Walsall Together Patient Engagement

Living and Managing with a Heart Condition

1. Introduction

Walsall Together is an integrated care partnership between the organisations that plan and deliver health, mental health, and social care services locally. They include:

- Walsall Healthcare Trust
- Walsall Clinical Commissioning Group (including local GPs & Primary Care Networks)
- Black Country Healthcare NHS Foundation Trust
- Walsall Council
- Walsall Housing Group
- One Walsall

One of the key aims is to help the population of Walsall stay well for longer, by supporting them to make better lifestyle choices to help them to live independent, active, and healthy lives. It is about helping people stay of out hospital when possible, by providing accessible, co-ordinated, and responsive care as close to home as possible. The aims of the partnership are to:

- Improve the health and wellbeing outcomes of their population.
- Increase the quality of care provided; and
- Provide long term financial sustainability for the system.

Healthwatch Walsall (is an independent champion for people who use health and social care services whose role includes finding out what matters to people and help make sure their views shape the support they need) has been commissioned by Walsall Together to capture the patient and service user voice around care pathways and living and managing with long-term health condition(s). The focus has been on the 6 priority Key Lines of Enquiry around Diabetes, Respiratory, Cardiology, Mental Health, End of Life & Palliative Care and the best start in life, early child. This report concerns the outcome of engagement work undertaken in relation to cardiology or heart conditions.

2. Heart Disease in Walsall

2.1 Introduction

Heart disease remains as one of the major causes of premature death in Walsall. There have been several reports produced locally by Public Health Walsall that evidence this but there is also other intelligence published by Public Health England e.g., CVD primary care intelligence pack (2021). We understand that a range of factors heighten the risk of heart disease and that generally premature deaths from this disease tend to be in the more deprived areas of Walsall where risk factors that can cause heart disease are more prevalent. As background data to support this report we have obtained some summary information from our local

Public Health department as well as undertaking a limited analysis of the CVD primary care intelligence pack 2021 and this follows.

2.2 What is Cardiovascular Disease?

Cardiovascular disease (CVD) is a general term for conditions affecting the heart or blood vessels. CVD is one of the main causes of death and disability in the UK, but it can often largely be prevented by leading a healthy lifestyle.
The four main types of CVD are:

2.2.1 Coronary heart disease (CHD)

Coronary heart disease occurs when the flow of oxygen-rich blood to the heart muscle is blocked or reduced. This puts an increased strain on the heart, and can lead to angina, heart attacks and heart failure. In 2019/20 the admission rate for CHD in NHS Walsall CCG was 617.1 for every 100,000 people in the population (1,595 admissions). This is significantly higher than England (469.9 per 100,000). In 2019/20 the admission rate for heart failure for all persons in NHS Walsall CCG was 196.1 for every 100,000 people in the population (525 admissions)[1]

2.2.2 Strokes and TIAs

A stroke occurs when the blood supply to part of the brain is cut off, which can cause brain damage and possibly death. A transient ischaemic attack (also called a TIA or "mini-stroke") is similar, but the blood flow to the brain is only temporarily disrupted. In 2019/20 there were 5,280 people who have previously been diagnosed with a stroke in NHS Walsall CCG. In 2019/20 there were 320 admissions recorded on the Sentinel Stroke National Audit Programme.

The early mortality rate (under 75 years of age) due to stroke in NHS Walsall CCG was 15.7 per 100,000 in the three-year period 2017-19. The early mortality rate is significantly higher than the England rate (12.5 per 100,000). Six-month assessment applicable patients who are assessed at six months following a stroke, 2018/19 (per cent) Outcomes - age-standardised mortality the later mortality rate (over 75 years of age) due to stroke in NHS Walsall CCG was 492.4 per 100,000 in the three-year period 2017-19. This is not significantly different to the later mortality rate for England (479.4 per 100,000).[2]

2.2.3 Peripheral arterial disease

Peripheral arterial disease occurs when there is a blockage in the arteries to the limbs, usually the legs, which can cause cramping, numbness, and weakness of the limbs as well as hair loss and persistent ulcers.

---

[1] Public Health England, 2021

[2] https://fingertips.phe.org.uk/profile-group/cardiovascular-disease-diabetes-kidney-disease/profile/cardiovascular/data#page/13

2.2.4 Aortic disease

Aortic diseases are conditions affecting the aorta, the largest blood vessel in the body which carries blood from the heart to the rest of the body. One of the most common aortic diseases is an aortic aneurysm, where the aorta becomes weakened and bulges outwards.

3 Risk Factors for CVD

There are many factors which increase an individual's risk of developing CVD, including:

3.1 High blood pressure (hypertension) is one of the most important risk factors for CVD as high blood pressure can cause stress and damage to blood vessels. Hypertension is a common condition affecting approximately 22% of the population nationally. The condition can be asymptomatic, this means that many people may not be aware they have hypertension and therefore may not be receiving treatment if required. Hypertension is one of the high-risk conditions that can increase the risk of developing cardiovascular disease. Early diagnosis and treatment are important, as it can help reduce the risk of developing heart disease and strokes. In 2019/20 around 44,903 individuals were on the GP hypertension register in Walsall GP, representing 15.4% of people registered[3].This is significantly higher than the national average for England of 14.1% In addition, on average, each CCG in England has 26,000 residents with undiagnosed hypertension - these individuals are unaware of their increased cardiovascular risk and are untreated[4].

3.2 Smoking is a strong risk factor for CVD. An estimated 19.6% of people in Walsall aged 15+ smoke[5]. This is higher than both the Black Country (18.5%) and the England national average (16.5%).

3.3 High cholesterol. Cholesterol is a fatty substance found in the blood, which can cause narrowing (constriction) of blood vessels, increasing the risk of blood clots.

3.4 Diabetes – increased blood sugar levels can also cause the narrowing of blood vessels. The prevalence of diabetes in Walsall is 9.3%, which is higher than the Black Country (9.0%) and England national average (7.1%).

3.5 Physical inactivity increases the risk of hypertension, cholesterol, and obesity, which are major risk factors for CVD. In Walsall, 32% of adults are physically inactive, which is worse than the national average of 21%[1].

3.6 Being overweight or obese also increases the risk of CVD. In Walsall, 14% of people aged 18+ are obese. This is higher than the England national average of 10.5%[1].

3.7 A family history of CVD also increases an individual's risk for developing CVD.

---

[3] https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2019-20

[4] https://fingertips.phe.org.uk/profile/cardiovascular-disease-primary-care/area-search-results/E38000191?place_name=NHS%20Walsall%20CCG&search_type=parent-area

[5] Quality and Outcomes Framework (QOF), NHS Digital

3.8 Ethnic background - In the UK, CVD is more common in people of south Asian and an African or Caribbean background. This is because people from these backgrounds are more likely to have other risk factors for CVD, such as high blood pressure or type 2 diabetes.

Under 75 mortality rate as a result of cardiovascular disease 2017 / 19 highlights a value of 97 compared to the West Midlands region of 77 and the national England average of 70.

The mortality rate from cardiovascular disease considered to be preventable by the 2016 definition values 61 in comparison to the national average of 45 and the West Midlands region value of 50.

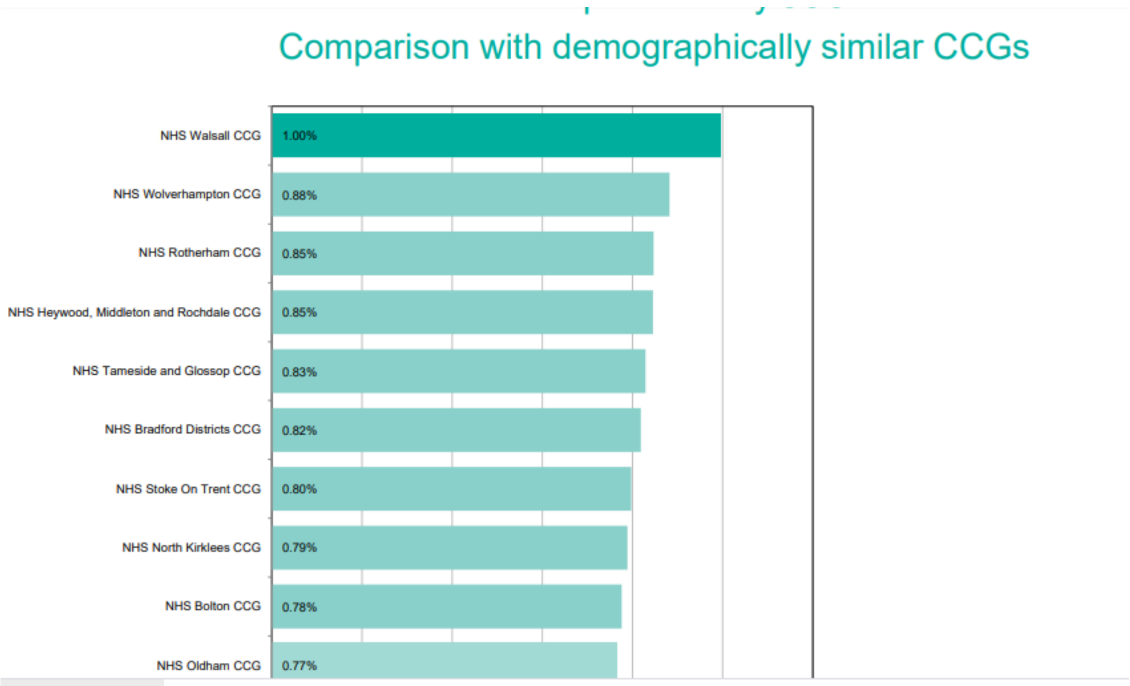
Emergency admissions from coronary heart disease in Walsall rate at 129 and as the 2nd highest within the West Midlands region. **Source: https://fingertips.phe.org.uk/ 2017 to 2019 data**

Whilst NHS Health checks offered for the eligible population between 40 and 74 in Walsall is 63% compared to 87.7% national average, however the uptake in Walsall is above national average. Hypertension diagnosis in Walsall is above the national average.

Source: CVD prevention pack Blackcountry & West Birmingham STP 2021

June 2017 there were an estimated 46 782 Smokers in Walsall.

The graph below shows heart failure prevalence in Walsall (top) in comparison to demographically similar CCG's.



Source: https://assets.publishing.service.gov.uk/ June 2017

The pathways for the prevention and treatment of this disease are complex but has operated for many years with its roots based on a national service framework and other subsequent clinical guidelines that maps what should or can be done to prevent and treat heart disease to achieve optimal care. The smooth operation of this pathway is therefore key to achieving the aim of reducing premature deaths but also avoidable demand for heart health care and therefore we have been engaging with Walsall patients and carers who have had direct experience of cardiac care in Walsall to learn about the strengths and weaknesses of the current pathway and identify improvements.

4 Methodology

This report is the culmination of engagement work undertaken and co-ordinated by Paul Higgitt, Senior Engagement Lead, Walsall Healthwatch, and Phil Griffin, Walsall Together Service User Group Chair. It is based upon several individual patient stories and 2 living and managing with a heart condition workshops attended by 25 patients and service users around living and managing with heart conditions held during November 2020.

The report is structured to give key findings and recommendations (these follow in Paragraph 4 below), a summary of what patients said in the virtual workshops held in November 2020 patient engagement workshops (these follow in paragraph 5) and included as Appendices the summary notes of and individual patient stories completed during the summer and autumn of 2020.

Cardiology covers a wide range of areas such as heart failure, angina, atrial fibrillation, systolic and diastolic functions etc. Our engagement has been generally around the cardiology system and we recognised that our engagement has not been specific to a particular element within the cardiac patient care pathway.

Whilst we have captured patient experience of the cardiac care pathway a recommendation would be to request whether the Clinical and Professional Leadership Group (CPLG) consider whether there is need for engagement around a specific element of the care pathway e.g., a specific focus on Angina or Heart failure for example.

5 Heart Disease Pathway: Summary of Recommendations

From the engagement work undertaken through the project the recommendations applicable to the Walsall Together Tiered Model of Care are as follows:

Tier 0 – Resilient Communities

i. Support to patients following cardiac event or surgical intervention – seemed to be a lack of emotional support and being left on their own to manage in the community once discharged. Idea Zoom calls 24 / 7 group session. It is the mental impact from heart attack. Mental support immense benefit. Talking therapies support for long term health conditions but not many that we spoke to had been referred or know about this support.

ii. Information on services available locally via an online directory
iii. Access to patient information leaflets and how these are kept up to date.
iv. Access to self-management courses
v. Establish virtual patient support group (like the Diabetes patient Support Group)
vi. More assurance to patients on the positive impact of cardiac rehabilitation and further engagement with those who have been reluctant to continue to cardia rehabilitation.

Tier 1 & 2 – Primary Care & Community and specialist services

i. Annual reviews by GP practice are these happening none on the call said they had had an annual review. The question arose that should practices be more proactive in arranging annual check-ups.
ii. Easier wording on clinical letters so that the patient can understand them.
iii. Anticoagulation clinic – time needed to answer patient queries.
iv. Direct telephone access to cardiac specialists in a crisis for advice and support.
v. GP-Patient consultation times need to be longer than 5 minutes.
vi. Perceived variation across GP practices of heart care approach but recognised that this might be explained by available GP and practice nurse time.
vii. GP consultations should pick up on mental health needs arising from a heart condition and not focus primarily on the physical side.
viii. Waiting times to see a specialist i.e., GP referral to being seen by a consultant perceived to be too long for heart patients.
ix. Occupational therapy input too brief to be of any value – patients need access to advice and support as part of aftercare.
x. Discharge planning for heart care patients - some patients not sure that this is working in a way that enables patient of family involvement in judgements being made.
xi. There needs to be more support and advice around co morbidities.

Tier 3 – Unplanned Care

Through our engagement we did not receive any recommendations on improvements around this tier.

Tier 4 – Acute Care

i. Patient and Doctor communication/manner.
ii. Variation in Consultant awareness of and referral to talking therapies and access to heart care patients.
iii. Inter and Intra speciality communications i.e., records management between and within hospital specialities.

6 Patient engagement work undertaken, on which the report's findings are based.

Heart disease is a major cause of premature death patients. Its prevention and effective treatment are key. The workshops and the experiences of patients and their carers who participated just emphasised the impact that having an acute heart e.g., a heart attack, stroke or major heart surgery event has on everyday living and why access to the right support/service, with the right information at the right time in a timely way is so important. It was also clear from what people said that acute as well as ongoing treatment interventions as well as ongoing mental health support to help patients manage their condition is very important. All this serves to highlight that the local coronary care pathway needs to work well so patients can remain in the community and avoid unnecessary exacerbations of their heart condition which eventually could require an urgent GP domiciliary visit or a visit to A&E and even admission.

The workshops captured a range of intelligence and that the comments on what could be improved and what could be done differently would be of interest to commissioners and could be used to support improvements in the care pathway in the spirit of co-production.

We also have some data gathered through the individual 1:1 patient story which we have used to strengthen the report.

7 Some of the key things patients and carers shared.

What follows is more detail of what patients said in the virtual cardiology workshops held in November 2020. The discussion was structured to allow patients to respond to the following questions:

I. Do you understand your conditions and how it impacts on your health?
II. What is working well in helping you manage your condition?
III. What has been your experience of you care pathway?
IV. In relation to surgery what is your experience?
V. What are the main positive things you would highlight?
VI. If you received hospital care experience of care pathway

Patients' comments are summarised under the headings above, below:

I. Do you understand your conditions and how it impacts on your health?

a) Most seem to understand their condition, but it is about managing medication which can be difficult. It is an ongoing process as your condition's changes, and some said they felt they needed more regular medication checks.
b) Difficulty in managing breathlessness. To understand the condition many have had parents who have passed but in early periods of time few were checked if it was congenital.
c) Patient with heart failure, leaky valve, angina, TIA, pacemaker. Dr explained everything as we went along. Learnt a lot living with it and the support from the self-care management group very useful. Mother was ill with heart failure, but you can still live for a long time. My consultant explained everything as we went along.
d) Talked about DC Cardioversion but my heart rhythm has stabilised. My main advice is coming from the hospital.
e) Through cardiac rehabilitation I learnt that exercising other muscles and not just the heart helps take pressure off the heart. Until people go to cardiac rehabilitation not many people know about the positive impact of this. I attend the self-care management course which is good. This biggest fear for many with a long-term health conditions is the fear of the future – am I going to be able to do what I used to do and how to cope how things are different.
f) Where I have struggled is the communication and information afterwards. I am taking all the medication I have been provided. I have some good booklets but would have like a better plan of sitting down with someone to sit down. GP explanation in 5 minutes is difficult.
g) I have congenital heart disease. I had a heart bypass. Depends on where you get the surgery and aftercare.

h) One patient had been seen outside of Walsall. I understand my condition, but I do not think a lot of people do. My heart is fixed, and it is getting to people who have had surgery to understand this. When you have a heart condition you do think a different way. I have a dye put in me and pushed to do exercise every 6 months. Because I am told I am fine its mentally helpful. It was difficult in the beginning to accept and you do panic. Many of the participants have had family members that have a heart condition.

i) Next of kin chats to go online with others. We need more zoom group discussions done locally for people to discuss. The mental impact. It took 5 years to come to terms of my initial heart attack.

j) Poor communication between other consultants and GP's is a problem.

II. What is working well in helping you manage your condition?

General Practice

a) Mine brilliant if I have a few things to discuss time is taking to go through things. GP is good, I started to sweat in the practice, and I was frightened. The Nurse was able to do an ECG straight away and send the details to Walsall ManorIt does depend on which practice though. When my mom gets to see a particular GP at her surgery she listens, we go through medication and we come to a shared decision. You can make suggestions and work through the treatment options. However, there is another GP in the practice and is at the other end of the scale. It is such a big difference to the outcomes which should not be the case.
b) I was having panic attacks and was able to call my GP as I thought it was my heart. We discussed meditation to calm me down. Always asks how I am with my medication. E.g., Right drug at the right time. If I go out playing golf my GP advises me to take Nikoran.
c) For me it is different. I am a patient at a much larger practice, and we have a lot of newer GP's coming through. This makes it very challenging as they do not know you as well and you spend a lot more time going over your history. Seems to be less stability for the patient.
d) Useful technique for patients that are anxious or wondering what to say when they visit the GP is to write questions down to ask the GP.

III. What has been your experience of you care pathway?

a) Mum went to A&E with a heart attack and water infection an in hospital to 2.5 weeks. She has a lot of fear. The medical side was good, and drug tested out, thorough and professional. Gave my mum and I confidence. The subsidiary care was not as good, patchy 2 out of our 3-visit poor treatment as she as abdominal hernia and nausea the distress and she was forced to shower but this was difficult. Standard of general treatment was not as good. Change over of shifts as staff were asking mum to do things that she could not do. Change of experiences there are issues.
b) My hospital care during and after my bypass was positive. Before hand had angiogram and a did not understand was what going on. I was asked if I wanted stents put in or bypass. I understand it was choice, but communication was poor. Since my operation 2 years ago. For the first year I was given check-ups and now given spray for angina.

IV. In relation to surgery what is your experience?

a) Surgery was well explained the main issues for some has been the aftercare. I was told after my 2 TIA's I was told that someone would call me and advise on exercises etc. This did not take place but has my husband had a heart bypass some years ago he was able to advise me on doing short exercises and building it up gradually.

b) I have been in Walsall Manor a few times as I collapsed due to low blood pressure. I also accessed Heartcare after rehabilitation on the ward. It was good and reassuring. The Cardiac Rehabilitation Nurses on the ward were professional but very compassionate. My Cardiologist referred me to Heartcare and boosted my confidence.

c) A lot of friendships are also made at Heartcare as you get to speak to other people who really know what it is like with the condition and share experiences.

d) My surgery came out the blue and I visited my GP with chest pains and was told to go to A&E immediately. After several tests, it was explained that I needed surgery at New Cross. I received a triple heart bypass and referred very quickly to Heartcare. It was well managed and efficient.

V. What are the main positive things you would highlight?

a) In relation to cardiac care, I went in for an angiogram, consultant was very thorough. He came into the recovery room and held my hand and explained everything and asked me questions about mum and dad who passed from heart related conditions.

b) What struck me the most the consultant sat us down and spoke to us in a calm and understanding way. He explained things in a very clear way about my mum's condition. Took as much time as needed to discuss prognosis. Positive experience in a distressing situation.

c) My individual surgeon prior to my heart bypass initial consultant at Walsall Manor explained what would happen in detail for surgery at New Cross.

d) For my pacemaker surgery he explained what it would be doings and how this would affect my heart, and because it was explained it was very reassuring.

e) In relation to specialist community services. I was contacted by a Cardiac Nurse for my mum, and they did come and visit once but there was no follow up. Not clear enough about what is happening. Communication between OT and Community Nurse could have been clearer.

f) We were supposed to get an assessment at home, but after assessment we did not get follow.
g) Coordination from discharge there were some hiccups around OT, home care. Seems in our experience that one person passes control to someone else, but we have not been involved in the follow up care co-ordination. There have been care co-ordination problems and better care navigation.
h) I feel that with my mum as a patient in our experience we were not part of the discharge arrangement process. For a heart patient the surgery and initial support is good and the referral to New Cross is very smooth, but the aftercare communication needs to be better.
i) A participant highlighted that their next-door neighbour had been discharged from hospital after a bowel cancer operation and was inundated with community after care. She had the yellow book, community nurses, telephone update calls etc. The other parts of the hospital should be doing the same thing.
j) Aftercare at Heartcare has been good in relation to advice on exercise and activity.
k) However, there were some comments that aftercare in terms of a plan was limited until supported through Heartcare.
l) Some service users that had accessed cardio rehabilitation found it uneasy to undertake exercise post-surgery due to fears of it having a negative effect on their condition. However, with reassurance and professional advice from staff at heartcare they were reassured that the rehabilitation was a positive move.
m) Booklet on life changes good but better to sit down with someone and not just for 5 minutes. Some views that it is about the conversation with the patient after surgery. One patient said he sees it has been fixed even though you still have a heart condition. Mental side when you have heart condition you think a certain way.
n) Patient goes to hospital every six months and they put a dye inside his veins and maintain heart rate really push heart and mentally it helps and do not have concerns.
o) AF Nurses at the hospital are really reassuring and supportive. You can phone the team and get support and advice.
p) Lot of trail on medicine management but in my experience in changing medication has been positive with the GP.
q) Some patients do not have the knowledge though to discuss medicine management with their GP and accept what is given.
r) Given pack and get a blood pressure monitor. Support for families when patients have a panic attack is important or signs of heart stress.

s) Idea Zoom calls 24 / 7 group session. It is the mental impact from heart attack. Mental support immense benefit. Talking therapies support for long term health conditions but not many that we spoke to had been referred or know about this support.
t) I have been on the anticoagulant clinic for many years. I am fortunate that when my AF kicks in I know as I will go dizzy. The clinic is not able to answer many of my questions. I have not been seen for a long time though now due to the pandemic.
u) People say have great fear of future after a heart attack. Value in looking at virtual network.
v) Like fact that specialist takes time to listen but brought lack of communication with others dealing with condition. If you have multiple health for those pain, it is very difficult.
w) GP practice can make double appointment. GP said I will take the time as there is a reason – Little London Surgery.
x) It does depend which GP practice you can work through diagnosis to make joint decisions. But some make mind up before you discuss issues. It should not be the case. GP good if discuss mental health side of heart condition.
y) Also, good liaison with consultants is essential. Been described Nikoran if going out to exercise. You get frightened when you go out and raise your heart rate of fear of negative impact on your heart.
z) Need consistency and stability with the patient and GP with a patient with a heart condition. Also, it can take a long time from the GP referral to see a specialist and you worry if you condition will worsen. There are so many different heart conditions so until you see a consultant who can explain things better to you, you can be left in the dark.
aa) Positive about cardiac care – surgeon communication very positive and have given opportunities to ask questions. Consultant communication with patients positive.
bb) Some consultants signpost to talking therapies but it is not consistent.
cc) Occupational Therapist have done assessments but not come back with advice or aids and adaptions for my mom. Not enough consistency of advice after care.
dd) Useful for patients to have a copy of Heart care pathway flow from hospital to aftercare and rehabilitation, i.e., algorithm for each patient. Some view no patient or family involvement in judgements. Do all patients get copies of aftercare from discharge co-ordinators?
ee) Some people informed us that early intervention is crucial and when patients have early symptoms that they seek medical attention early as some heart conditions can exacerbate very quickly.
ff) There needs to be more support and advice around comorbidities. I have type2 diabetes. I am overweight and have had a poor diet. This may have been the result of my heart arrythmia. I am now being supported through My Time Active who have been giving me great support on health and exercise. However, you must put yourself in the right mind frame and really want to overcome the issues and with that the will power. You also need to be truthful with your GP about your lifestyle. It is important to let your GP know exactly what the issues are and what are your top issues.

VI. If you received hospital care experience of care pathway

a) Mum had heart attack and UTI in for 2 weeks and mental health due to medication. Medical side good at Walsall Manor and thorough. However subsidiary care was poor as staff not fully understanding condition and difficulty in mom doing things.
b) Other experience hospital environment heart bypass good quality of care but aftercare for check-up angiogram and consultant said what would you like doing.
c) Difficult continuity of diagnosis with mis information about discharge. Changeover of shifts when in hospital some weaknesses. Change over points biggest weaknesses.
d) Question how many patients are referred to cardia rehabilitation and how many attends.
e) Heartcare Walsall after heart bypass boosted my confidence and friendships come from it offering opportunities being part of a group who understand what it is like and share experiences.
f) I have AF and this was picked up early by my GP who sent me for an urgent ECG. I was soon seen by the consultant and prescribed anticoagulants which have made a big difference. I am now less worried about my heart beats.
g) Question, as part of the GP contractual arrangements are patients with a heart conditions supposed to have a yearly check-up. Some participants informed us that they did not have yearly check-ups. Should the GP surgeries be more proactive in arranging check-ups with patients.
h) People need to be empowered to managing their conditions better and this includes communication and leaflets. Are patients accessing information during the pandemic? The BHF leaflets are very useful but face to face or telephone calls are still as important.

8 Conclusion

Walsall Healthwatch, patients, and members of the Walsall Together Service User Group want to see Walsall Together commissioners and providers of health and social care, to act in a demonstrable way to the intelligence provided via this report and in particular the specific recommendations given earlier in paragraph 4.

It is only by tangible and measurable improvements made, can it be said that the principle of co-production of care pathways is being achieved in Walsall and that the words in the Walsall Together terms of reference which are based on strong partnerships and working together with service users are not just rhetoric.

We recognise that during this challenging period commissioners and providers of services have prioritised efforts to support those affected by the COVID-19 pandemic and this may have affected the provision of heart care services and therefore patient experience of this pathway. We further accept that some developmental work around co-production will be challenging. However, there will be some improvements that can be made relatively easily while others will take longer and will need clinician time and leadership.

We would also like to thank Dr Claire Heath for supporting us with the report by providing narrative intelligence around cardiology data.

Paul Higgitt – Senior Engagement Lead, Healthwatch Walsall
Phil Griffin – Chairman Walsall Together Service User Group

Appendix

Patient Stories

Mr H's Story

Year Birth - 1958

Dad has never had any heart issues or complaints. Dad went to the GP for a regular check-up and was told to go to hospital as he had a suspected heart attack.
He was admitted and blood highlighted that there was something just not right – suspected heart attack. Dad had no chest pains, but this may have been down diabetes medication which had a numbing effect.
The next day on admission the consultant told us that heart and kidney were weak but not going to refer to New Cross. Told if do an angioplasty it would damage the kidneys more.
Dad was uncomfortable and after 7 days was told to go home once there was a bowel movement. At home Dad was not 100% and had difficulty breathing, so we called 999.
At Walsall Manor we were told Dad had water on the lungs and Dad was put on ventilation. GP decided Dad was to be referred to New Cross. After 7 days (the care was amazing) an angioplasty was undertaken as we were told that there were different ways to do it.

We were told that Dad needed surgery and they undertook a triple heart bypass. Dad visited the renal consultant a few weeks after he was discharged about his kidneys and they had no idea that Dad had a triple heart bypass. Nothing had been passed on.
No pass over to the next hospital.

What has made the situation worse is that Dad's main language is Urdu, so he has been reliant on his daughter all the time to keep him informed of his care.
Dad is now attending Heartcare Walsall. He was first very frightened to attend not knowing what it entails but the staff there have been very friendly and supportive of dad through his rehabilitation.

Johns Story

Year of Birth - 1950

John has been active throughout his life doing a variety of sports and as a proactive squash player, cyclist, and motor racing driver. John has always kept himself fit. He also rings church bells across Walsall and beyond and with his family.
John although slim and active told that he had type 2 diabetes over 18 years ago which John has had under control through healthy eating.
About 12 months ago John started getting minor muscle pain in his chest and as his father suddenly passed away due to a heart attack at the age of 59 John took it seriously and went to the GP. John's GP took it very seriously, especially with his family history and sent John to A&E at Walsall Manor straight away.

Whilst in Walsall Manor John waited just 20minutes to be seen. John before he had been examined heard the younger consultant say to the Senior consultant "I'm *not quite sure what he is doing here but his GP sent him*". The Senior consultant took it seriously and arranged for John to reattend Walsall Manor less than 2 weeks later for an angiogram and heart stress test. John was then informed that we would need to have either a triple or quadruple heart bypass.

John underwent a Quadruple Heart bypass at New Cross Hospital.

The only key issue about the treatment John highlighted that the food at New Cross was not geared around those with diabetes however he had asked the question to be informed it was not an option.

After his operation John was referred to Heartcare for a 13-week course of rehabilitation and exercise. It has done John a great deal of good physically and mentally.

John highlighted that he feels *he is one of life's lucky people* and is grateful for the support and the programme that Heartcare put him on.

Heartcare also explained that before John had the operation and not feeling pain regularly, they were able to explain that silent ischemia is particularly prevalent in people with diabetes.

Asking John what keeps him motivated – his family bonds, the importance and love for his wife, children, and grandchildren and to see them grow up.

John continues to go to Heartcare after the 13 weeks.

John had lost his motor racing licence but with letters of medical support from Dr Anthony has had his licence reinstated.

Case Study - Sally's Story

Year of Birth 1981

In September 2020 I had been going to the gym a few times but started to get pains in the bottom of right her arm. It started to get worse carry a bag on my right arm.

I explained to my GP what was going on, but he said that it was due to my back related issue, thus I attended a Chiropractor again. The pain did not go away, so I called my GP again the following week as the pain was severe. My GP prescribed Codeine. A few days later in December 2020 I called 111 and was taken into hospital and give morphine. I was also given a CT scan and blood test were taken. I was discharged the same day. 2 days later I received a phone call asking me to go to New Cross hospital as I was having a potential heart attack.

I was told that I had blood clots but only on my lungs. After further tests I was informed that I would need to have an angioplasty procedure.

I had 2 stents fitted at New Cross. I was not told what had been done until the day after. The consultant explained that I had a heart blood clot in my main left artery.

My aftercare had not been positive as I was finding it difficult to get medication for pain management from my GP.

I was then referred to heart care for an 8-week physical cardiac rehabilitation but had not received any follow due to the pandemic. I was concerned as my father had a triple heart bypass but there was no indication if this was hereditary.

After my surgery I never received any follow up calls my GP. My GP though had told me that it was not typical for pains in the right side to be a sign of a heart attack. I was shocked by this response.

I was not able to go back to work for many months and the psychological impact was significant. I have been worried what if I did not wake up, will I have further complications. My anxiety has really been affected.

GP is not Walsall based but Wednesbury.

Case Study - R's Story

Year of Birth - 1968

R lives in Brookhouse, Walsall but has kept her GP surgery in Pleck. R is 53 years of age. R has been experiencing menopausal health issues with heavy bleeding but between 2017 and 2019, she was also experiencing shortness of breath, dizziness, and fluctuating blood pressure. R had been to her GP several times and it had been dismissed as part of her menopause. R continued to experience shortness of breath, dizziness, and fluctuating blood pressure. R attended her GP again to be given iron tablets.

R felt that she had continuously not been listened to by her GP and was feeling anxious. R in 2018 – 2018 started to get chest pains. She visited her GP again in February 2019 and saw a trainee GP who referred R to Walsall Manor for an ECG. The ECG was showing up normal. The consultant referred R for a heart scan in June 2019. Soon after this time the consultant had left the Trust, but R did not hear anything for 6 months and was still getting the symptoms and becoming more anxious. R had called the GP many times for the results and finally called the hospital to chase the results, after being passed around a few departments she found out that the report had not been signed off by the consultant hence had not been sent to the GP. The letter was received by the doctor in January 2020, but it was still backdated to June 2019. When speaking to the secretary the remarks had been it should have been on FUSION.

R was diagnosed with calcification of the arteries and was prescribed Atorvastatin's and aspirin. R was informed that this should help to break down the calcification however R is concerned that this could cause a clot elsewhere, but R does not seem to be able to get a straight answer from the GP . As the consultant has left R has not tried to contact the hospital to speak to a consultant.

Now in March 2021 R is still having some of her symptoms but has not had a medication review or a review from the consultant.

R explained how this has been impacting on her psychologically and many people do not know their way around the system.

R also explained that in February 2020 she collapsed at home and was taken into hospital where she was diagnosed with menorrhagia, she is taking additional medication for that. She had a biopsy at Manor hospital February 2020 results of which she has just chased up from the hospital, March 2021. The hospital secretary said the results should have been available via Fusion for the GP, but GP's receptionist said there was no record available. It has taken a considerable amount of time to get a Gynaecologist.

R is a well-educated lady who feels that there needs to be an independent body to oversee primary care.

Case Study – L's Story

Year of Birth - 1958

L has lived in Blakenall most of her life. L's husband passed away 3 years ago from Cancer. L and her husband had been heavy smokers for most of their lives and had not eaten healthily with non-active lifestyles. L has diabetes and rheumatoid arthritis and was diagnosed with COPD in 2019.

In October 2019 L started to suffer significantly with her breathing and sharp pains in her upper body. The pain started to be sharper, and L attended her GP. L stated that her GP had been very abrupt about her lifestyle and asked if she would like to be referred to lifestyle choices which L declined. Her GP also referred L to Walsall Manor for an ECG, as an urgent referral. L attended the ECG appointment within 2 days and after having a thorough ECG test and bloods taken, she was soon highlighted that she had angina.

L was referred to her GP who prescribed GTN and beta blockers. Her GP stated that she may need to have surgery but continued to ask L if she would like to access lifestyle change support. The GP stated very firmly that her lifestyle had put her as risk.

L reluctantly agreed to be supported and was referred to One You Walsall. L met with one of the Lifestyle Team who explained opportunities to support L both with her physical health challenges and the impact on her mental health.

L was able to join a support group for people with respiratory and heart conditions. She was explained and looked at tools such as the Vicious Health Cycle. L has also been able to access smoking cessation support and has found talking to people a great help as it has taken her mind off losing her husband. L has cut her smoking back significantly and is eating more healthily. She has also joined a local walking group.

During 2020 L found the isolation very difficult as she said *to kept on track with quitting smoking, eating healthy and exercising in groups I am struggling.*

One You Walsall have been able to support L with telephone calls and helping to motivate her, but it was not until September when she was able to meet up safely with others and go walking.

In talking to others in her walking group she had found people in similar situations where living on your own and with the national lockdown has had a significant impact on her health.

Case Study – D's Story

Year of Birth - 1945

D lives in Caldmore for over 25 years, aged 76. D first had a stroke in 2008 with 6 small episodes a day. D is a very determined lady. It took 2 months before she could start walking again. She was then diagnosed with AF in 2010. D has high and low blood pressure which meant that she has had many falls due to dizziness. D cannot feel her AF but knows when she has had an AF experience as she goes very tired.

D is now in heart failure diagnosed in 2015. D's mom also had heart failure but was not identified whether this is congenital. She was also diagnosed with a leaky valve which very much concerned her. Di also had a pacemaker fitted in 2016.

In 2019 whilst having routine checks at Walsall Manor D was diagnosed with angina. During 2020 D started to get very bad AF symptoms with a heart rate over 180.

D contacted her GP in 2020 as was referred to the AF clinic but they were not able to see her, however she was able to see a Heart Specialist who advised changing medication from Perindopril and to move to another drug. The consultant was also to inform the GP that there was a medication change. However, in December 2020 the GP had still not received the letter. D's GP though agreed to change the medication as they knew her well.

In December 2020 D contracted COVID-19. The GP suggested rapid response as how unwell she was, and with all the medication D suffers from bad gastro issues which causes dehydration. Rapid Response were able to put D on an IV drip at home. D quickly felt much better.

D has explained that it has been a struggle, however D explained that the pacemaker clinic is fabulous, but trying to get in to see a heart specialist is difficult to say the least. Access to the pacemaker clinic is very good. The Cardiology Consultant spat Walsall Manor is very good, explains everything in detail. Even through lockdown D has still be able to get her pacemaker checks.

D attended the Walsall self-care management group and found and still finds many ways to help cope with her condition such as distraction techniques, meditation, better breathing. All the tools in the self-care management programme.

It has been difficult though being clinically vulnerable not being able to see her children and grandchildren.

In asking the question is there scope for a virtual heart support group D said very much. There are many people have been diagnosed but just left and do not know where to turn to for advice. D explained that some people that she knows who have a heart condition do not get follow ups.

D explained you can live a long time with heart failure. If it were not having to deal this with her mum, she would have been terrified. It can be a terrifying experience when being diagnosed with a heart condition.

D explained that the term heart failure to some means it is the end, however it depends on the mentality of the individual. D is not aware of any psychological services on offer to patients that have been diagnosed with a heart condition.

One of the problems that D has faced is the clinical wording in letters from consultants to GP.

In asking what she would like to see anything change in the cardiac service would be more emphasis on aftercare.

D explained that her heart conditions have not been down to lifestyle choices, but possibly due to congenital issues.

D also has Chronic Kidney Disease and well supported by ensuring that she has regular blood tests.

D also suffers from depression due to all her health conditions and feels at times that she is losing her independence. Her GP has put D on Citalopram, which has helped. D had her Citalopram medication increased to 20mg during 2020.