



Cecile's story with mitral valve regurgitation

A costed integrated patient scenario (CIPS)

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Introduction

Background

The heart's four valves ensure that blood flows correctly through the heart so that the body can receive oxygenated blood. The mitral valve allows blood to flow from the left atrium to the left ventricle.

Mitral valve regurgitation is a form of mitral valve disease and is one of the most common heart valve diseases worldwide, affecting around 2% of the population.¹

Mitral valve regurgitation (MVR), also referred to as mitral valve insufficiency, occurs when the mitral valve between the two left heart chambers cannot close properly, causing blood to flow in the wrong direction.² In patients with severe MVR, there is a reduction of forward blood flow through the heart and to the rest of the body, leading to symptoms of fatigue and breathlessness.²

Many people with MVR are unaware of their condition because the disease can progress slowly.^{1,2} As a result, people can remain asymptomatic for many years.^{1,2} However, in some patients, MVR develops rapidly, causing sudden signs and symptoms.²

There are two types of MVR. Primary MVR, sometimes referred to as degenerative MVR, is caused by an abnormality in the leaflets or chords of the valve.¹ Secondary MVR, sometimes called functional MVR, is caused by an abnormality of the left atrium or the left ventricle, usually causing dilatation, which results in the mitral valve not closing properly.¹ A clinician may detect MVR in a patient by conducting a chest and heart auscultation. A transthoracic echocardiogram, or standard echo, is used to confirm a diagnosis of MVR, to determine its severity and to understand its effect on overall cardiac function.³

MVR can be treated medically or surgically.¹ However, medical therapy only helps with symptom management and does not slow disease progression.¹ Therefore, most patients with severe MVR require mitral valve intervention, which can be surgical (mitral valve repair or mitral valve replacement) or by mitral valve transcatheter edge-to-edge repair.¹

The choice between mitral valve repair or replacement depends on factors such as risk of MVR recurrence and postprocedural morbidity and mortality.^{1,4-6}

Cahill et al. estimated community prevalence of moderate to severe MVR among adults ≥ 65 years to be 3.5%.⁷ Using this model in combination with Office for National Statistics (ONS) and Hospital episode statistics (HES) data, we can predict the number of people with moderate to severe MVR in England and determine how many people with MVR are diagnosed and treated.

Due to HES limitations, it is not possible to determine severity of MVD, limiting our understanding of how many patients diagnosed would meet criteria for treatment. However, Cahill's model allows us to estimate yearly incidence of moderate to severe MVR in England, which shows that 5,059 patients in England meet the criteria for treatment each year (Table 1). However, HES data demonstrates that only 39% of these patients are receiving treatment (Table 1).

HES does not code for MVD severity. Due to this limitation, some patients reportedly diagnosed with MVR may not meet the criteria for treatment.

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An estimated 61% of patients with moderate to severe MVR in England have not received necessary treatment.

Table 1. Headline prevalence, incidence, diagnosis and treatment figures for MVD in England 2017 – 2021.⁷⁻⁹

Prevalence estimate (population aged ≥ 65 years)^{7,8}		
Moderate to severe MVR (mid-2020)	366,240	total
Annual incidence estimate (population aged ≥ 65 years)^{7,8}		
Moderate to severe MVR - annual average (mid-2017 to mid-2020)	5,059	per year
Diagnosis⁹		
MVR* (2017-2021)	261,895	total
MVR* - annual average (2017-2021)	64,360	total
Treatment⁹		
Mitral valve replacement (2017-2021)	3,770	total
Mitral valve repair (2017-2021)	6,265	total
Mitral valve replacement or repair (2017-2021)	9,850	total
Mitral valve replacement/repair - annual average (2017-2021)	1,970	per year
Annual average treated versus annual average diagnosed	3%	per year
Estimated treatment rate⁷⁻⁹		
Patients treated with mitral valve replacement or repair annually versus annual estimated incidence moderate to severe MVR aged ≥ 65 years.	39%	

**Note that mitral valve insufficiency is the term used by HES for mitral valve regurgitation (MVR).*

There is a disparity between the numbers of those diagnosed and those treated for mitral valve disease (MDV).⁹ There were 261,895 people diagnosed with MVR* between 2017-2021, though only 9,850 patients were treated with either mitral valve repair or replacement during this same period (Table 1).

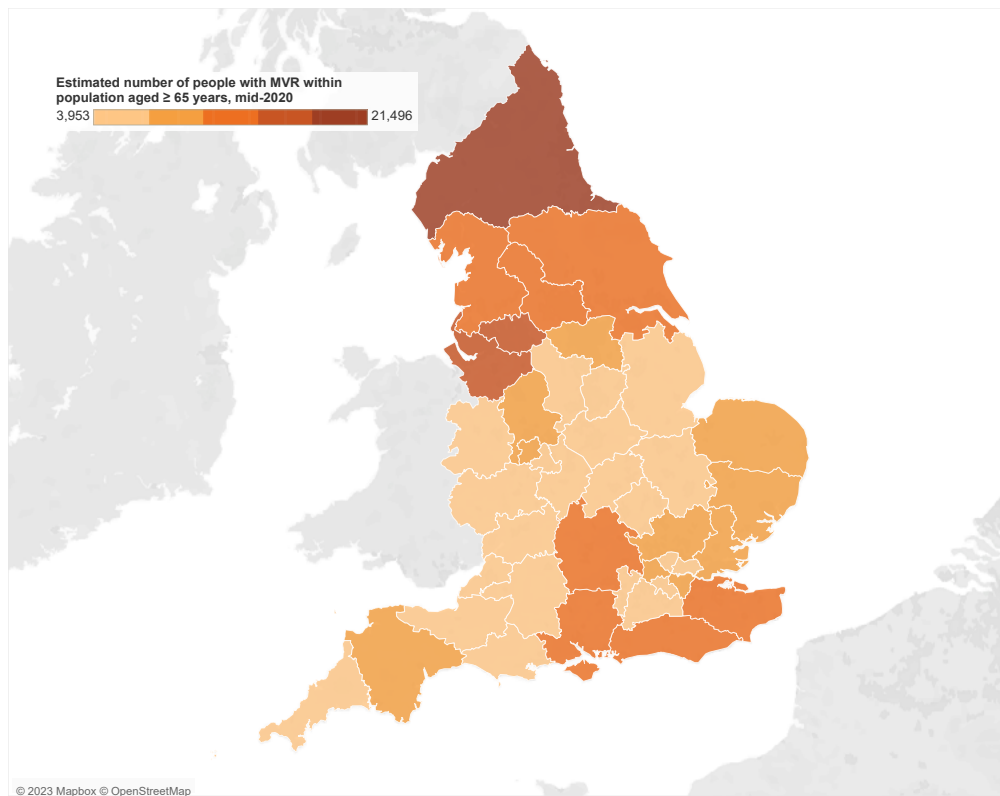
Because HES does not code for MVR disease severity, we cannot determine if the diagnosed patients have moderate to severe MVR. Although the data suggests nearly 13x more patients are diagnosed annually than the estimated incidence of moderate to severe MVR, it is unclear if the system is

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identifying and diagnosing the right patients for treatment – those with moderate to severe MVR.

Figure 1 demonstrates the distribution of MVR in England by Integrated Care System (ICS).

Figure 1. Estimated number of people with MVR within the population ≥ 65 years by ICS, mid-2020 based on Cahill model and ONS.^{7,8}

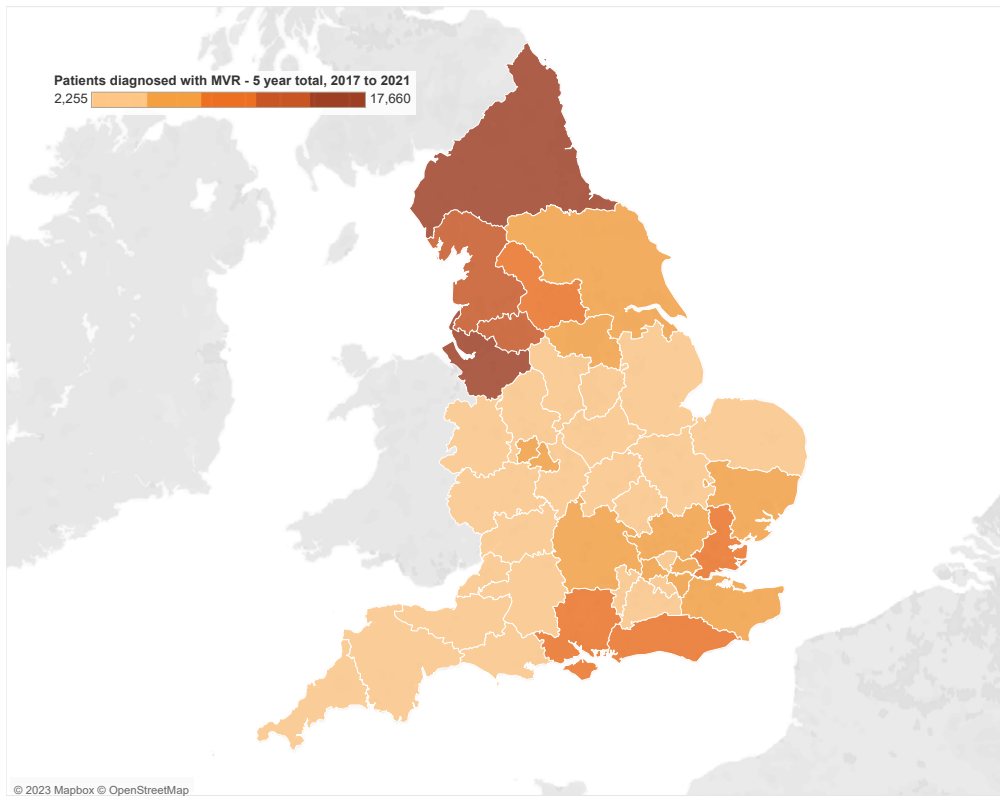


The largest number of people with moderate to severe MVR are estimated to be in the north and southeast regions of England.⁷

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Figure 2 illustrates the number of patients diagnosed with MVR in England by ICS based on Hospital Episode Statistics (HES).⁹

Figure 2. Patients diagnosed with MVR* by ICS: 5-year total for 2017-2021.⁹



**Note that mitral valve insufficiency is the term used by HES for MVR due to ICD-10 code terminology. See appendix 2 for the full list of ICD-10 codes used.*

The largest number of patients diagnosed with MVR are in England's north and southeast regions. However, in some ICSs there were fewer people diagnosed with MVR between 2017-2021 than there were estimated people with moderate to severe MVR, implying that some patients in England remain undiagnosed.⁷⁻⁹

For example, within the Kent and Medway ICS, there are an estimated 12,880 people with moderate to severe MVR, yet only 5,970 patients were diagnosed between 2017-2021.⁷⁻⁹ This indicates that up to 54% of patients with MVR in Kent and Medway ICS may not have an appropriate diagnosis. Data limitations in HES may also contribute to this observation.

There also exists variation in patient treatment across deprivation level and by sex in England.



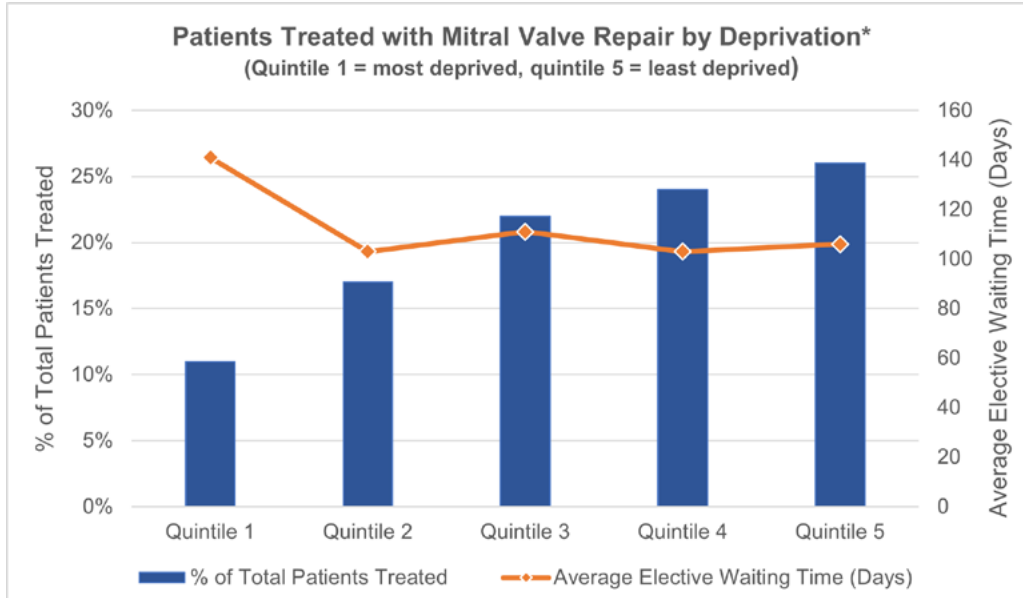
Patients who live in areas of high deprivation are less likely to receive mitral valve repair than patients who live in areas of low deprivation.⁹



People living in the most deprived areas in England are more likely to experience longer elective waiting times than those living in less deprived areas.⁹

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Figure 3. Percentage of patients treated with mitral valve repair and average elective waiting times (days) by deprivation: 5-year average, 2017-2021. Quintile 1 (Q1) = most deprived, quintile 5 (Q5) = least deprived.⁹

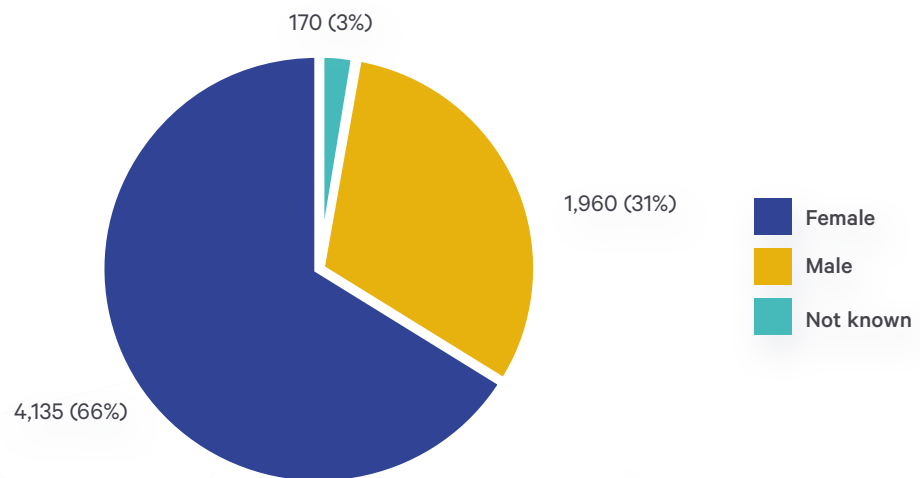


*Deprivation is measured by the Index of Multiple Deprivation (IMD), as published in the English Indices of Deprivation 2019. Patients are split into quintiles based on the level of deprivation within the Lower layer Super Output Area (LSOA) level of the patient's residence (where quintile 1 = most deprived and quintile 5 = least deprived).



Males are more than twice as likely to receive mitral valve repair as females.⁹

Figure 4. Patients treated with mitral valve repair by sex: 5-year total, 2017-2021.



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Variation in MVR treatment across England is a multifaceted issue. For example, though many heart centres perform mitral valve repair,¹⁰ travelling to heart centres may be more difficult for those in areas of high deprivation than for those in low deprivation. Additionally, each referral and heart centre are likely to have different patient pathways, including pathways to diagnosis, referral and treatment.

There are documented differences in diagnostic testing and treatment of MVR in women compared to men.¹¹ Women are more likely to receive mitral valve replacement than surgical repair and have worse outcomes with mitral valve surgery than men.¹¹ Additionally, surgical guidelines may not be sex-specific or indexed to body size.¹¹

To ensure all patients with moderate to severe MVR receive equitable access to treatment, streamlined patient pathways must be put in place across the UK. Left undetected or untreated, MVR could cause worsening heart failure and premature death.¹² Additionally, commissioners and service designers must ensure there are no biases toward gender nor deprivation when developing care pathways.

The data presented in this report indicate the presence of barriers to treatment for patients with MVD. Increased awareness of moderate/severe MVD and better methods for pathological murmur detection in the community are needed. A greater systems-level understanding of what is required to treat the burden of moderate/severe MVR needs to be established when designing integrated systems and pathways. Additionally, sex and deprivation biases must be considered when designing pathways of care.

Analysis Style

This case study uses a Delphi-style consensus process involving experts in this specialist field alongside an economic analysis methodology. This has been developed using fictitious, but realistic, patient journeys which are compared to highlight potential care improvement opportunities.

Use of behavioural methodology drives engagement through the combination of objective clinical data, clinical expertise and financial analysis wrapped in a journalistic style. The study includes prompts for commissioners and service transformation leads to consider when evaluating their local health economy.

The goal is to inspire more stakeholders to take note and act towards positive change by thinking strategically and collaboratively about engagement, education and designing optimal care for people with mitral regurgitation.

Look out for black boxes to see suboptimal pinch points in many pathways throughout the country.

Look out for purple boxes to see standard or reasonable practice based on a consensus of the specialists.

Look out for blue boxes to see best practice points. In some cases these may be beyond current recommended practice but trialled in some care pathways across the country.

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In this scenario, we use the fictional patient Cecile to compare a suboptimal patient pathway with an optimal patient pathway within the current NHS landscape.

At each stage of the pathway, we have modelled the costs of care, not only financial to the local health economy, but also the impact on the patient and their family's experience.

This document is intended to help commissioners and providers understand the implications, both in terms of quality of life and costs, of different care pathways for individual patient needs and expectations, particularly for patients with MVR.

This method demonstrates how changes in treatment and management can help clinicians and commissioners improve the value and outcomes of the care pathway.

Timeline justification

While the timeline for Cecile's patient journey occurs during the COVID-19 pandemic, careful considerations were made by the expert clinical group to not include delays in the patient journey that would have occurred due to actions taken by NHS England during the pandemic. For example, Cecile attends a face-to-face cardiology appointment in May 2020. We acknowledge that this appointment may have been delayed due to the pandemic, but for the purpose of keeping this document relevant, we have used realistic timelines in the patient journey suitable to both pre- and post-pandemic.

The document holds true in the current NHS climate and contains contemporary best practice that resulted from, or was expedited by, the pandemic. For example, Cecile attends virtual GP appointments before she is asked to be seen in person, and her cardiac rehabilitation involves a facilitated home-based programme. Therefore, it was inappropriate to consider Cecile's journey pre- pandemic and thus the timeline used is August 2019 – August 2022.

Meet Cecile

- Cecile is a 70-year-old woman who lives in York with her husband, who is 78. She and her husband emigrated to the UK from Poland 35 years ago. They speak Polish at home, and as English is not their first language, they sometimes find communication about medical matters to be difficult.
- Cecile previously worked as a school dinner lady, but she and her husband have now been retired for five years. They live off private and state pensions and have few savings.
- Cecile has a daughter who is a single parent with two young children, ages two and four. Cecile helps her daughter with childcare twice a week so that her daughter can work. Cecile very much enjoys spending this time with her grandchildren. They play lots of games outside at the local park.
- Cecile used to smoke when she was younger but quit once she had her daughter. She enjoys a couple of glasses of sherry in the evening and enjoys going for walks outdoors. However, walking has left her feeling breathless recently, so she's been going less often. She also has mild chronic obstructive pulmonary disease (COPD), for which she sees her GP occasionally during winter.
- Cecile volunteers for the local Women's Institute twice a week and has many friends there. She enjoys being sociable and doesn't like to be alone. She feels the most herself when she's making others laugh and smile.
- Her husband has type 2 diabetes and is not very active. Therefore, Cecile is responsible for doing most of the housework and cares for him when he is unwell.



Cecile's goals and values



- **Enjoy an active retirement**
- **Volunteer at the Women's Institute**
- **Spend quality time with her grandchildren**
- **Support her daughter the best she can**

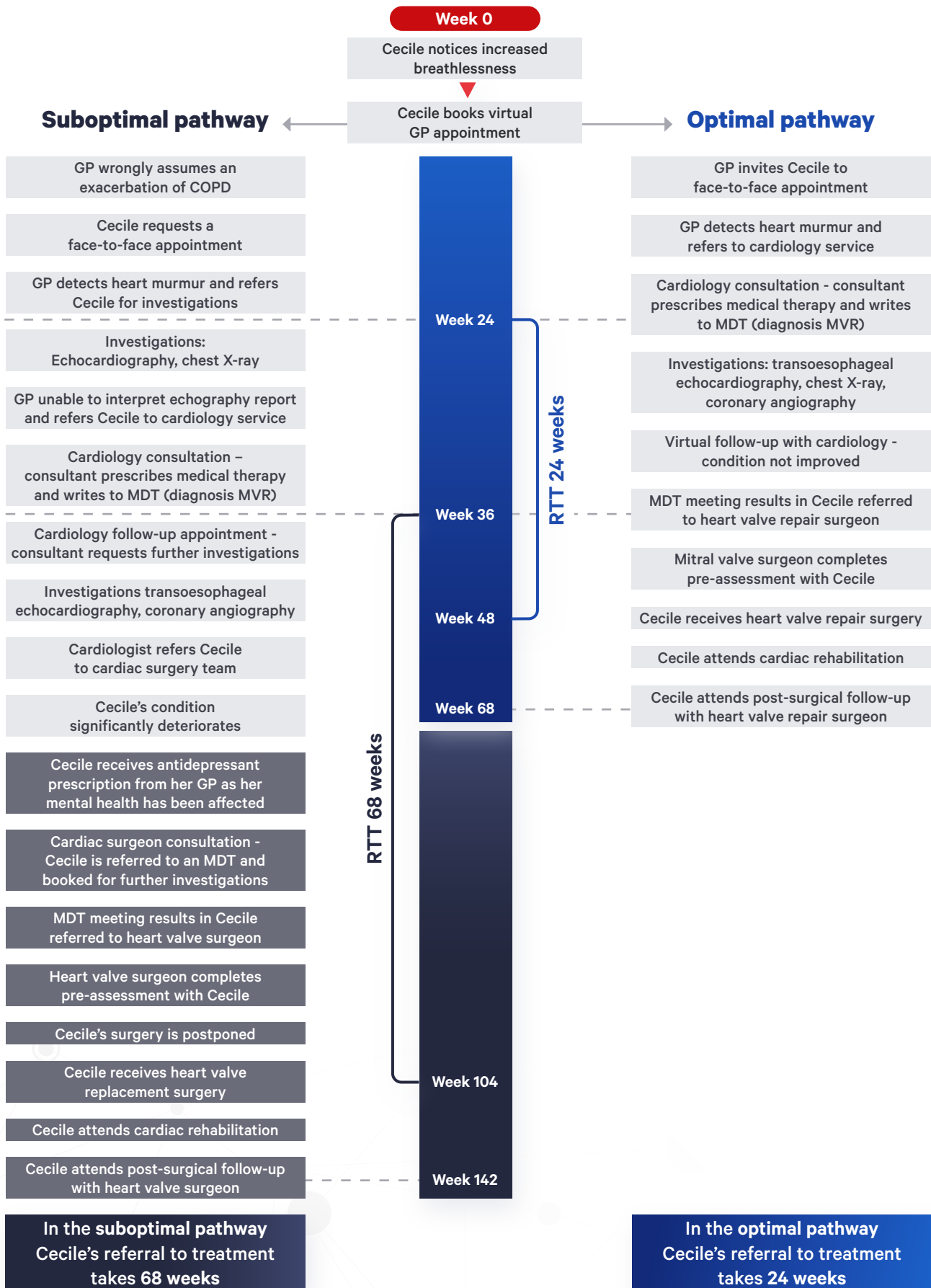
Cecile's challenges



- **English is her second language**
- **Financial instability**
- **Mild COPD**
- **Becoming less active due to breathlessness**
- **Caring for her husband**

Pathway overview:

Figure 5. Summary schematic of Cecile's optimal and suboptimal pathways with approximate timeline.



Cecile's experience with MVR

In August 2019, Cecile noticed she was frequently feeling tired and getting out of breath, particularly when she was going for her daily walk. She thought this was probably just old age and didn't want to bother her GP, as they're always so busy. Plus, she gets nervous and self-conscious because English is her second language and articulating symptoms can be difficult.

Real-life patient stories documented by Heart Valve Voice indicate that signs and symptoms of HVD can go unnoticed by patients. Patients might also assume their symptoms are normal signs of ageing.¹³

Both of Cecile's pathways start this same way, with a GP appointment. However, the difference in the suboptimal and optimal journey starts here, in primary care management.

By October, Cecile's breathlessness had become worse, so she decided to book an appointment to see her GP at the request of her husband.



Suboptimal (average) management pathway

GP telephone consultation (November 2019)

Cecile had a telephone consultation with her GP. Given her history of COPD, the GP assumed she was having an exacerbation and prescribed antibiotics.

 Amoxicillin 500 mg three times daily for one week


GP assumed COPD and did not ask about additional relevant symptoms

GP prescribed antibiotics unnecessarily

A week later, Cecile's breathlessness had not improved. She called to arrange another GP appointment, worrying the antibiotics had not worked as intended.

GP telephone consultation (December 2019)

Cecile had another telephone consultation with her GP and was prescribed an alternative antibiotic for one week. She felt she was unable to convey her symptoms fully to the GP.

 Doxycycline 200 mg once daily for one day followed by 100 mg once daily for six days

GP wrongly assumed COPD and prescribed more antibiotics

Cecile still noticed no improvement in her breathlessness after a week on the new antibiotic. She felt guilty requesting a face-to-face appointment, but with encouragement from her husband she phoned her GP and asked to be seen in person for examination.

Suboptimal (average) management pathway

GP face-to-face appointment (December 2019)

At the face-to-face consultation with a different GP, Cecile tried to explain her symptoms. The GP carried out chest and cardiac auscultation after noting peripheral oedema and detected a heart murmur. Cecile was referred for an echocardiogram (echo) and chest X-ray in the community.

GP carried out chest and cardiac auscultation

By the end of February 2020, Cecile had reduced any exertion and overall had become less active. She still felt poorly but was hesitant to bother the NHS with her worsening symptoms. She felt slightly reassured knowing she was referred for further testing instead of being put on another antibiotic.

Echocardiography and chest X-ray (February 2020)

Cecile attended a local clinic for an echo and chest X-ray.

Multiple investigations scheduled for same appointment

Community echocardiogram report (March 2020)

Please visit page 9 for justification and explanation of the timeline used.

A community echo report was issued, but it was a technical report, and the GP didn't feel they could appropriately interpret the findings. The GP referred Cecile to Cardiology at the district general hospital (DGH), prescribed a diuretic, and advised her to avoid demanding exercise due to her increased breathlessness.



Furosemide 20 mg once daily for one month

GP not comfortable interpreting the technical echo report

GP referred Cecile to Cardiology and prescribed a diuretic

Later in March 2020, Cecile started to feel that her symptoms were improving a little while on the diuretic. She received a repeat prescription of furosemide after a follow-up call with her GP.

Suboptimal (average) management pathway

Cardiology consultation (May 2020)

Cecile was seen by a cardiologist at the local DGH. The echo was interpreted as moderately severe mitral regurgitation with well-preserved left-ventricular (LV) systolic function.

Cecile was prescribed more furosemide at a higher dosage and the cardiologist advised her GP to start her on the angiotensin-converting enzyme (ACE) inhibitor ramipril. She was booked for a follow-up appointment in 3 months' time. The consultant wrote to Cecile's GP to continue the prescriptions and advise ramipril.



Furosemide increased to 40 mg once daily

In April 2020, Cecile's husband contracted coronavirus disease 2019 (COVID-19). With careful isolation, Cecile avoided the infection.

By July, Cecile had noticed that her ankles were less swollen, but she was still feeling breathless and was becoming less and less active with time. Her husband was experiencing persistent symptoms after his episode of COVID-19 and had limited mobility. He was increasingly relying on Cecile for support, which was getting more and more difficult for her as time went on.

Cardiology follow-up appointment (August 2020)

Cecile attended her follow-up appointment with the cardiologist at the DGH, who noted that she was still deteriorating. An ECG and repeat echo were performed in the clinic. Coronary angiogram and transoesophageal echo (TOE) tests were arranged to assess her condition. The consultant advised her GP to start ramipril again, as Cecile mentioned that this had not yet been started.



Ramipril 1.25 mg once daily for two weeks, then 2.5 mg on an ongoing basis

**Consultant
advises GP to
start ramipril**

Suboptimal (average) management pathway

Transoesophageal echocardiography (October 2020)

Cecile attended the DGH for TOE, which indicated severe mitral valve regurgitation. It was noted that her LV function had worsened since the community echo.

Length of pathway results in reduced LV function

Coronary angiography (November 2020)

Cecile attended the DGH as a day case for her coronary angiogram, which showed normal coronary arteries. The cardiologist at the DGH referred her to the cardiac surgery team at a tertiary centre.

Later in November, Cecile was still breathless and finding it increasingly difficult to care for herself and her husband. She felt she would soon need assistance, and the local authority conducted a needs assessment for them both. She was also no longer able to support her daughter with childcare.

By December, Cecile's husband had become very worried about her and was concerned about the extra pressure on her from having to look after him while he still was struggling with symptoms of long COVID. He was frustrated with the amount of time it had taken for Cecile to meet with the cardiac surgery team. He convinced Cecile to speak to her GP and she called to book a face-to-face appointment. At this point, she and her husband start receiving care assistance, and a carer visits once a week for 30 minutes to help with housework.

Suboptimal (average) management pathway

GP face-to-face appointment (January 2021)

Cecile attended the face-to-face GP appointment. She explained that she was breathless and weak. Her mental health and wellbeing were significantly affected, as the multiple hospital and GP visits were taking a toll on her. She also was not as active as she once was, which was very disappointing to her. She felt she was letting down her husband and her daughter as she required assistance in the home and could no longer help her daughter with childcare.

The GP wrote to the cardiac surgery team to request a follow-up appointment and that Cecile's surgery consultation appointment be expedited. The GP continued Cecile on 2.5 mg ramipril and increased furosemide due to increased breathlessness. After discussing options, the GP also prescribed the selective serotonin reuptake inhibitor (SSRI) antidepressant sertraline to be taken on an ongoing basis through repeat prescriptions.



Furosemide increased to 80 mg once daily'

Sertraline 50 mg once daily

Repeat hospital visits, travel and less active lifestyle take a toll on Cecile's mental health

Cardiac surgeon consultation (February 2021)

Cecile attended the DGH for an appointment with the cardiac surgeon. The team referred Cecile to an MDT to discuss suitability for surgery versus transcatheter intervention. She was booked in for another echo to assess her LV function and for pulmonary function tests.

Cecile referred to MDT to determine suitability for surgery

Getting it right the first time (GIRFT) recommends that candidates for mitral valve surgery should be seen by an MDT for consideration.¹⁴

Suboptimal (average) management pathway

Echocardiography (March 2021)

Cecile attended the DGH for an echo, which indicated severe mitral valve regurgitation and reduced LV function.

Length of pathway results in reduced LV function

Hospital MDT meeting (April 2021)

After the MDT meeting was pushed back a few times, partially due to imaging delays, Cecile's case was assessed by an MDT and previous investigations were reviewed. She was thought to be most suited for surgery and so was referred to the heart valve surgeon who attended the MDT, to be seen in clinic.

Imaging delays push back the MDT meeting

Referral to heart valve surgeon in MDT and not one specialised in mitral valve repair

Heart valve surgeon consultation (July 2021)

Cecile attended a consultation at the DGH with the heart valve surgeon, who reviewed the most recent echo and coronary angiogram, took a chest X-ray and organised routine bloods tests.

Surgeon schedules Cecile for surgical valve replacement rather than repair

Suboptimal (average) management pathway

Cancelled heart valve replacement surgery (November 2021)

Cecile was admitted at the tertiary centre for her heart valve replacement with a xenograft, but a lack of beds on the intensive care unit (ICU) meant that her surgery was cancelled and rescheduled for the next available slot. Hours of the surgeon's and anaesthetist's time were wasted waiting to see if a bed would open up. Cecile is noted to be in atrial fibrillation (AF) and started on edoxaban.

Cecile was sent home. She felt defeated and down about the whole process. She had such high hopes that the surgery would give her back her old life and was frustrated that she still couldn't do the things that made her happy, like volunteering for the Women's Institute and looking after her grandchildren. At this point she and her husband require even more help at home and a carer comes in 2x a week for an hour to help with cleaning and preparing meals.



Edoxaban 60 mg daily

Surgery cancelled after Cecile was prepared for surgery

Length of pathway results in deterioration and onset of AF

Rescheduled mitral valve replacement surgery (January 2022)

Cecile attended the surgical centre for her rescheduled mitral valve replacement. Her recovery was slow, and she was an inpatient for 9 days. Edoxaban was stopped and Cecile was started on warfarin* and digoxin. She underwent a pre-discharge echo and was referred for a medical therapy optimisation appointment and cardiac rehabilitation prior to discharge.



4 weeks of analgesia (codeine 30 mg four times daily, paracetamol 1 g four times daily, and ibuprofen 400 mg three times daily)

Warfarin 5 mg once daily

Digoxin 0.25 mg once daily

No surgical intervention for AF

Mitral valve replacement rather than mitral valve repair by a specialist mitral surgeon

Referral to cardiac rehabilitation

*Some UK surgeons will convert to warfarin post-operatively

Suboptimal (average) management pathway

Cecile was still recovering from surgery in February. This had been difficult, as her condition had been worsening leading up to the procedure, and she'd become progressively frail in the past year and a half. Cecile was still very down and continued to take the SSRI to help cope with her depression. She booked a face-to-face appointment with her GP to discuss her ongoing concerns.

Her husband is unable to support her during recovery and they receive a short-term increase in care assistance. A carer visits four times daily for six weeks to help with cleaning, cooking and maintaining necessary hygiene.

Medical therapy optimisation appointment (February 2022)

Cecile attended the arranged medical therapy optimisation appointment with a heart failure nurse. She was continued on furosemide and her ramipril dose was increased. Cecile also attended cardiac rehabilitation appointments as per the referral she received after her operation.



Ramipril increased to 7.5mg once daily

GP face-to-face appointment (February 2022)

The GP advised Cecile to raise her concerns at her follow-up appointment with the surgeon. In the meantime, the GP prescribed digoxin and the direct oral anticoagulant edoxaban on an ongoing basis. She stops taking warfarin.



Digoxin 0.25 mg once daily

Edoxaban 60 mg once daily

GP advises Cecile to discuss related concerns with heart valve surgeon at follow-up appointment

Post-surgical follow-up (April 2022)

Cecile's condition was reviewed by the surgeon at her post-surgical follow-up appointment. She underwent post-surgical echo, was continued on digoxin and edoxaban.



Digoxin 0.25 mg once daily

Edoxaban 60 mg once daily

Suboptimal (average) management pathway

Cardiac rehabilitation (June 2022)

Cecile completed her cardiac rehabilitation programme.

As of August 2022, Cecile continues to recover but has reduced LV function, AF and struggles with depression. She feels like she is letting down her family, as she cannot look after the grandchildren as she used to, or join in with their games when they visit. She feels like she and her husband are missing out on the happy retirement they had planned because of her continuing health issues and depression. She attends annual face-to-face cardiology/valve clinic review appointments. She and her husband continue to receive care assistance twice a week for an hour.

While we've ended Cecile's patient journey and associated costs here, it's important to acknowledge that there would realistically be continued costs associated with her condition. Notably, she now has AF, reduced LV function and depression. It is difficult to predict what these costs might be, but they would be a continued additional burden on the NHS. Furthermore, she and her husband require care assistance and she's unable to help her daughter with childcare, both contributing to economic cost to the wider system.

Now let's look at an optimal journey for Cecile, starting with her first GP appointment and see how things could go differently.

Optimal management pathway

In August 2019, Cecile noticed she was frequently feeling tired and getting out of breath, particularly when she was going for her daily walk. She thought this was probably just old age and didn't want to bother her GP, as they're always so busy. Plus, she gets nervous and self-conscious because English is her second language and articulating symptoms can be difficult.

By October, Cecile's breathlessness had become worse, so she decided to book an appointment to see her GP at the request of her husband.

GP telephone consultation (November 2019)

Cecile had a telephone consultation with her GP, who asked about peripheral oedema when she explained she felt breathless. The GP scheduled a face-to-face appointment to examine her and prescribed an antibiotic in case she was having an exacerbation of COPD.



Amoxicillin 500 mg three times daily for one week.

GP asked about peripheral oedema and scheduled face-to-face appointment for examination



During this first GP consultation, the GP is aware of the differential diagnoses (respiratory/cardiac) and asks Cecile to come in for a face-to-face appointment for chest and heart auscultation.

A week later, Cecile's breathlessness had not improved while being on antibiotics.

GP face-to-face consultation (December 2019)

Cecile's GP carried out a chest and heart auscultation and detected a heart murmur. The GP referred her to the local cardiology service at the district general hospital (DGH) for a further opinion, prescribed the diuretic furosemide and referred her for a chest X-ray.



Furosemide 20 mg once daily

Heart murmur detected through heart auscultation

Referrals for chest X-ray and to Cardiology for further opinion

Diuretic prescribed

Optimal management pathway

Later in December, Cecile was feeling slightly better, but she was still breathless on exertion. She and her husband thought the medication was helping a little but still had concerns and wanted to do more.

Chest X-ray (December 2019)

Cecile attended the DGH for a chest X-ray.

Cardiology consultation (February 2020)

Cecile attended her appointment with the cardiologist at the DGH. Severe mitral valve regurgitation was diagnosed by auscultation and confirmed by an echo during the appointment. The cardiologist continued the trial of medical therapy, increasing furosemide and starting the ACE inhibitor ramipril until next clinical review. A follow-up appointment was arranged in 2 months' time and TOE and coronary angiogram were organised. The cardiologist also wrote to the MDT for an opinion about Cecile's case.



Furosemide 40 mg once daily

Ramipril 1.25 mg once daily

Trial of medical therapy before considering surgery, with follow-up in two months

Referral to MDT to determine suitability for surgery

In April 2020, Cecile's husband contracted coronavirus disease 2019 (COVID-19). With careful isolation, Cecile avoided the infection.

Transoesophageal echocardiography (April 2020)

Cecile attended the DGH for a TOE in the valve clinic.

Please visit page 9 for justification and explanation of the timeline used

Coronary angiography (April 2020)

Cecile attended the DGH as a day case for her coronary angiogram.

Cardiology telephone follow-up (April 2020)

Cecile had a follow-up appointment over the phone with the cardiologist at the DGH, who noted that Cecile's condition had not improved.

All investigations completed

Hospital MDT meeting (May 2020)

The MDT discussed Cecile's case at the first opportunity and decided to refer her for surgery. She was booked in to see a valve surgeon able to undertake mitral valve repair.

MDT meets shortly after investigations, which are within appropriate timeframe, for consideration

The MDT assess Cecile fit for heart valve repair and refer her to a specialist mitral valve surgeon

Mitral valve surgeon consultation (May 2020)

Cecile saw the specialist mitral valve surgeon in the surgical clinic and was booked in for surgery. Blood work, pre-assessment and anaesthetic pre-assessment were completed during the same appointment. She was booked in for a baseline echo.

All required pre-surgical tests and assessments completed during surgical consultation

Optimal management pathway

Echocardiogram (July 2020)

Cecile attended for an echocardiogram at the surgical centre as a baseline before her mitral valve surgery. This showed severe mitral regurgitation but preserved LV function.

By July, Cecile had noticed that her ankles were less swollen, but she was still feeling breathless, was becoming less and less active with time. Her husband was experiencing persistent symptoms after his episode of COVID-19 and had limited mobility. He was increasingly relying on Cecile for support, which was getting more and more difficult for her to do as time went on.

Mitral valve repair surgery (August 2020)

Cecile underwent mitral valve repair surgery at the surgical centre. She was an inpatient for five days. She was referred to cardiac rehabilitation and underwent transthoracic echocardiogram (TTE) prior to discharge.



Ramipril 5.0 mg once daily

Four weeks of analgesia (codeine 30 mg four times daily, paracetamol 1 g four times daily, and ibuprofen 400 mg three times daily)

Inpatient for only five days, as surgery performed promptly and condition had not deteriorated

Referral for cardiac rehabilitation

Cecile returns home and doesn't require assistance with her recovery. She finds her breathlessness has improved, she's happy and hopeful for the future.

Cardiac rehabilitation assessment (October 2020)

Cecile started cardiac rehabilitation by going for an assessment at the DGH. She was prescribed 12 weeks of cardiac rehabilitation in total, with two sessions per week. The first two weeks were face-to-face at the DGH and the remaining 10 weeks involved a facilitated home-based rehabilitation programme.

Optimal management pathway

Post-surgical follow-up (October 2020)

Cecile's condition was reviewed by the surgeon at her post-surgical follow-up appointment. She underwent post-surgical TTE, which showed less than mild MVR.

Cardiac rehabilitation (January 2021)

Cecile completed her cardiac rehabilitation programme.

As of August 2022, Cecile continues to recover well. She has minimal issues after her surgery, is less breathless and more able to exercise and exert herself. Cecile continues to volunteer at the Women's Institute and looks after the grandchildren twice a week while her daughter works. Cecile attends annual cardiology/valve clinic review appointments.

Cost Implications

For the financial evaluation, a detailed analysis was performed by mapping the lifecycle of each pathway (patient journey). Through this process, it is possible to identify the cost drivers that would be incurred in primary and hospital care using, where appropriate, the NHS National Tariff Payment System,¹⁷ NHS reference costs¹⁸ and MIMS.¹⁹

We have included the wider social and economic impacts in the story but not the cost outside of the health and social care remit, longer term costs, or the social, emotional, physical, and financial costs to the patient and family members. In an integrated care service and with integrated budgets there is a need to understand the overall cost of the total patient journey.

The financial calculation presented here represents an indicative level of efficiency potential of the presented case only. Firstly, as the case is an example pathway, differential pathways for other patients may increase or reduce the potential benefit. Secondly, the potential releasing of resource associated with implementing the optimal pathway across a larger cohort of patients will be subject to over-arching contractual arrangement in place between providers and commissioners, which may differ across the country. For example, some of the financial benefits identified in the case, may not be fully realisable where the elements of the pathway are subject to block contracts or risk/gain shares in place between contracting parties. Equally, the release of resource may only be realised should there be a critical mass from within the targeted patient population.

Note: The financial costs are indicative and calculated on a cost-per-patient basis. Local decisions to transform care pathways would need to take a population view of costs and improvement.

While there is also an increased cost to providing suboptimal management (Table 2), there is notable impact on patient and family wellbeing. For example, in Cecile's suboptimal pathway, slow referral and delays to treatment lead to:

- Cecile unable to continually provide family care and assistance.
- Repeat investigations (Table 3).
- A life with depression, AF and reduced LV function.

It should also be noted that the financial calculation is considered from a commissioner perspective. The impact on income and costs (including capacity management) for provider organisations will require consideration in the implementation of the optimal pathway.

Each healthcare organisation and system will need to assess the potential for realising the financial benefits identified in the case.

Cost implications

Table 2. Summary of financial costs

	Suboptimal (£)	Optimal (£)
Primary care management	769	229
GP appointment	235	78
Amoxicillin	4	4
Doxycycline	2	–
Furosemide	112	89
Ramipril	22	50
Sertraline	32	–
Codeine	2	2
Paracetamol	4	4
Ibuprofen	7	2
Edoxaban	349	–
Secondary care management	16,001	12,477
Electrocardiogram monitoring or stress testing – outpatient	375	125
Chest X-ray	56	56
Cardiology referral	183	183
Cardiology follow-up	192	96
Complex echocardiogram – outpatient	252	252
Coronary angiogram	973	–
Coronary angiogram (no LVF)	–	893
Cardiology follow-up MDT	148	148
Cardiac surgery – first appointment	293	–
Routine blood tests	10	–
Cardiac surgery (mitral valve replacement)	9,096	–
Cardiac surgery – follow-up appointment	126	252
Cardiology nurse-led – first appointment	77	–
Mitral valve repair surgery	–	9,096
Cardiac rehabilitation	1,374	1,374
Cardiac surgery follow-up MDT	152	–
Digoxin	9	2
Warfarin	2	–

Cost implications

	Suboptimal (£)	Optimal (£)
Prothrombin-time blood test	19	–
Hospital home recovery carer	2,664	–
Community care	3,576	
Social carer	3,576	–
Grand Total	20,346	12,706

GP, general practitioner; LVF, left ventricular failure; MDT, multidisciplinary team.

Table 3. Number of investigations

Investigation	Suboptimal (£)	Optimal (£)
Chest X-ray	2	2
Echocardiogram	4	3
Coronary angiogram	1	1
Total	7	6

Furthermore, in Cecile's suboptimal pathway, she becomes unable to help her daughter with childcare.

Estimated additional cost of childcare of

£8,530*



over the analysis period results in a **total cost** to the system of



£28,719

in the **suboptimal** (average) **pathway**.

The **optimal pathway**, in comparison,



costs the system



£12,706

*Assuming £6.69 per hour²⁰ at 8.5hrs per day = £56.87 per day = £113.73 per week. (19 months / 82 week - 7 weeks holiday = 75 weeks to pay for childcare) = £8,530.



Cecile's suboptimal pathway is 126% more expensive than the optimal pathway.

Learning points and key considerations

Moderate to severe MVR is a serious but treatable disease. If detected early and timely treatment is provided, patients can recover and live healthy lives. However, of the annual estimated population of patients with moderate to severe MVR, only 39% are receiving treatment (Table 1). Furthermore, it is unclear if the system is identifying treatable patients. Only 3% of those diagnosed annually receive treatment with valve replacement or repair (Table 1).

Additionally, MVR detection and treatment is not equitable. Patients who live in areas of high deprivation are less likely to receive mitral valve repair than patients who live in areas of low deprivation. And people living in the most deprived areas are more likely to experience long elective waiting times (Figure 3). Males are also more likely to receive mitral valve repair than females.

Furthermore, providing suboptimal care is not cost-effective. As demonstrated by Cecile's story, patients who wait longer for treatment are more likely to require repeat GP and hospital visits and can deteriorate as they wait for appropriate diagnosis and treatment. This can lead to increased health and social care costs as well as other costs to the wider economy (Table 2).

Stakeholders must consider the wider burden of MVR that exists in England. Detection of moderate to severe MVR must be improved so that the right patients are identified and treated appropriately. Additionally, existing biases relating to gender, sex and deprivation must be considered and eliminated to ensure equitable access to services.

Key considerations and Recommendations

For GPs and other clinicians

- Compared to pre-pandemic levels, GPs are seeing fewer patients face-to-face. This can lead to missed opportunities for conducting cardiac auscultation, and subsequent heart murmur detection.
- Chest auscultation should be performed if patients present with any symptoms that may indicate heart valve disease,^{15,16} such as breathlessness, chest pain, presyncope or syncope. If a murmur is found, patients should be referred promptly for echocardiography.¹⁵
- Low levels of awareness of MVD among community clinicians may lead to incorrect or delayed diagnoses and referral for diagnostic testing.
- Primary care could proactively screen for symptoms of MVD during routine long-term condition annual reviews and NHS health checks.^{15,16}
- There are limitations in access to echocardiography in the community due to a lack of resource, which could add to the delay in diagnosis and treatment for patients with MVD.

Learning points and key considerations

- Complicated echocardiography and imaging reports can be difficult for GPs to interpret and can lead to incorrect referrals or referral delays. Reporting of echocardiography needs to be addressed to provide clear advice on the next steps for patient care.
- Clear community detection pathways for MVD that include diagnosis and referral into specialised services needs to be commissioned in every ICS, with clinical leadership from the Cardiac Clinical Networks.
- The use of digital stethoscopes with AI-driven detection software may prove useful in identifying murmurs that need onward investigation. Digital stethoscope technology has the potential to reduce unnecessary echoes thereby relieving unwarranted pressure on the service.

For commissioners and Cardiac Clinical Networks

- Cardiac clinical networks should actively provide clinical leadership to the ICSs that they cover to support them with commissioning fully integrated patient pathways that allow timely detection, diagnosis, and treatment of MVD.
- ICS commissioners need to provide adequate services to meet the current demand for moderate/severe MVD patients, so that all patients have access, if clinically appropriate, to best practice treatment options .
- Commissioners need to provide enough capacity in echocardiography to meet the demands for diagnosis across a range of cardiac diseases, including MVD. These services could be provided in a community diagnostic hub.

For Patients

- There needs to be increased public awareness of MVD, its seriousness, and that it can be successfully treated, to encourage patients with symptoms to present to clinicians.
- Health literacy and patient activation impact the speed at which a patient may be diagnosed; patients need increased education regarding breathlessness and management of MVD.
- Setting treatment goals is key – discuss with your Healthcare Professional (HCP) what you would like to be able to do and achieve.

Contributors

Many thanks to all those who contributed to this report.

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Abbreviations

A&E	accident and emergency	ICS	integrated care system
ACE	angiotensin-converting enzyme	ICU	intensive care unit
AF	atrial fibrillation	LV	left ventricular
ARB	angiotensin receptor blocker	LVF	left ventricular failure
BCS	British Cardiovascular Society	MDT	multidisciplinary team
BCIS	British Cardiovascular Intervention Society	MVD	mitral valve disease
COPD	chronic obstructive pulmonary disease	MVR	mitral valve regurgitation
COVID-19	coronavirus disease 2019	NA	not applicable
CT	computed tomography	NEC	not elsewhere classified
DGH	district general hospital	NICE	National Institute for Health and Care Excellence
DOAC	direct oral anticoagulant	ONS	Office for National Statistics
ECG	electrocardiogram	OPCS	Office of Population Censuses and Surveys Classification of Interventions and Procedures
ESC	European Society of Cardiology	Q	quintile
GP	general practitioner	QOF	Quality Outcomes Framework
GPSI	general practitioner with special interest	SSRI	selective serotonin reuptake inhibitor
HES	Hospital Episode Statistics	TOE	transoesophageal echocardiogram
HSCIC	Health and Social Care Information Centre	TTE	transthoracic echocardiogram
ICD-10	International Classification of Diseases, 10th revision	WI	Women's Institute

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Appendix

Please note: mitral valve insufficiency is another term for MVR and is used in HES data. For consistency in the main report, we use the term MVR throughout. However, to be consistent with HES in the methods section we use mitral valve insufficiency when referring to HES.

Appendix 1: Analysis methods

Estimated number of people with mitral valve regurgitation (MVR) within population aged ≥65 years, mid-2017 to mid-2020^{7,8}

MVR prevalence within population aged ≥65 years^{7,8}

The population with MVR has been estimated using the adjusted prevalence benchmark from the Heart article by Cahill et al (2021).⁷ In this article, the estimated community prevalence of moderate or greater MVR within adults aged 65+ is 3.5%. These benchmarks have been applied to ONS mid-year population estimates for CCGs and aggregated to ICS level.^{7,8}

Average MVR Incidence within population aged ≥65 year^{7,8}

MVR incidence has been estimated by calculating the change in prevalence over three time periods: mid-2017 to mid-2018, mid-2018 to mid-2019 and mid-2019 to mid-2020. The average change over these three time periods represents an estimate of the incidence of MVR within the population aged ≥65 at ICS level.

Patients diagnosed with mitral valve insufficiency, 2017 to 2021⁹

A count of the number of inpatient spells and patients where there was a diagnosis of mitral valve insufficiency over the period 2017 to 2021 (inclusive). Please refer to Table 4 for the list of ICD-10 codes used. Data were analysed by:

- individual ICD-10 code at national level
- by calendar year at national, ICS and trust level.

Patients treated with mitral valve repair, 2017 to 2021⁹

A count of the number of inpatient spells and patients where there was a mitral valve repair procedure for those patients who have been diagnosed with mitral valve insufficiency over the period 2017 to 2021 (inclusive). The data tables also show average elective waiting times and average days from the initial diagnosis of mitral valve insufficiency until treatment with mitral valve repair. Please refer to Table 4 for the list of the OPCS and ICD-10 codes used. Data was analysed by:

- individual OPCS code at national level
- calendar year at national, ICS and trust level
- 5-year totals at national, ICS and trust level
- 5-year totals at national, ICS and trust level split by broad ethnic group (patients and elective waiting time only)
- 5-year totals at national, ICS and trust level split by level of deprivation (patients and elective waiting time only)

Appendix

- 5-year totals at national, ICS and trust level split by gender (patients and elective waiting time only).

Please note that where average elective waiting times = NA, this means that there were no elective spells with a valid record of an elective waiting time for that particular organisation and set of parameters. However, an average elective waiting time = 0 means that the average elective waiting time was zero days.

Similarly, where average days from initial diagnosis = NA, this means that there are no records for average days from initial diagnosis for that particular organisation and set of parameters. However, an average days from initial diagnosis = 0 means that the average days were zero.

Backlog in mitral valve repair procedures due to COVID, March 2018 to December 2021⁹

The COVID backlog represents the difference between the number of mitral valve repairs carried out during the COVID period (March 2020 to December 2021) compared to the number of mitral valve repairs carried out during the pre-COVID period (March 2018 to February 2020, i.e. the two years prior to COVID). The backlog was analysed in two ways:

- As an annual average - i.e. the difference between the annual average during the COVID period versus the annual average during the pre-COVID period.
- As a total - i.e. the accumulated backlog over the 22 months of COVID.

Patients treated with mitral valve repair per annum as a rate – annual average, 2017 to 2021⁷⁻⁹

The data were analysed in three ways:

- the number of patients treated with mitral valve repair per annum as a % of the estimated incidence of MVR (based on the estimates from section 1, Cahill model) at ICS and national level
- the number of patients treated with mitral valve repair per annum as a % of the number of patients diagnosed with mitral valve insufficiency per annum, at ICS and national level
- the number of patients treated with mitral valve repair over the 5-year period (2017 to 2021) as a % of the estimated prevalence of MVR in 2020 (based on the estimates from section 1) at ICS and national level.

The OPCS and ICD-10 codes used are shown in Table 4.

Appendix

Table 4. ICD-10 and OPCS codes

Mitral valve insufficiency	
ICD-10 codes	Diagnosis description
I05.0	Mitral stenosis
I05.1	Rheumatic mitral insufficiency
I05.2	Mitral stenosis with insufficiency
I05.8	Other mitral valve diseases
I05.9	Mitral valve disease, unspecified
I34.0	Mitral (valve) insufficiency
I34.2	Non-rheumatic mitral (valve) stenosis
I34.8	Other nonrheumatic mitral valve disorders
I34.9	Non-rheumatic mitral valve disorder, unspecified

Mitral valve repair	
OPCS code	Operation description
K25.5	Mitral valve repair NEC
K25.8	Other specified plastic repair of mitral valve
K25.9	Unspecified plastic repair of mitral valve

ICD-10, International Classification of Diseases 10th Revision; NEC, not elsewhere classified; OPCS, Office of Population Censuses and Surveys Classification of Interventions and Procedures.

Rounding and suppression

Where values for the number of inpatient spells or patients are above 7 they have been rounded to the nearest 5; due to this, totals may not sum across columns/rows. Where values for the number of inpatient spells or patients are between 1 and 7 (inclusive) they have been suppressed and are represented by *.

About Hospital Episode Statistics – and some limitations

The analysis uses admitted patient care data from the Hospital Episode Statistics (HES) dataset. The data has been coded based on information documented within medical records and is therefore dependent on the quality of the coding.

HES data covers all patients using secondary care services in England, including:

- private patients treated in NHS hospitals
- patients resident outside of England
- care delivered by treatment centres (including those in the independent sector) funded by the NHS.

Appendix 2: Further HES

Figure 6. Patients treated with mitral valve repair (HES) as a percentage of total estimated prevalence of mitral valve regurgitation within population aged ≥ 65 years: 5-year total from 2017 to 2021.⁷⁻⁹

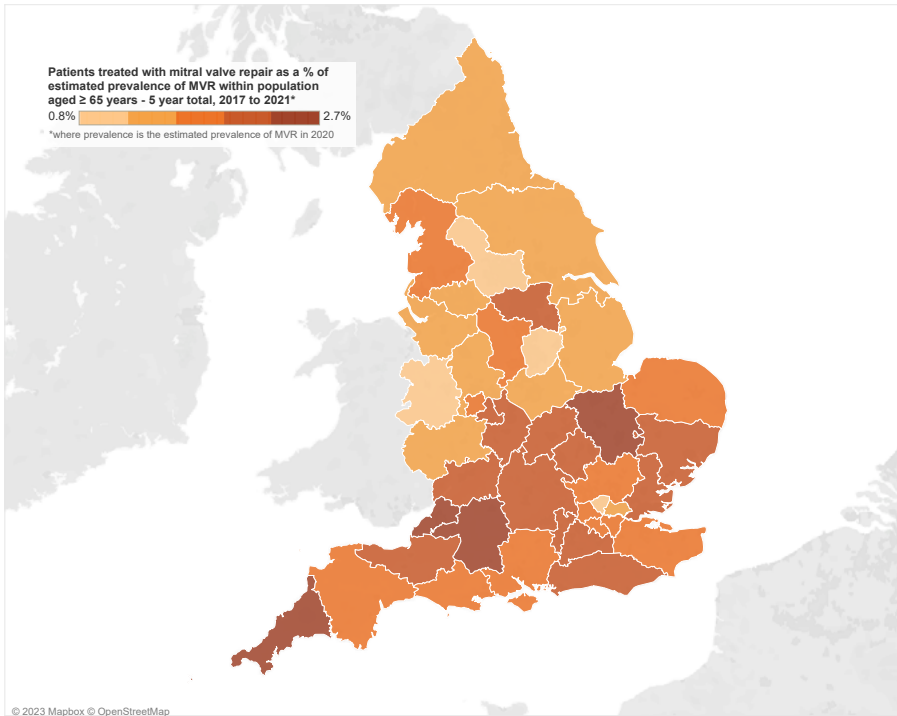
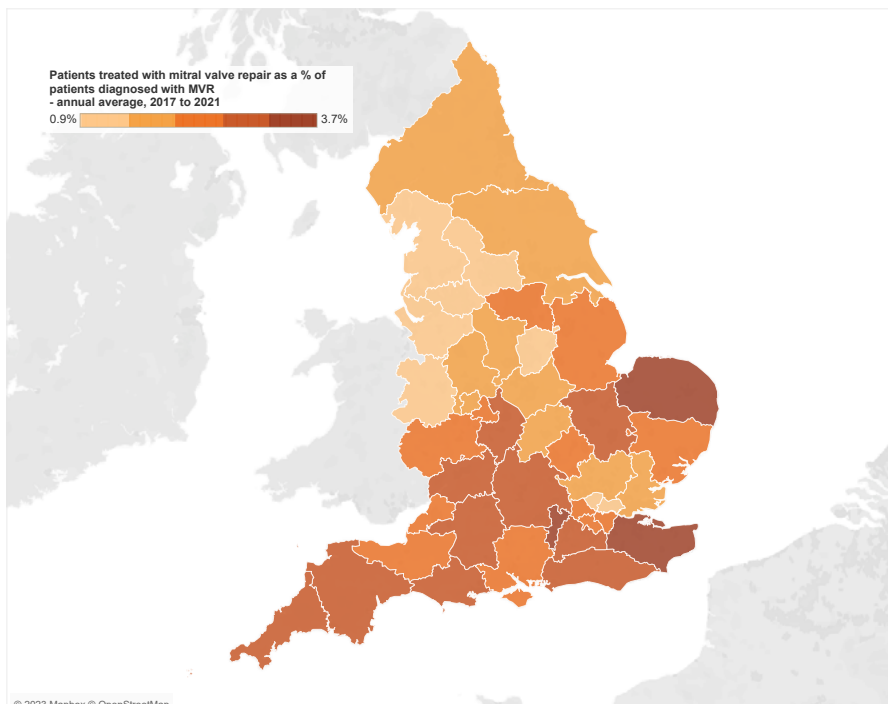
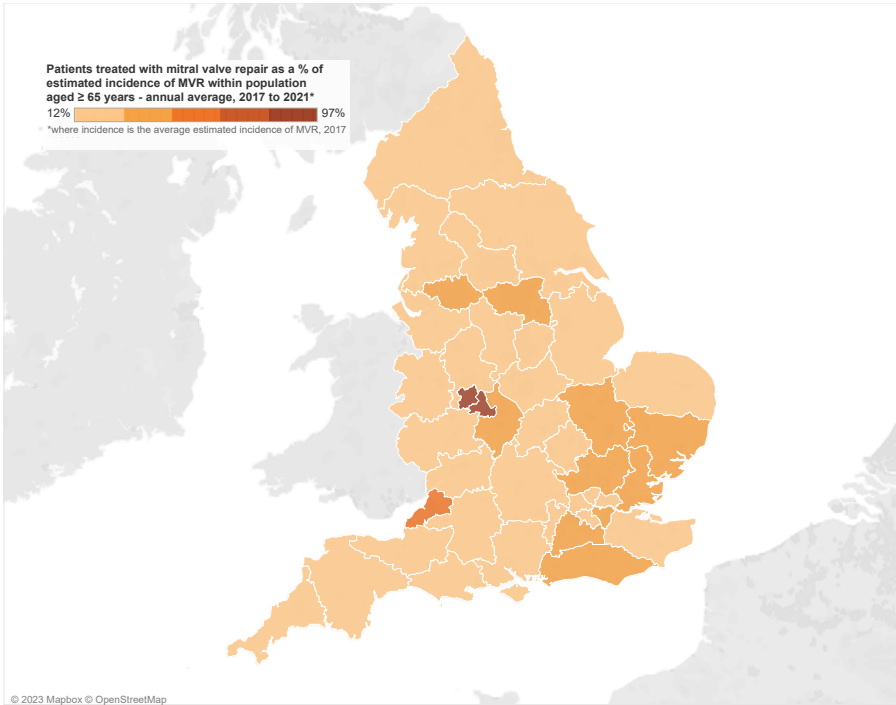


Figure 7. Patients treated with mitral valve repair (HES) as a percentage of patients diagnosed with mitral valve regurgitation: annual average 2017–2021.⁹



Appendix

Figure 8. Patients treated with mitral valve repair as a % of estimated incidence of MVR within population aged ≥ 65 years: annual average, 2017 to 2021.⁷⁻⁹





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