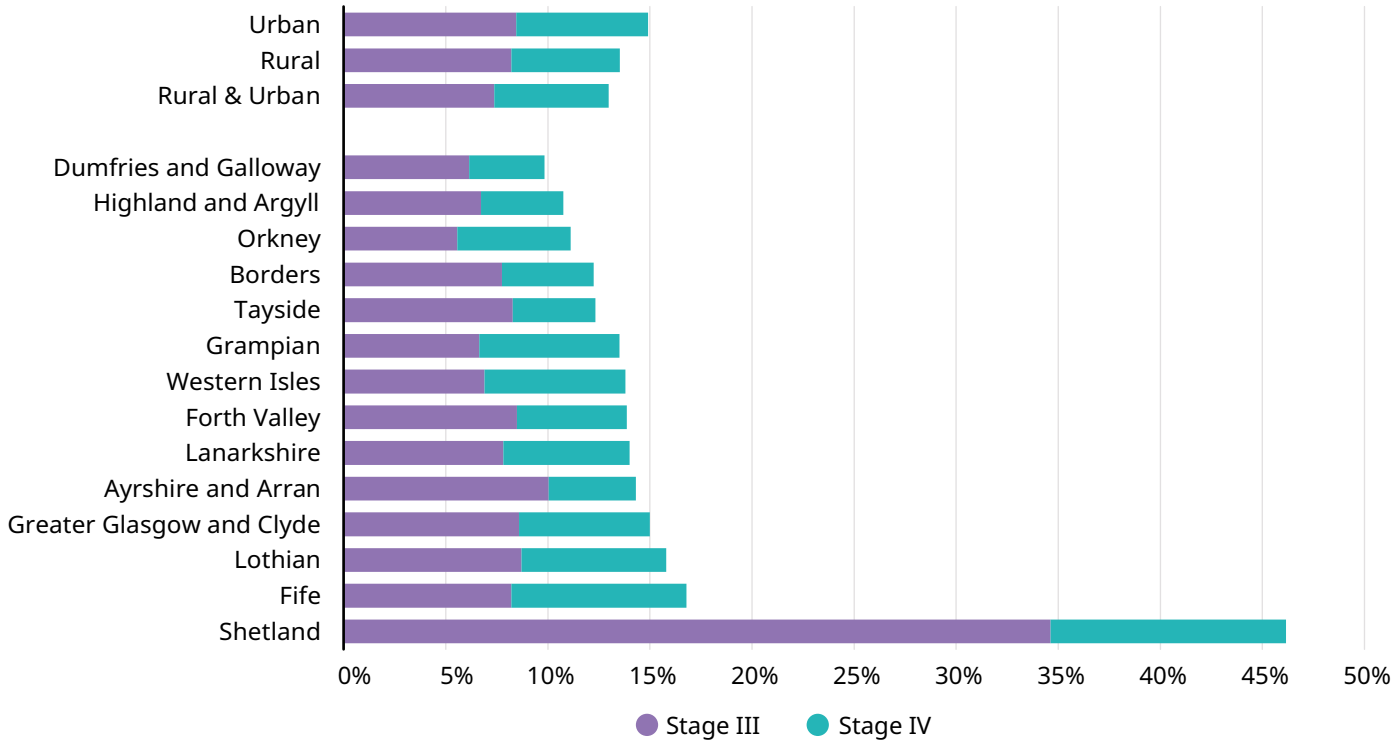
Health boards met the 62-day target over 2022[8]

Geographic inequalities highlighted variation across the country

Late-stage cancer diagnosis mostly varied between 10% and 17% across health boards

Percentage of patients diagnosed with Stage III or Stage IV breast cancer across health boards (2020-2021)[6]



Lack of detailed pathway data by health board limits the understanding of what might be driving these variations. It is important to consider all areas of the pathway and health board characteristics to identify where investment would be most valuable.

Note that Shetland had very small numbers of patients, and hence the large % for this year should be interpreted with caution

Greater Glasgow and Clyde had the highest deprivation[32] and diversity[32] and some of the lowest early-stage diagnosis[6]

Our analysis of health board characteristics and diagnosis pathway

We ranked each health board by percentage of patients; in the most deprived 40%[32], of non-white ethnicity[32] and diagnosed with early-stage cancer[6]. We classified each health board as urban, rural or urban, and rural based on urban-rural classifications[33] (see Appendix).

The health boards are ordered in the table to the right by the overall average ranking for each health board.

- Greater Glasgow and Clyde had the highest deprivation[33] and diversity[32] and one of the four lowest early-stage diagnosis[6].
- The four health boards with highest early-stage diagnosis are rural. The health board with lowest early-stage is also rural, this variability may be due to smaller populations[33].
- Tayside however had the sixth highest deprivation[32] and fourth highest ethnic diversity[32] and one of the highest non-rural early-stage diagnosis[6].

Ranking of health boards by characteristics and stage at diagnosis

Urban, Rural & Urban, Rural[33]	Characteristics of health board[32]		Stage at diagnosis[6]
Low rank (1)	Most deprived	Most ethnic diversity	Lowest % early stage
High rank (14)	Least deprived	Least ethnic diversity	Highest % early stage
Greater Glasgow and Clyde	1	1	4
Fife	4	5	2
Lothian	8	2	3
Lanarkshire	3	7	6
Forth Valley	5	6	7
Ayrshire and Arran	2	12	5
Tayside	6	4	10
Grampian	11	3	9
Shetland	14	8	1
Highland and Argyll	9	9	13
Borders	10	10	11
Dumfries and Galloway	7	11	14
Western Isles	13	13	8
Orkney	12	14	12

Further work should be done to understand what other factors have influenced Tayside's diagnosis pathway to share with similar health boards and to understand what drives variability between rural health boards

The three health boards with the highest overall potential additional life years are Greater Glasgow and Clyde, Grampian and Fife[30]

Modelling PALYs

The PALYs per patient and overall if geographic inequalities were removed by health board.

- Greater Glasgow and Clyde, Grampian and Fife had the highest estimated per patient and overall PALYs on average[30]. These health boards also had higher diversity compared to the majority of health boards[32].
- The link to rurality is less clear in this analysis and indicates there are other drivers affecting stage at diagnosis in these health boards.
- Without additional data on ethnicity it is difficult to comment on the potential impact that may have compared to deprivation.

Detailed route to diagnosis data may help understand what is driving this variation in diagnosis across health boards

Ranking of health boards by PALY[30]

Urban, Rural & Urban, Rural[33]	If stage at diagnosis inequalities removed for... Per patient	Overall
Low rank (1)	Highest PALYs	Highest PALYs
High rank (14)	Lowest PALYs	Lowest PALYs
Greater Glasgow and Clyde	3	1
Grampian	2	3
Fife	1	5
Lothian	4	2
Lanarkshire	5	4
Ayrshire and Arran	6	7
Tayside	9	6
Orkney	7	11
Highland and Argyll	10	8
Forth Valley	12	9
Western Isles	8	13
Borders	13	10
Shetland	11	12
Dumfries and Galloway	14	14

Modelling Methodology

We estimated the number of PALYs if:

- All health boards had the same stage at diagnosis distribution as Dumfries and Galloway (the health board with the lowest percentage of patients diagnosed with Stage IV breast cancer)[6].

Modelling Assumptions

Due to data limitations, we used assumptions to model the estimated survival:

- We estimated the mean survival in years by age and stage by extrapolating NHS England survival data[31] (due to data limitations with Scotland survival data) as detailed on page 26-27. The survival assumptions do not vary between health boards.
- We estimated the number of cases in each health board using the incidence data[30] by age group and health board.
- For this model we estimated the stage at diagnosis proportion of patients diagnosed in each Stage by health board[6]. (See Appendix)

Data gaps and limitations

The analysis carried out relied on the public data published by official bodies such as Public Health Scotland.

These datasets provide a good overview of many elements of the breast cancer pathway and many of the datasets published include analysis by socioeconomic deprivation.

Data is timely (fully standardised data available up to 2021) and the stratifications across nearly all datasets include health board and SIMD. The data made publicly available in Scotland is easy to work with and requires no or very little additional manipulation or mapping. If data gaps could be solved, this ease of analysis could be very powerful in allowing quick and thorough understanding of inequalities.

Publishing data looking at more than one area of inequality though currently technically challenging due to disclosure requirements, would be incredibly valuable – investing in technical capacity would allow the NHS to develop ways to publish such data while still maintaining privacy and confidentiality.

Public Health Scotland should publish data it currently collects to help identify and tackle health inequalities in breast cancer

However, granular data stratified by multiple domains of inequality (e.g., by both deprivation and geography) was often lacking

- Data on ethnicity is lacking throughout Scottish datasets as well as data on additional measures such as co-morbidities, etc. There are data gaps across both nations including limited ethnicity reporting in England but absence of any Scottish data other than deprivation or health board is in stark contrast to the data published in England.
- In contrast to England there is a lack of focus on sub-populations that may suffer worse health outcomes (e.g. homeless people, patients in the justice system). Data for these populations should be collected and considered to ensure a robust and holistic inequalities programme is in place
- Data including more than one stratification (e.g. age and ethnicity) could help provide deeper understanding of inequality drivers, in line with that observed in England.
- Information on the number of patients diagnosed with different tumour markers is limited or lacking, there is very little or no stratification limiting detailed analysis of these patients. Having the data available would allow deeper understanding of the differing treatment pathways patients undergo depending on markers identified.
- Data by route to diagnosis is very valuable to understand where in the pathway patients are entering the system as detailed in the English analysis. This is reported nationally but no additional detail is provided limiting understanding of what is driving cancer inequalities in Scotland.

Other UK nations data

- This report has used Scottish data and some English survival data where not available for Scotland. A similar report has been produced to understand the inequalities in England, based on data publicly available.
- Similar granular data was not accessible for Wales and Northern Ireland at the time of analysis. This variation in what metrics and how it is presented has been highlighted in Cancer Research UK's 2023 Cancer in the UK overview[34] calling for more standardisation across nations to allow analysis.

What can you do to support reducing inequalities?

Patient groups

- Groups such as Breast Cancer Now and Black Women Rising have called out the need for more granular data[26,35]. Ethnicity data is particularly lacking in Scotland which is required to enable needs of all patients to be understood and met.
- Patient groups can help provide deeper understanding of barriers to earlier diagnosis and attending screening.
- Patient groups can help identify and implement solutions to later diagnosis and screening attendance as well as provide insights into what might help improve quality of life to groups most impacted such as black women.

Health board leads

- Health board leads can understand on a local level what areas of the pathway are most pressing for them and make tackling inequalities in breast cancer a priority.
- Data analysts can help to identify inequalities in the breast cancer pathway using locally collected NHS data which, will complement analyses of publicly available data to enrich understanding and tailor investments.

Public Health Scotland

- Where technically feasible, national cancer statistics should be published in a timely way that allows for inequalities in breast cancer to be identified and to allow efforts to tackle these inequalities to be measured and evaluated.
- There should be particular focus on making data that is currently collected available (e.g. ethnicity data and detailed information on referral route by different populations).

Pharmaceutical manufacturers

- Pharmaceutical manufacturers should engage with patients and the NHS to collaborate with and support local areas in tackling breast cancer inequalities.
- By collaborating together manufacturers can help improve access to breast cancer treatments to ensure patients receive optimal benefit from innovative medicines.

Policymakers

- Policymakers should endeavour to implement an overarching health inequalities strategy to help drive focus and innovation. This should aim to capture more than just the most deprived populations, for example groups that might suffer worse health outcomes such as those in contact with the justice system or patients experiencing homelessness.
- The policy should aim to improve collection and access to data for these groups so actionable and targeted initiatives can be implemented to reduce health inequalities.

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The use of our work

In collaboration with Lane Clark & Peacock LLP ("LCP"), and using information gathered from publicly available sources that are believed to be reliable, reasonable efforts have been taken to ensure that the subsequent analysis and derived data and referenced as 'Data on File', are accurate. The data and information in the analysed data set (cited in the reference pack as "Data on File"), are intended for use by persons possessing technical skill and knowledge in epidemiology, surveillance and data management. While every effort is made to ensure the analysed data quality, the data is provided "as is" by LCP. This report is prepared for general information purposes only, does not constitute advice and may not be relied upon by you or any other person. The authors of this report do not give any warranty or guarantee, or make any representation, as to the accuracy or sufficiency of the content of the report. The authors shall have no liability to you or any other person for any losses (whether direct or indirect) arising out of or in connection with such person's use of, or purported reliance upon, the report.

Technical Appendix

Overview

Summary of approach

This analysis relied on publicly available data. Where data was not available simplifying assumptions were made and set out below.

Our approach was to provide a descriptive analysis of variations across the breast cancer pathway for females in Scotland by deprivation, geography (health board and rurality) and ethnicity.

The elements of the pathway described were:
- Route to diagnosis (screening and referral route) – national figures only
- Stage at diagnosis
- Time to treatment

The descriptive analysis aimed to report the data already published, with any data adjustments made to allow for variations in data reporting (e.g. aggregating to higher geographies).

We modelled the potential additional life years (PALYs) if variations in **stage at diagnosis** were removed. To model PALYs we estimated survival by stage and age. To do this we used a parametric survival model to extrapolate NHS survival data covering the first 5 years from diagnosis.

NHS Health Board demographic characteristics

Patient level data was not available, so we characterised the health boards based on publicly available demographic data.

Deprivation was measured using SIMD 2020[32]. This data is reported nationally and by NHS Health Board.

Ethnicity was reported using the 2011 census data (the most up to date census release available at the time of analysis)[34]. We measured 4 broad ethnicity groups: White, Asian, Black and Mixed/Other. The census data was grouped to match these categories for the female population as follows: **White** (encompassing Scottish, Other British, Irish, Gypsy/Traveller, Polish, and Other White), **Asian** (Bangladeshi, Chinese, Indian, Pakistani, and Other Asian), **Black** (African Scottish or African British, Other African, Caribbean Scottish or Caribbean British, Black Scottish or Black British, and Other Caribbean or Black), and **Mixed/Other** (Mixed or multiple ethnic groups, Arab, Arab Scottish or Arab British and any other ethnic group). Similar to deprivation, we estimated the proportion of patients in each ethnicity for the population.

We also categorised each NHS Health Board as rural, urban, or rural & urban, based on the classification by the Scottish Rural Medicine Collective (SRMC)[33]. The 4 NHS Health Boards not included within SRMC were classified as urban, the two NHS Health Boards that have cities excluded were rural & urban, and the 8 remaining NHS Health Boards rural.

Rural

Ayrshire and Arran	Highland
Borders	Orkney
Dumfries and Galloway	Shetland
Fife	Western Isles

Rural & Urban

Tayside
Grampian

Urban

Forth Valley
Greater Glasgow
Lothian
Lanarkshire

Technical Appendix

Overview

Datasets used

We mostly used data from 2021, the most recent year in which comprehensive data was available. We did not use data which only used 2020 data due to the impact of the pandemic but have used 2020-21 data which captures 2021 data as well. Waiting time data was available up to 2022 (full year) and ethnicity data was from 2011 as more recent census data is not currently available.

The age-standardised incidence data is 2021 cancer statistics reported by Public Health Scotland (PHS)[29]. We used mid-2021 population data by 2020 Scottish Index of Multiple Deprivation (SIMD) quintile from the National Records of Service (NRS)[32] to split the national and NHS Health Board populations by deprivation. Population data by ethnicity, both nationally and by NHS Health Board, was obtained from the 2011 census[32].

Incidence rates were split by stage at diagnosis using crude staging data from PHS. We used data from 2021 to split by stage nationally and by SIMD quintile[6]. Staging data by NHS Health Board is reported in two-year intervals, and we used the most recent data from 2020-21[6]. Staging data by ethnicity was not available.

Route to diagnosis data is only available nationally, not split by geography, deprivation or ethnicity. We used PHS route to diagnosis data from 2021[7].

Time to treatment was measured as the proportion of patients treated within the 31- and 62-day targets. The cancer waiting time target data was based on 2022 data from NHS Scotland as this was the most recent full year of data[9].

Although data availability was generally better for Scotland than for England, the authors acknowledge there may be variations in output if more recent data was available; this strengthens the call and need for timely data to allow up to date analysis to be completed.

Geographic aggregation

The geographic analysis was reported at NHS Health Board level. Ethnicity data from the 2011 census was aggregated from local council area level to NHS Health Board level using Area of Residence data from NHS Scotland[32]. All other sources of geographical data were reported at NHS Health Board level, so no further aggregation was needed.

Technical Appendix

Descriptive analysis

Stage at diagnosis by deprivation

We measured the proportion of patients diagnosed with Stage I, II, III or IV cancer.

We reported 2021 data published by PHS on the percentage of cancers diagnosed by stage for the 16 most common cancer types in Scotland[6].

This dataset reports the number of patients diagnosed with breast cancer nationally and by SIMD 2020 deprivation quintile. It reports the number of patients diagnosed in 2021 with breast cancer at stages I, II, III, IV and stage not known. We excluded those with unknown stage (5.9% of patients nationally) from our calculation of the proportions diagnosed at each stage.

We used the same dataset to measure the proportion of patients diagnosed by stage at a national level by aggregating across the deprivation quintiles.

Stage at diagnosis by geography

We reported data from 2020 and 2021 combined on the proportion of patients diagnosed at each stage within each NHS Health Board[6]. As for the splits by deprivation, we excluded patients reported as having unknown stage at diagnosis (3.4% of patients nationally in this dataset).

We calculated the proportion of patients with stages I-IV in each NHS Health Board to determine the number of patients diagnosed by stage and geography. For example, over 2020 and 2021 in Greater Glasgow and Clyde, 1,747 patients were diagnosed with breast cancer Stages I-IV. Of those, 630 patients were diagnosed at stage I (36.1%).

PHS publishes[30] the age-standardised incidence rate per 100,000 for each NHS Health Board. We multiplied these figures by the proportion of patients in each stage to estimate the age-standardised incidence rate by stage and geography.

For Greater Glasgow and Clyde, the age-standardised incidence rate in 2021 was 183.7. We therefore estimated the Stage I incidence rate for Glasgow and Clyde to be 66.3 patients (36.1%x183.7) per 100,000.
We calculated staging distributions by rurality by aggregating across NHS Health Boards using the urban-rural classification on the previous page.

Technical Appendix

Descriptive analysis

Route to diagnosis

We measured the proportion of patients diagnosed by screening, primary care/GP urgent referral, GP other referral, direct referral to hospital, and other routes, as reported in the PHS data[7]. The data reports the number of patients eligible for the 31-day and 62-day referral target and the source of referral per month.

We calculated the proportion of 31-day eligible patients diagnosed by each referral route between January 2021 and December 2021[7]. We used the 31-day measurement as this includes all patients diagnosed regardless of referral route excluding those who die before treatment, refuse treatment or have a clinically complex pathway[28]. Data on route to diagnosis is not available split by geography, deprivation or ethnicity, so we were unable to analyse inequalities across these domains of equity at the screening and referral element of the pathway in Scotland.

To calculate the proportion of English patients diagnosed in each route we used the Route to diagnosis 2018 data published by the National Disease Registration Service[25]. We measured the proportion of patients diagnosed by screening, two week wait, non-urgent GP referral, hospital admission and emergency presentation. The data reported the proportion of patients diagnosed by screening, two week wait, in-patient and out-patient admission, GP referral, unknown, emergency presentation and diagnosis on death. We excluded the patients diagnosed on death or with an unknown route and recalculated the proportion of patients based on the remaining categories. The hospital admission category is the “inpatient elective” and “other outpatient” categories combined[25].

Time to treatment

We measured time to treatment as the proportion of patients meeting the 31- and 62-day target waiting time for treatment nationally and by NHS Health Board.

We used quarterly cancer waiting time data for breast cancer in 2022[8]. This data reports total patients receiving treatment by NHS Health Board and total receiving treatment within the target.

We used 2022 data which was the most recent full year of data; October to December 2022 data was provisional at the time of analysis.

We measured time to treatment by rurality by aggregating across rural, urban and rural & urban NHS Health Boards.

Technical Appendix

Modelling of potential additional life years

Modelling overview

The modelling aimed to estimate the potential additional life years (PALYs) that could be obtained if inequalities in stage at diagnosis were removed.

We estimated the number of patients diagnosed with breast cancer in each stage and age group by deprivation, ethnicity and NHS Health Board ('observed cases') based on current data. To estimate the number of cases by age and stage, we supplemented our calculated staging distributions, which were based on 2021 data, with 2017-21 Public Health Scotland incidence data split into 5-year age bands[30]. We assumed the same age distribution for each stage at diagnosis.

Due to a lack of granular survival data for Scotland, we used survival data from NHS England covering the first 5 years from diagnosis to estimate the survival of patients by age group and stage ('survival assumptions')[31]. We extrapolated the NHS survival data to estimate mean long-term survival in years across age and stage using maximum likelihood estimation and a bespoke parametric survival function based on the Gompertz and log-logistic distributions.

We multiplied the estimated survival by the observed cases by stage and age for each mode to estimate **the expected life years now**.

To estimate the potential additional life years we recalculated the expected number of patients by age and stage if stage at diagnosis inequalities were removed (i.e. if all groups had the same stage at diagnosis patterns as the group with the lowest stage IV diagnosis proportion).

We then calculated the estimated life years based on the survival assumptions for the new distributions of patients and subtracted the expected life years of patients now to calculate potential additional life years.

Technical Appendix

Modelling approach

Observed cases by age

We first estimated the number of patients diagnosed with breast cancer in 2017-21 by age group by NHS Health Board[30]. This dataset is split into 5-year age bands, which we combined to align with the age bands in the NHS England survival data (15 to 44, 45 to 54, 55 to 64, 65 to 74 and 75 to 99). We applied the resulting age distributions to the crude incidence figures for 2021 to estimate the number diagnosed within each age band and NHS Health Board in 2021.

In the absence of similar data by deprivation, we assumed the age distribution within each deprivation quintile is the same as for Scotland nationally. We applied this distribution to the crude 2021 incidence figures by SIMD quintile to estimate the number diagnosed within each age band and deprivation quintile in 2021.

Observed cases by stage

To split the number of observed cases by age and stage we estimated the proportion of patients diagnosed between stage I and IV. As part of the descriptive analysis, we calculated the proportion of patients diagnosed at each stage with breast cancer in 2021 by deprivation quintile[6] and in 2020-21 by NHS Health Board[6].

We multiplied the observed cases by age band by the proportions diagnosed within each stage. This assumes the proportion of patients diagnosed in each stage remains the same across age bands.

For example, we estimated 76 patients were aged 15-44 in the most deprived quintile. Staging data from 2021 indicated 41.4% of patients in the most deprived quintile were diagnosed at stage I. We therefore estimated 32 observed cases in the stage I age 15-44 group in Greater Glasgow and Clyde (41.4% x 76).

As discussed in the subsequent pages, we then multiply this number by the mean survival time for the stage I age 15-44 group to estimate the number of estimated life years now.

We applied the same approach to estimate observed cases by age and stage within each deprivation quintile.

Technical Appendix

Modelling approach

Survival assumptions

In order to estimate the life years across groups we must assign survival by age and stage. As cancer-specific and general population mortality is similar in Scotland and England, we applied the same survival curves we had calculated for England in the calculations for Scotland.

NHS England publishes survival data based on patients diagnosed between 2016-2020. This data provides the percentage of patients who survive 1, 2, 3, 4, and 5 years. As the data is not split simultaneously by stage and age and does not contain survival estimates beyond 5 years, we used statistical analysis to estimate survival fitting the output to the survival data[31].

We used RCRD data from 2022 to split the survival data by age and stage[31], as the RCRD data has an early/late-stage breakdown across a selection of age bands. These age bands don't match those in the survival data (15-44, 45-54, 55-64, 65-74, 75-99), so we estimated the proportion of total and early-stage patients in each age band of the survival data by fitting a normal distribution to the RCRTD data. This was done using maximum likelihood estimation.

Likelihood function

The likelihood function expresses the probability of observing the actual number of patients in each age band, given a normal distribution with unknown mean μ and standard deviation σ. If we denote the cumulative standard normal distribution function by Φ, the age bands by $A\_i = [a\_(i-1), a\_i]$, and the number of patients in age band A_i by p_i, the likelihood function is:

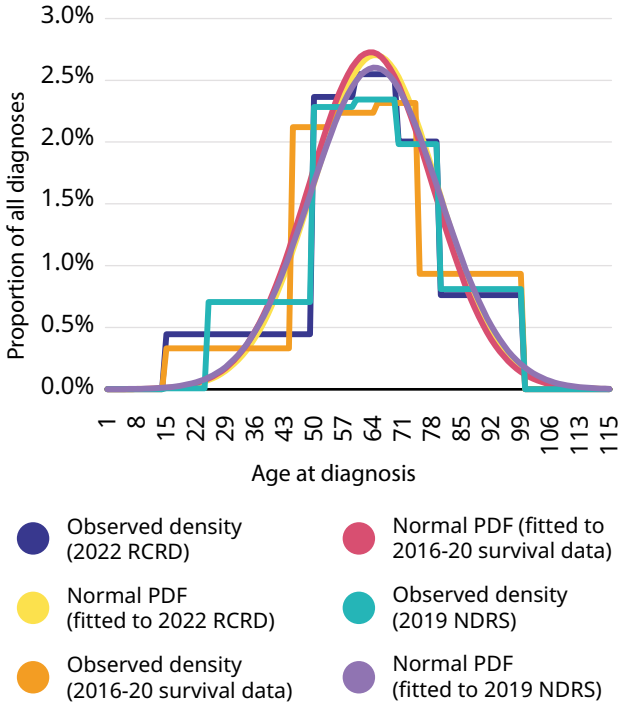
$$L(\mu,\sigma) = \prod_{i=1}^{n} \left(\Phi\left(\frac{a_i - \mu}{\sigma}\right) - \Phi\left(\frac{a_{i-1} - \mu}{\sigma}\right) \right)^{p_i}$$

The log-likelihood function is therefore:

$$l(\mu,\sigma) = \sum_{i=1}^{n} p_i \ln\left(\Phi\left(\frac{a_i - \mu}{\sigma}\right) - \Phi\left(\frac{a_{i-1} - \mu}{\sigma}\right) \right)$$

We used numerical methods to find the values of μ and σ that maximised the log-likelihood function by ensuring its first derivative was zero and its second derivative was negative.

Fitted age distribution (all stages)



We found that a normal distribution was a good fit against all 3 data sources (RCRD, survival data and NDRS).

Abbreviations: RCRD, Rapid Cancer Registration and Treatment Data Dashboard

Technical Appendix

Modelling approach

Survival assumptions

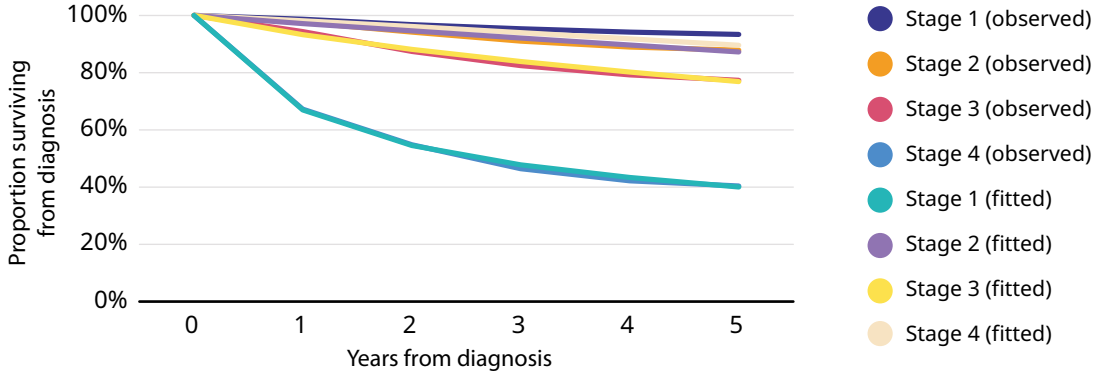
We constructed a bespoke survival function, taking elements from the log-logistic distribution (as a proxy for cancer-specific mortality) and the Gompertz distribution (as a proxy for general population survival) to model short- and long-term survival for breast cancer patients. We used the survival function:

$$S(t,x) = \left(1 - z\frac{t}{\alpha + t}\right)\exp\left(\eta\left(e^{bx} - e^{b(x+t)}\right)\right)$$

where t is time from diagnosis, x is age at diagnosis, "α" is the scale parameter of the log-logistic distribution, b and "η" are the shape and scale parameters of the Gompertz distribution respectively, and z is a parameter that determines the relative weight to be placed on the log-logistic element of the function.

We fitted b and "η" to the ONS 2018-20 UK female life table[31] and fitted "α" and z to the NHS cancer survival data using maximum likelihood estimation to approximate the survival time by age and stage. We checked the resulting curves against the 5-year age and stage data for reasonableness, as shown in the chart below left. The table below right sets out the final estimated mean survival times.

Overall survival by stage



	Mean survival times from diagnosis (years)				
	15 to 44	45 to 54	55 to 64	65 to 74	75 to 99
Stage 1	45	33	25	17	9
Stage 2	43	32	24	16	8
Stage 3	37	27	21	14	8
Stage 4	18	13	10	8	4

Technical Appendix

Modelling approach

Observed cases if inequalities were removed

To estimate the potential additional life years, we estimated the observed cases if the stage at diagnosis matched that of the 'best performing group', where the best performance was determined by the group with the lowest stage IV proportion (least deprived quintile and Dumfries and Galloway).

To calculate the observed cases by age and stage if inequalities were removed, the observed cases by age are multiplied by the proportion in each stage for the best performing group. For example, 44.1% of least deprived patients were diagnosed with stage I breast cancer. For the most deprived group, we therefore estimate that 34 patients (44.1% x 76) are diagnosed with stage I breast cancer at 15-44 if inequalities are removed, compared to the previous 32 (41.4% x 76).

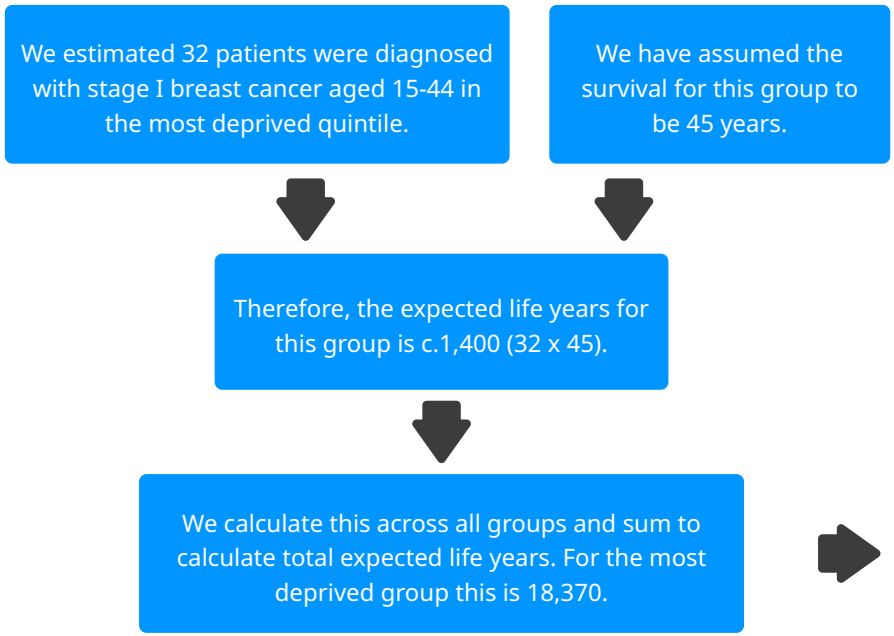
This is calculated across all stage and age bands.

Technical Appendix

Modelling approach

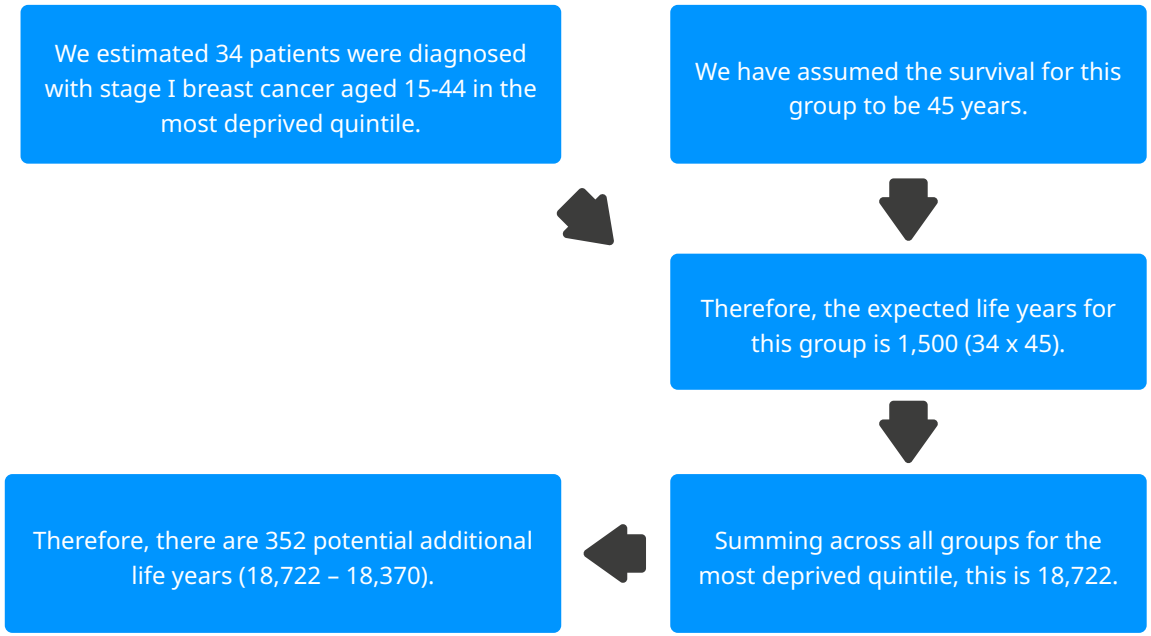
Estimated life years now

To estimate the number of life years given the current diagnosis pathway, we multiply the observed cases by age and stage by the estimated survival. For example, for the stage at diagnosis model:



Potential additional life years

The potential additional life is estimated by multiplying the observed cases if inequalities were removed by the corresponding survival assumption and subtracting the expected life years calculated previously. For example, for the stage at diagnosis model:



This was calculated across geography and deprivation. We also estimated the potential additional life years expected based on deprivation of the health board by multiplying the per patient additional life years for each deprivation quintile by the proportion of patients in each quintile for each health board.

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