



Heart Valve
VOICE

Towards a Heart Healthy Future

A Gold Standard in the Diagnosis, Treatment and Management
of Heart Valve Disease in Adults

The more we listen, the more lives we save



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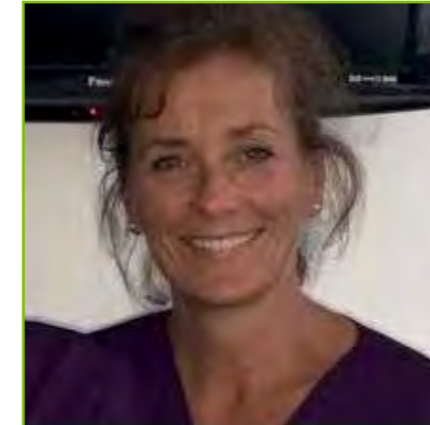
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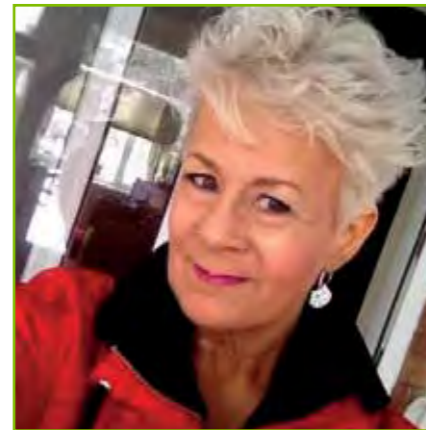
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Heart Valve Disease Patient



Ms Marina McGrath
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additional contributors

A number of clinical sub-groups were formed to consider specific stages of the patient pathway. These were made up of members of the core Working Group, as well as the following clinicians:

Clinical Sub-Groups

- **Professor Olaf Wendler**
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Support

- **Four Public Affairs**
Acted as secretariat to the Working Group.



Actions

In order to ensure the Quality Statements and Recommendations set out in this report are implemented and that standards of care are improved across the country, including supporting the development of a NICE guideline, Heart Valve Voice is committed to a series of actions in 2019.

Implementation Group

- An implementation group will be convened to agree upon the best way to realise the Quality Statements and Recommendations set out in this report. This will include core members of the Working Group.

NICE Guidelines

- Heart Valve Voice welcomes the announcement that NICE is developing a new guideline on the investigation and management of heart valve disease in adults. We will continue to call for the proposed guideline to echo the Gold Standard of Care as set out in this report.

Regional Meetings

- A series of regional meetings will be convened across the UK to raise awareness of the guidelines and enable a discussion on how the Working Group quality statements and recommendations can be implemented at a local level.

Awareness Raising

- Heart Valve Voice will continue to raise awareness amongst key stakeholders of heart valve disease and the Gold Standard of Care as set in this report and highlight the need for both the rapid publication of official NICE guidance and the uptake of best practice procedures across the UK.

Gathering Data

- Heart Valve Voice will seek to gather evidence and data to highlight the clinical and financial burden of heart valve disease on NHS England, given the impact on patients' lives and the cost to the NHS of not treating patients early enough, or not treating them at all.

Introduction

Wil Woan
Chief Executive, Heart Valve Voice

Heart Valve Voice is the UK's dedicated heart valve disease charity. Formed in 2013, the charity is comprised of people with real experiences of heart valve disease, including patients and clinical experts such as cardiologists, cardiac surgeons, general practitioners and nurses.

As Chief Executive, I work with many patients who have been diagnosed with, and effectively treated for the condition. Unfortunately, many people with heart valve disease in the UK continue to go undiagnosed and access to effective treatment is variable across the country. Our mission is to improve the diagnosis, treatment and management of the condition by raising awareness of the need for timely detection and intervention in order to ensure all patients receive the best possible care and support.

Following on from our report: *'Towards a Heart Healthy Future: A 2020 Vision for Heart Valve Disease'* published in November 2016, I am pleased to present the 'Best Practice in the Diagnosis, Treatment and Management of Heart Valve Disease in Adults'. We have brought together leading clinicians from across the treatment pathway, as well as a group of heart valve disease patients, to identify what best practice in heart valve disease care looks like. This gold standard is set out in a series of Quality Statements and Recommendations which cover the treatment pathway in its entirety.

I would like to thank everyone who has been involved in the production of this report over the past year for taking the time out of their busy schedules to help make a lasting difference in the care of heart valve disease patients. I look forward to seeing these best practice guidelines become standard practice across the UK and for them to be a vital resource as the National Institute of Health and Care Excellence (NICE) progresses with the development of its official guideline. This will help realise our 2020 Vision of creating effective and standardised services, and realising greatly improved outcomes for heart valve disease patients.

Wil Woan
Chief Executive, Heart Valve Voice





Foreword

Professor Huon Gray
National Clinical Director for Heart Disease,
NHS England



Heart valve disease affects around 1.5 million people above the age of 65 across the UK. Moreover, since the over-65 age group is set almost to double by 2050 we should anticipate a significant future increase in those affected, adding to the challenges faced by the NHS and social care. Early diagnosis and treatment is vital if we are to lengthen and improve the quality of life, reduce unplanned hospital admissions, and ensure those with valve disease are able to play an active role within their communities.

Significant variation in the rates of diagnosis and treatment of heart valve disease exists across the UK. Our challenge as professionals, and those supporting charities such as Heart Valve Voice, is to work together to achieve earlier diagnosis of this condition and timely provision of the treatments which can do so much to improve length and quality of life for those affected. Understanding why variation in services exist and learning from areas of best practice is one of the first steps.

I was delighted to attend the Parliamentary launch of Heart Valve Voice's report 'Towards a Heart Healthy Future: A 2020 Vision for Heart Valve Disease'. I heard a number of positive stories from patients about their treatment, including one person who was able to return to full-time work as a midwife post-treatment, having previously thought she would be forced into retirement as a result of her condition.

I commend Heart Valve Voice for bringing together this Working Group of leading clinicians and patients to describe the challenges faced by professionals and patients in managing valve disease and for suggesting ways in which services might be improved. This will help us in our collective ambition to achieve the best possible outcomes for patients, and will support objectives related to heart valve disease set out in the NHS Long Term Plan¹. I look forward to working with Heart Valve Voice and others in achieving this.

Professor Huon Gray CBE MD FRCP FESC MACC
National Clinical Director for Heart Disease

¹ <https://www.longtermplan.nhs.uk>

Objectives

- To develop a 'gold standard' in the diagnosis, treatment and management of heart valve disease that will support all healthcare professionals involved in the patient pathway to deliver high quality care of the disease.
- To support heart valve disease patients in order to better understand what they should expect from their healthcare professional and treatment pathway when being diagnosed and treated for their condition.
- To address challenges in the system preventing the optimal care of heart valve disease patients.
- To provide NICE with a 'gold standard' that can be used to support the development of the heart valve disease specific national guidelines.

Overview and Process

Scope

It was agreed upon in the initial meeting that the project would cover the diagnosis, treatment and management of adult heart valve disease specifically and would not cover congenital heart valve disease or other non-related cardiac diseases.

It was also agreed that the group would not consider or include medicines or technologies that are not currently approved or licensed to be used in the UK for the treatment and management of heart valve disease.

Membership

The core Expert Working Group is made up of professionals from across the heart valve disease treatment pathway, including: general practitioners; clinical nurse specialists; research nurses; surgeons; cardiologists; and patient representatives. Those involved also included members of various existing heart valve disease groups and professional organisations, such as: the British Heart Valve Society; British Society of Echocardiography; Society for Cardiothoracic Surgery; and European Society of Cardiology.

Process

Overview

The Expert Working Group met on two separate occasions (4th May 2018 and 17th October 2018). During the time in between the two meetings, a series of sub-groups formed in order to focus on specific stages of the heart valve disease treatment pathway. Those who made up these sub-groups, which included members of the core Working Group alongside additional clinical contributors, worked via teleconference as well as e-mail.

Full write-ups of each meeting and sub-group teleconference were produced by the secretariat and agreed by members. These are available in their entirety on the Heart Valve Voice website.

First Working Group Meeting

During the first meeting in May, the Expert Group agreed on the scope and ways of working set out for the project. The members also agreed on the way in which the patient pathway should be divided into individual stages for the purpose of this project. The resulting sub-groups were: case finding and initial awareness;

overview and process

assessment and diagnosis; treatment; and post-treatment management. The areas to be covered in each of these sub-groups and their proposed membership were agreed. It was also agreed that a patient sub-group should be formed in order to ensure the patient voice was central to the development of the gold standard.

Clinical Sub-Groups

As described above, four clinical sub-groups were formed that were each made up of approximately four members, including one 'lead'. A teleconference was organised for each group, where the respective stage of the pathway was discussed in great detail. After these calls, a series of draft quality statements and recommendations were developed before being shared with the sub-group to ensure that they were an accurate representation of discussions.

Patient Sub-Group

In between the two Working Group meetings a patient group was also convened which was made up of five heart valve disease patients and an NHS England Patient Adviser, Neil Betteridge. Members were asked to describe their own experience of the heart valve disease treatment pathway and provide any comments or feedback they had on the outcomes of the clinical sub-groups.

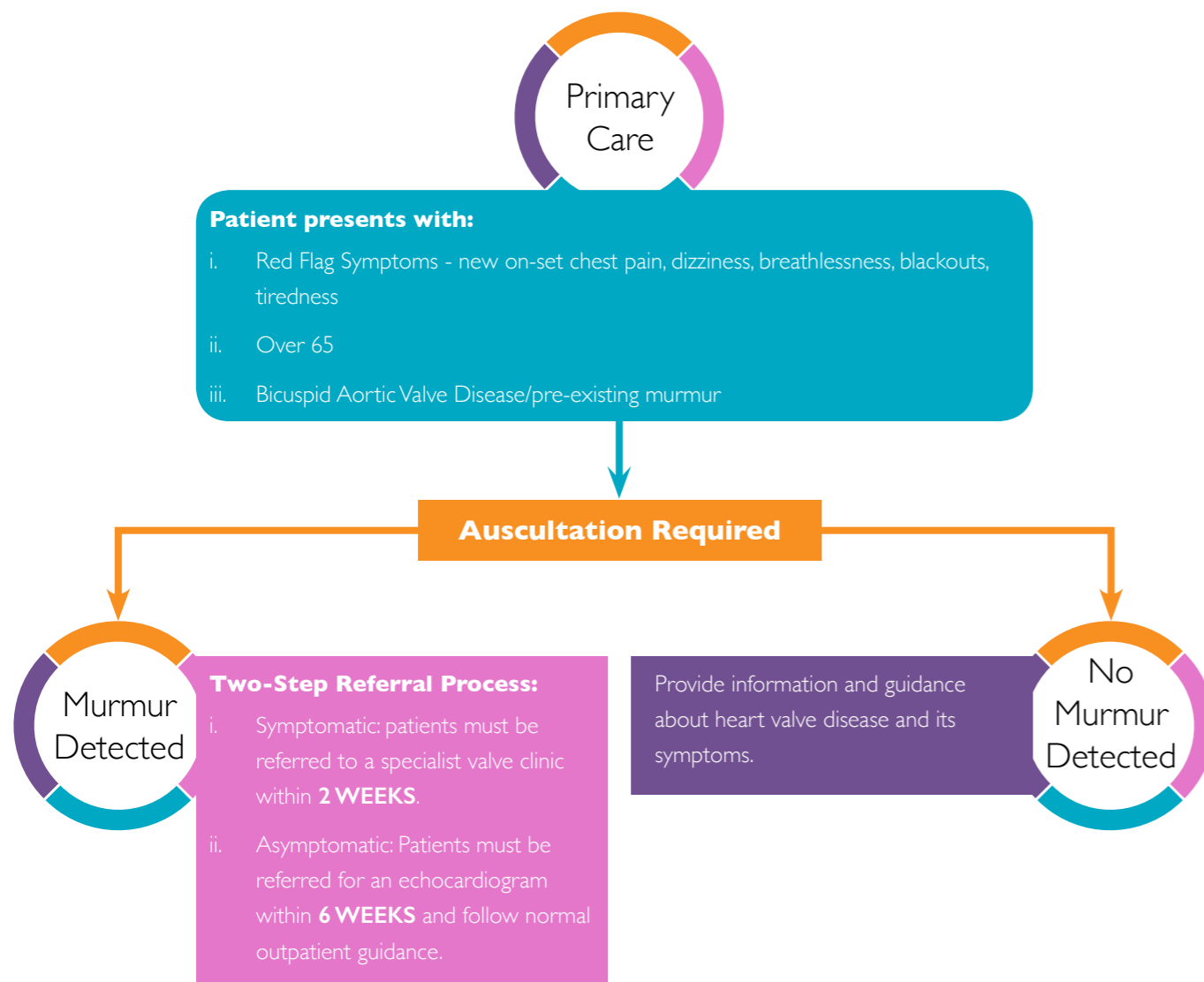
Second Working Group Meeting

During the second Working Group meeting, core members were given the opportunity to discuss the work that had been completed over the previous months, as well as hearing a presentation on patient sub-group feedback from the patient representative Marina McGrath. They were also given the opportunity to review each of the draft quality statements and recommendations individually and comment on their wording and content. Following this meeting and taking the discussion into account, the quality statements and recommendations were redrafted. These were then shared with all those who had been involved in the project to ensure that they gave a comprehensive account of the treatment pathway and that they represented the highest quality of care possible.

Quality Statements and Recommendations

The Quality Statements and Recommendations set out in this report detail a comprehensive summary of best practice in the diagnosis, treatment and management of heart valve disease across the treatment pathway. The Quality Statements set out a level of care and knowledge that would ensure the best possible patient care from healthcare professionals at each stage of the process, whilst the Recommendations set out specific actions that should be undertaken to improve service delivery and outcomes.

a. Case Finding and Initial Referral



Raising Awareness

Quality Statements

- Primary care clinicians should be aware of the red-flag symptoms of heart valve disease (new on-set chest pain, breathlessness, tiredness, dizziness or blackouts and atrial fibrillation (AF)) and have an understanding of the broad range of treatment options available. They should also be aware of the need to listen to the hearts of patients who are over the age of 65 and be prepared to refer on for further assessment should any abnormality be identified.
- People at increased risk of heart valve disease, such as those over the age of 65, those with murmurs identified earlier in life and those with a family history of bicuspid aortic valve disease, should be made aware of the signs and symptoms of heart valve disease and encouraged to ask their GP to listen to their heart.

Recommendations

- A campaign to raise awareness of heart valve disease should be initiated and targeted at GPs and other healthcare professionals that do not specialise in cardiovascular conditions in order to increase their knowledge of red-flag symptoms and the various treatment options available.
- An awareness campaign should be initiated in order to raise awareness of the red-flag symptoms of heart valve disease amongst the general public. Separate messaging should be developed for symptomatic and asymptomatic patients, for example:
 - Symptomatic: "Dizzy, breathless or just not feeling right, could it be heart valve disease?"
 - Asymptomatic (only targeted at high risk cohorts): "Going for a check-up? Ask your doctor to listen to your heart."

Identification of Patients

Quality Statements

- All healthcare professionals with appropriate training should be encouraged to investigate patients for evidence of heart valve disease. In the event a murmur or other abnormality is found, they should liaise with the patient's GP who should be responsible for referring the patient on for further assessment.
- All patients presenting with the following clinical symptoms and signs should be given a stethoscope check: new on-set chest pain, breathlessness, dizziness

or blackouts, tiredness and AF. Following auscultation, these patients should then be referred on for echocardiography if a murmur is detected or no second heart sound is heard, which indicates problems with valve function.

Recommendations

- A two-speed approach for the testing of symptomatic and asymptomatic patients should be developed, with advice on the recommended frequency of follow-up checks published for specific cohorts.
- A priority list should be developed highlighting a spectrum of opportunity for intervention and patient identification, from the extreme level of symptomatic presentation to the routine testing of specific cohorts.
- A specific best-practice pathway should be developed for the identification of patients with heart valve disease to ensure those presenting with the relevant symptoms are referred onwards for further diagnosis.

Self-Diagnostic Tools

Recommendation

- Further research should be conducted into the development of self-diagnostic tools in heart valve disease and the field of cardiology more broadly.

Referral

Quality Statements

- Symptomatic patients should be referred to a specialist valve clinic, which should incorporate access to echocardiography. Asymptomatic patients should be referred directly to echocardiography and then be put into a specialist valve surveillance programme dependent on the result of the echocardiogram.
- The primary images from the echocardiogram should be visible to local cardiology teams and results should be analysed by a clinical cardiologist with the required training to interpret the results fully and advise accordingly.
- The timeline to referral for symptomatic heart valve disease patients should be in line with the two-week urgent referral pathway.

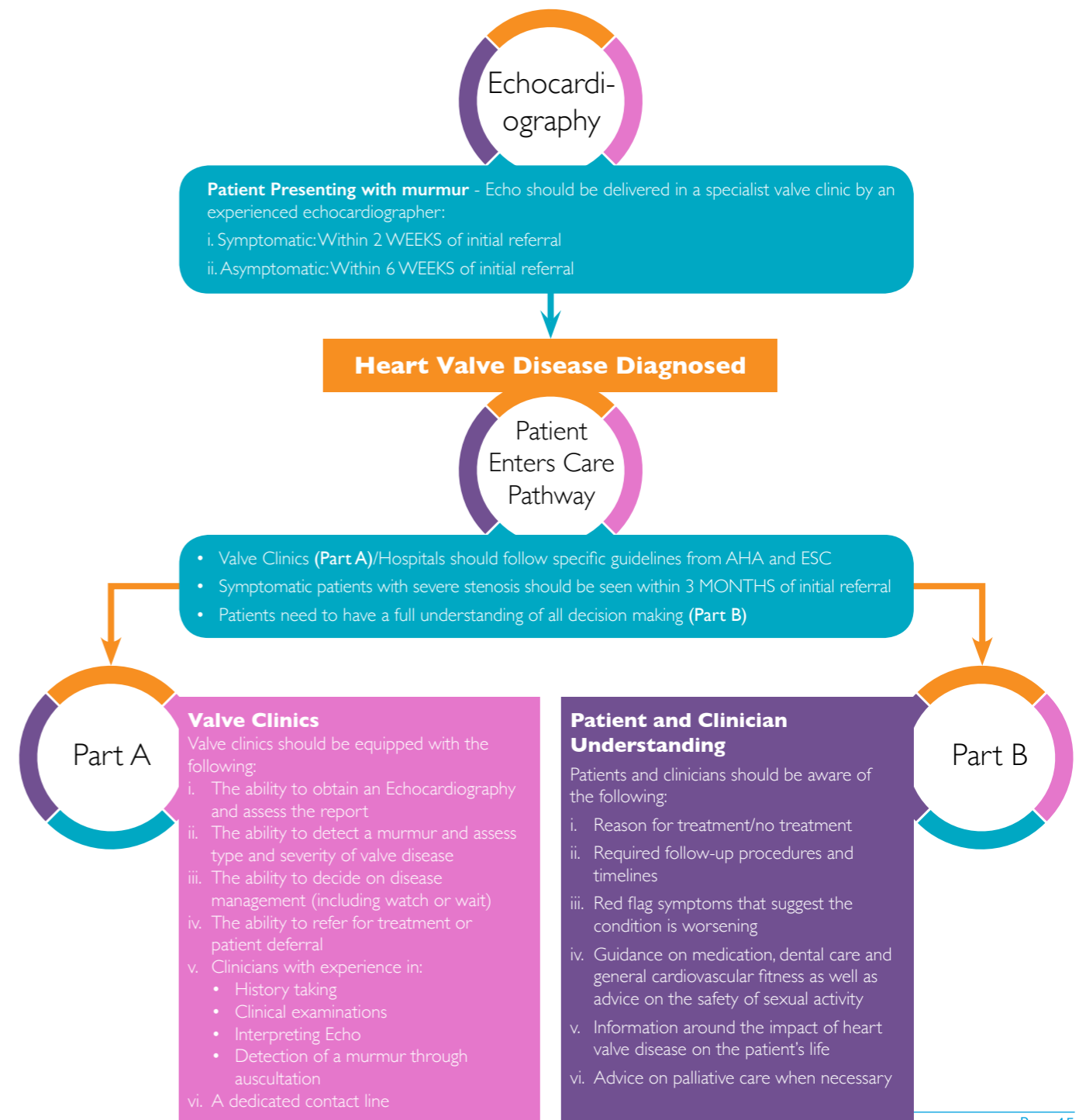
Recommendations

- Future commissioning contracts with CCGs should require that any echocardiography, whether delivered in the community or by independent providers, must be made available to local cardiology teams so that images can be reviewed to ensure there is no immediate need for repetition. All

echocardiography should be performed by appropriately accredited individuals, e.g. proficiency accreditation through the British Society of Echocardiography or equivalent.

- A GP education programme or event should be organised in order to raise awareness of heart valve disease and its symptoms, as well as the key parameters in echocardiography that would trigger specialist referral.

b. Assessment and Diagnosis



Access to Echocardiography

Quality Statements

- All patients presenting with a heart murmur should be referred for echocardiography within a specialist heart valve clinic in order to obtain an accurate and holistic diagnosis.
- All echocardiograms should be assessed by a clinician with experience in echocardiography in order to ensure an accurate and effective diagnosis.
- Symptomatic patients with suspected severe heart valve disease should undergo echocardiography and a clinical review within two weeks of referral. Asymptomatic patients with suspected heart valve disease should undergo echocardiography and a clinical review within six weeks of referral in line with standard non-urgent outpatient referral guidelines.

Recommendation

- NHS policy makers should take the necessary steps to increase the number of practising echocardiographers across the UK in order to ensure patients who require further investigation are able to access echocardiography in a timely manner.

A Care Pathway for Patients with Heart Valve Disease

Quality Statement

- All clinicians involved in the diagnosis and management of heart valve disease should be aware of and follow existing best practice guidelines on the frequency of follow-ups for different heart valve disease patients, as specified by the American Heart Association⁽¹⁾ and European Society of Cardiology⁽²⁾.

Recommendations

- All heart valve disease patients and clinicians should be aware of: the required follow-up procedures and timelines; red-flag symptoms that suggest the condition is worsening; and other information around the impact of heart valve disease on a patient's life. In order to simplify the management of follow-up, a flow chart should be developed and disseminated amongst relevant healthcare professionals detailing best practice on the frequency of follow-up checks for heart valve disease patients not yet requiring intervention.
- In order to prevent patients from falling through the net once a decision has been made to defer treatment, all hospitals should provide patients with a

dedicated heart valve disease phone line to ensure they are easily able to receive an update on their healthcare plan, as well as to alert clinicians to the onset of symptoms should they occur.

A Rapid Access Valve Assessment Process

Quality Statements

- Valve clinics should be overseen by the most appropriate clinician with an interest in heart valve disease within the respective local health economy. Services must be able to provide echocardiography so that there is a safe and seamless one-stop service to assist with diagnosis and treatment recommendations with minimal delay. The service should have the ability to: detect a murmur; obtain an echocardiogram; assess the report; and decide on further management, whether watchful waiting, referral for treatment or a decision that treatment is not needed. This should be done with minimal delay in accessing comprehensive and accurate diagnostics. For symptomatic patients with severe aortic stenosis, definitive treatment should be completed within three months of initial referral.
- Valve clinics should also include clinicians with experience in: history taking; clinical examinations, including the detection of murmurs through auscultation; and interpreting the results of echocardiography.

Recommendation

- Where possible, follow-ups should be completed over the phone. This is particularly relevant for patients who are unlikely to be referred on to surgery due to comorbidities or other restricting circumstances.

Communication, Surveillance and Deferral

Quality Statement

- Patients should have a clear understanding of their disease and the reason that treatment/no treatment has been prescribed at the earliest point on their pathway. This holistic understanding should include: the timing of surveillance; guidance on medication, dental care and general cardiovascular fitness; individual advice on the feasibility of exercise – based on their specific condition and their favoured activities; advice on the safety of sexual activity; as well as knowledge of potential triggers to treatment, red flag symptoms and palliative care, where appropriate. Information should be provided via a range of sources, including face-to-face communication and telephone consultation, as well as through written and online materials.

c. Treatment



Surgery

Quality Statements

- Decisions on the most appropriate treatment should follow existing guidelines as developed by the American Heart Association⁽ⁱ⁾ and the European Society of Cardiology⁽ⁱⁱ⁾. However, the clinician should use their own individual judgement and must consider the specific needs of each individual patient.
- Patients should be referred to a multi-disciplinary team ahead of the decision on whether to treat or not, unless the individual clinician is confident beyond reasonable doubt the patient requires either a specific course of action or deferral, in keeping with the clinical guidelines mentioned above.
- The decision to treat and the most appropriate treatment for patients should be a joint decision between the patient and clinician, and based on their wants and needs, and quality of life factors. It should also be made according to current medical evidence.

Recommendations

- In line with guidelines developed by the British Cardiovascular Society; British Cardiovascular Intervention Society; and Society of Cardiothoracic Surgery (BCS/BCIS/SCTS)⁽ⁱⁱⁱ⁾, all MDTs should be made up of the following core team of healthcare professionals: an interventional cardiologist with a specialist interest in TAVI, a cardiac surgeon with a specialist interest in TAVI and SAVR, an imaging cardiologist who specialises in echo and CT, a general cardiologist, and a clinical nurse practitioner. Dependent on the needs of the individual patient, an MDT should also have access to a wider team, including: a care of the elderly physician, a vascular surgeon, a vascular radiologist, a cardiac anaesthetist, and palliative care clinician.
- A specific guideline should be developed on a process that would allow for swift and appropriate referrals onward following the identification of valvular heart lesions.
- Where possible, discussions held within MDTs should be captured and this decision making process should be communicated clearly with the respective patient to ensure they understand the reasons behind their treatment decision.

Deferral

Quality Statements

- Patients who have been deferred treatment following clinical review should be fully informed about their healthcare plan and should have access to clear and readily available information regarding the frequency of their follow-up appointments.
- Patients who have treatment deferred should receive a minimum of one echocardiogram a year. However, the frequency of follow-up appointments will depend on the requirements of each individual patient and the severity of their heart valve disease. An example best practice follow-up procedure guideline, suggested by Dr Rick Steeds, below.

Severity of HVD

Follow-up Procedure

Mild	Follow-up every three years with a clinical assessment +/- echocardiography if required
Moderate	Follow-up every year with a clinical review and annual echocardiography
Severe	Follow-up every six months with a consultant led clinical review and echocardiogram

Recommendations

- To prevent patients from falling through the net, all hospitals should provide patients with a direct means of contacting the relevant healthcare professional to ensure they can easily receive an update on their healthcare plan. The direct contact could be with a clinical secretary, a nurse, or other appropriate individuals within the hospital.
- Both patients and the relevant primary care physicians should be aware of the management plan in place during the deferral process to ensure symptoms are dealt with in the appropriate timeframe and manner.
- On presentation with symptoms following deferral, patients should receive an echocardiogram within two weeks as per the existing urgent referral guidelines.

Palliative Intervention

Quality Statements

- A patient should not be denied intervention based on age alone.
- Clinicians and patients should be aware that in specific circumstances, comorbidities and frailty may mean that intervention is not likely to provide benefit and is therefore not advised. Such a decision must be clearly communicated and discussed with the patient unless there are exceptional circumstances.
- A patient who is referred onto palliative care should be signposted towards relevant charities and patient groups for further information and support.

d. Post-Treatment Management



Decisions about post-operative care and management should be made by the most suitable heart valve specialist in the local healthcare network; they should provide the patient with the following:

- i. A management plan post valve treatment agreed upon with the patient
- ii. The required follow-up procedures and timelines
- iii. The appropriate medication
- iv. Information on the risk of infection
- v. Knowledge on the need for antibiotic prophylaxis
- vi. Knowledge on appropriate anti-coagulation
- vii. Information on other potential problems following surgery including endocarditis



Where possible, all hospitals and tertiary centres should have a dedicated heart valve clinic that provides:

- i. Post-treatment management services provided by clinicians with relevant valve disease experience
- ii. A dedicated contact number so patients receive an update on their healthcare plan or flag the onset of relevant symptoms
- iii. Relevant materials and guidance for patients on what to expect during post-op recovery in a hospital setting
- iv. Information and guidance on anti-coagulation bridging and endocarditis



Patients should be fully involved in the decision making process and should have a full understanding provided by their clinician/hospital of the following:

- i. Their disease
- ii. Where they are on their treatment pathway
- iii. What symptoms to look out for
- iv. Materials and guidance on what to expect during their post-op recovery
- v. The appropriate medications
- vi. The importance of maintaining appropriate anti-coagulation
- vii. Information on other potential problems following their treatment including endocarditis
- viii. A dedicated contact number from their local heart valve clinic or hospital

Follow-up

Quality Statements

- Decisions on post-operative care and management of patients should be made by the most suitable heart valve specialist within the respective local healthcare network, be that a nurse, doctor or other healthcare professional with the required experience.
- Patients should have a full understanding of: their disease; where they are on the treatment pathway; and what symptoms to look out for. They should also be fully involved in the decision-making process.
- Where possible, all hospitals and tertiary centres should have a dedicated heart valve clinic which has been developed and is led by someone with relevant expertise.
- In order to prevent patients from falling through the net following treatment for heart valve disease, all hospitals should provide patients with a direct contact number to ensure they are easily able to receive an update on their healthcare plan, as well as flag the onset of any relevant symptoms. The direct contact could be with a clinical secretary, a nurse or other appropriate individuals within the hospital.
- Patients should be provided with relevant materials and guidance on what to expect during post-operative recovery in a hospital setting.
- Clinicians should be aware of the need for post-operative bridging anticoagulation and should refer to existing guidelines^{(i),(v)} for further information. However, final decisions should be made based on the individual circumstances of the patient.
- Patients and primary care physicians must be aware of the importance of maintaining appropriate anti-coagulation, including the use of anti-platelet agents, following the treatment of heart valve disease.

Recommendations

- A national awareness raising campaign should be run in collaboration with relevant patient groups to ensure patients are able to recognise the red-flag symptoms of post-operative heart valve disease.

Frequency and Point of Delivery

Quality Statement

- As part of the valve clinic model, all hospitals should develop their own published guidance on the required follow-up and frequency of echocardiography for patients with the different types of heart valve disease and the different types of replacement valve used (mechanical and bioprosthetic), as well as for patients who have undergone a heart valve repair.

Recommendation

- The NHS and policy makers should support the development, dissemination and implementation of best practice guidelines on the most effective follow-up procedures for patients with heart valve disease across the UK.

Professional Awareness and Endocarditis

Quality Statement

- The specialist clinician, general practitioner and patient should agree on a management plan post valve treatment. This should include: the required follow-up procedures and timelines; appropriate medication; awareness of the increased risk of infection; the need for antibiotic prophylaxis; and patient awareness of other potential problems following heart valve surgery.

Recommendations

- Patients and non-cardiology clinicians should be aware of the signs and symptoms of endocarditis and the serious consequences of the condition if not identified and treated early.
- Clinicians should have access to clear guidelines on the prevention, treatment and management of endocarditis, and should be aware of the continuing risk of developing endocarditis after treatment for heart valve disease.
- A national awareness campaign on the symptoms of endocarditis should be targeted towards heart valve disease patients to ensure that they go to see the relevant healthcare professional as soon as red-flag symptoms such as a fever present.
- An awareness campaign should also be targeted at primary care physicians on the increased risk of endocarditis in patients who have previously undergone heart valve disease surgery. This will ensure doctors do not delay in referring patients onward with what could be relatively routine symptoms.

A Need for Change

The Patient Perspective

Membership

- Mr Neil Betteridge, Patient and Public Advisor, NHSE
- Ms Marina McGrath, Heart Valve Disease Patient
- Ms Pat Khan, Heart Valve Disease Patient
- Ms Sue Jardine, Heart Valve Disease Patient
- Ms Anne Bedish, Heart Valve Disease Patient

Overview

This group included patients with a wide range of experiences and different types of heart valve disease. It was convened in order to better understand the patient perspective of the current treatment pathway and ascertain what they feel could have been improved at each stage of the diagnosis, treatment and management of their condition. Each member was invited to submit a summary of their experiences and comments, as well provide feedback on the outputs of each of the clinical sub-groups.

The key points raised by the patient group on ways in which the patient pathway could be improved were:

- Increased awareness amongst the public of heart valve disease and its symptoms.
- Improved awareness amongst non-specialist healthcare professionals of heart valve disease, its symptoms, available treatment options and post-treatment care.
- The importance of clear, comprehensive and compassionate communication from healthcare professionals at each stage of the treatment pathway.
- The need for early access to specialist treatment centres to improve both the care received and the patient's peace of mind.
- The need to incorporate the views of the patient in clinical decisions and secure joint-decision making throughout the patient pathway.

Marina McGrath

It was after a set of routine tests at an HRT clinic that Marina McGrath first learned she had valve disease. The diagnosis explained why she had been feeling tired and breathless for the past while. Following her aortic valve replacement in 2014, Marina was soon back to full health and back to work as a midwife.

“An aura of purpose and authority”

Patient on the specialist valve clinic at the University Hospital of Southampton

Terri Richmond

Terri, 66, was diagnosed with mitral valve stenosis in 2017 after suffering a stroke. She had never realised anything was wrong with her heart and has always been active with sports and ballroom dancing. She is now just beginning her patient pathway and is keeping a positive mindset while waiting to hear back from her cardiologist on her next steps.

Initial Presentation and First Contact with Primary Clinicians

It was agreed that there was a significant lack of awareness amongst the public of heart valve disease. Many of the symptoms exhibited are synonymous with ageing more generally and people can be unaware of the severity of red flag symptoms, such as shortness of breath and dizziness. Further along the patient pathway, following diagnosis, this lack of awareness can also mean patients do not fully understand their diagnosis and their prospects, adding to the already substantial stress of the situation.

Secondly, there was a perceived lack of awareness amongst non-specialist healthcare professionals with various examples of misunderstandings, poor diagnosis and unclear communication. Tackling this lack of awareness to ensure that patients know what to ask and doctors know what to offer was seen as crucial in improving the initial stages of the heart valve disease patient pathway. This is coupled with the need for doctors to ensure they communicate in a sensitive and empathetic manner with patients.

Referral to Secondary Diagnostics

The lack of knowledge amongst non-specialist healthcare professionals can lead to further problems along the patient pathway. This is why there is a need for patients to be seen by a specialist heart valve disease clinician as soon as possible to avoid misleading or conflicting information from generalists. If at all possible, as specified in the Quality Statements, this should be within a dedicated heart valve clinic.

The Treatment Decision Process

As discussed previously, the most crucial aspect of the treatment decision process is clear communication between the relevant clinician and the patient. This includes the empowerment of the patient to actively participate in the decision making process around their treatment; an often daunting prospect when talking with experienced healthcare professionals.

Beyond improved communication, and in line with the overall objectives of the report, clinical practice needs to be improved so that the best clinical decisions are being made for each and every patient, which incorporates patients' views and looks to maximise their quality of life.

Patient experience of errors and miscommunications from their surgeon:

“Betrayal of trust”

“A no man’s land where help and guidance is only given when sought in stress or pain”

Patient experience of the post treatment management following discharge from hospital.

Post-Treatment Management

Best practice guidelines on the post-treatment management need to focus on developing a shared understanding and knowledge between the patient, the respective heart valve clinician, and the general practitioner. There is also a need for increased patient understanding, including of what red-flag symptoms to look out for and who to contact if they were to worry about any specific issues. This also involves guidance on how to maximise their quality of life and specific advice on issues such as: endocarditis; dental procedures; warfarin; and more general symptomatic guidance.

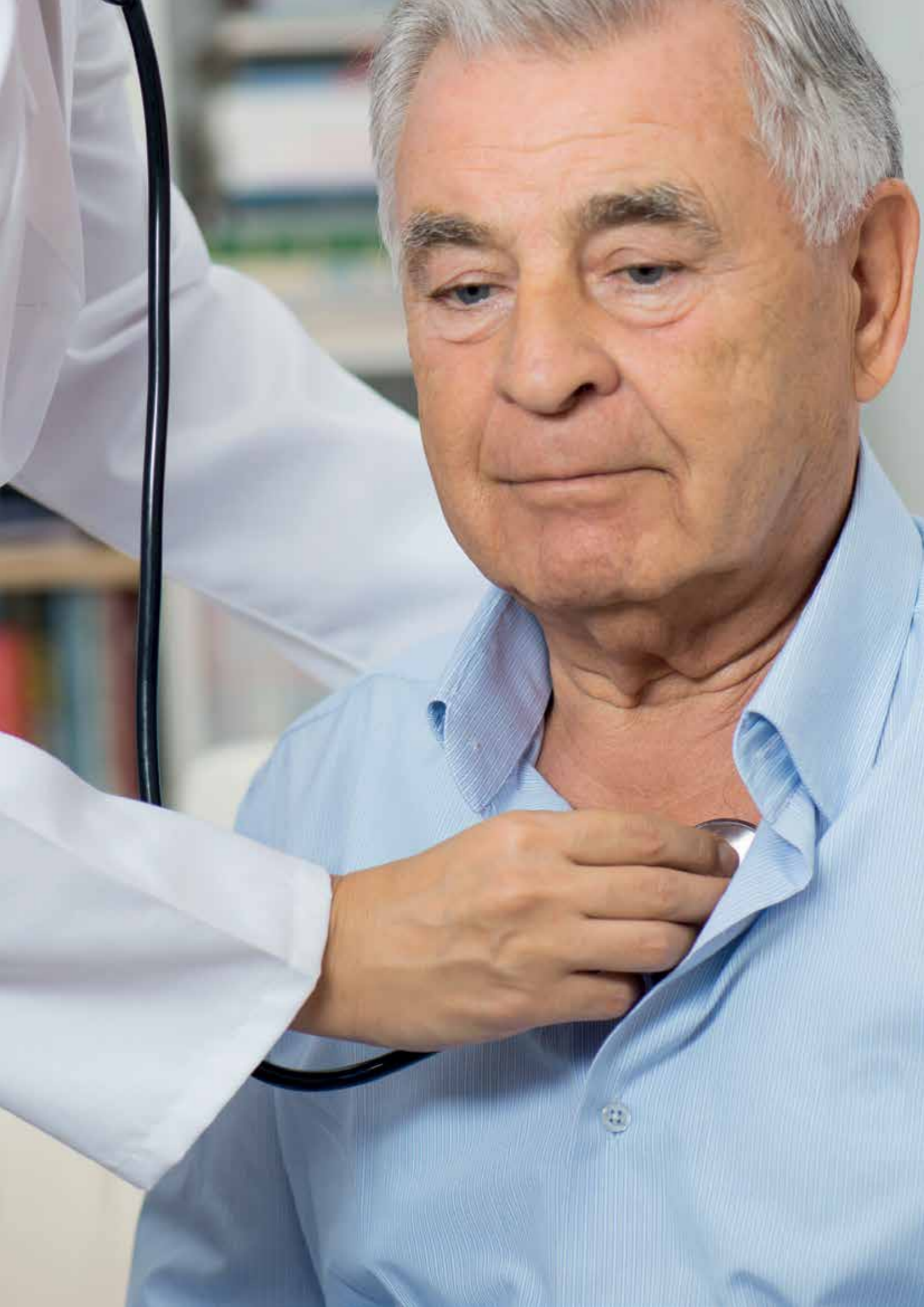
As described above, there is also a need to improve awareness amongst non-specialist healthcare professionals of patients who have undergone treatment for heart valve disease to ensure the care and medication prescribed is both suitable and effective for their specific circumstances.



Alan Tancred

A GP referred 77 year old Alan Tancred for further tests which led to an echocardiogram and put Alan on a patient pathway leading to a TAVI treatment at the Royal Sussex Hospital.

Alan speedily bounced back and just two weeks after leaving hospital, joined BBC Strictly’s Oti Mabuse on stage at a dance event, and has attended other major events in Brighton and Italy since as well as providing care for his 90 year old friend.



The Treatment Pathway

A Clinical Perspective

The decision to divide the pathway into the following four stages was made at the first Working Group meeting: case finding and initial referral; assessment and diagnosis; treatment; and post-treatment management. As set out previously, the individual sub-groups convened via teleconference and over e-mail to agree upon a set of quality statements and recommendations. These were then discussed and finalised at the second Working Group meeting. Following is a summary of the main topics and conversation points that arose during both Working Group meetings and the respective sub-group discussions. The full write-ups of each sub-group can be found on the Heart Valve Voice website.

a. Case Finding and Initial Referral

Membership of Clinical Sub-Group

- Dr Yassir Javaid, GpSI in Cardiology
- Dr Guy Lloyd, Consultant Cardiologist
- Professor Olaf Wendler, Professor of Cardiac Surgery
- Dr Rick Steeds, Consultant Cardiologist
- Mr Ishtiaq Ahmed, Consultant Cardiac Surgeon

Overview

The Case Finding and Initial Referral Sub-Group looked at ways in which to increase the identification of heart valve disease and the entry point markers which exist within the system in order to ensure more patients could be identified. The group also looked at initial presentation and referral, focussing on raising awareness amongst GPs and the public of red-flag symptoms of heart valve disease. It examined the best methods of referring patients on to a specialist valve service for further investigation and case management, as well as discussing a two speed timeline for symptomatic and asymptomatic patients.

Discussion

Issues in Primary Care and the Merits of Auscultation

The number of patients treated for heart valve disease in the UK is significantly lower than in comparable European countries such as France and Germany. Though, due to a number of factors, one of the major issues is the way in

which heart valve disease patients are seen in primary care. Three core issues exist around initial presentation: patient awareness of heart valve disease and its symptoms; primary care awareness of heart valve disease, the limitations of clinical examination and auscultation, the effective treatment options available; and primary care awareness and knowledge of the varied treatment options available. Combined, these result in the following scenarios: patients not being diagnosed and not receiving echocardiograms; and patients occasionally being diagnosed correctly but not being referred onwards.

On an actionable level, the feasibility and desirability of increased auscultation in primary care is a debatable issue when considering best practice in case finding and initial referral. On one hand, it is argued that those performing a stethoscope check do not need an in-depth knowledge on potential heart conditions; only the ability to identify an abnormality before referring onwards. Therefore an increased use of auscultation in primary care should be encouraged. On the other hand are the issues of time pressures in general practice, resource pressures in echocardiography and the potential inconsistencies of auscultation.

It is, however, important to realise that in order to capture an increased percentage of those with heart valve disease, there would need to be an increased use of auscultation in primary care, albeit opportunistic and targeted. As such, all healthcare professionals with appropriate knowledge and training should also be encouraged to investigate patients for evidence of heart valve disease. However, in order to prevent overburdening echocardiography, GPs should be ultimately responsible for referring on for further assessment.

Whilst in these circumstances it is essential to prioritise symptomatic patients to a certain extent, cohorts of high risk patients, regardless of whether they are symptomatic or asymptomatic, should also be targeted to ensure they are being checked periodically. This includes highlighting to both the potential patients themselves and general practitioners the need for increased auscultation when at a greater risk of developing heart valve disease. Those over the age of 65, with murmurs identified earlier in life and with a family history of bicuspid disease, are generally deemed to have a higher probability of developing the condition.

Referral: Method and Timeframe

With regards to referral on to further diagnostics, views on the issue of open access to echocardiography and other forms of referral, such as instant referral to Multi-Disciplinary Team (MDT), are varied. There are numerous opinions on the most effective method, particularly on the efficacy of open access given the resource pressures this can place on echocardiography. Most important, however, is simply ensuring the patient is seen within a specialist environment by those qualified to assess their condition.

A two-speed referral pathway is required for symptomatic and asymptomatic patients. Whilst targets come with additional cost and resource implications, in order to provide a gold standard of care, symptomatic patients should be seen in line with the two-week urgent referral pathway and they should be referred on to a specialist valve clinic, incorporating one-stop access to echocardiography. Asymptomatic patients should be referred directly to echocardiography in line with the standard outpatient timeframe of six weeks and put into a specialist valve surveillance programme. This reflects recent studies from the European Society of Cardiology that highlight the importance of being seen within a specialist setting at an early stage; a sentiment expressed strongly by the patient representatives. Furthermore, severe, symptomatic patients should receive treatment within three months. With an annual 6% risk of sudden death in this severe, symptomatic condition, this three month wait amounted to a 2% risk; however this timeframe is seen as effective and feasible.

Technological Advancements

Whilst self-diagnostic tools and advances in diagnostic technologies show great potential across a variety of conditions, they are not yet seen to be sophisticated enough to aid in the effective diagnosis of heart valve disease. However, there is strong support for further research into its possibilities and the potential to alleviate pressures seen in primary care.

b. Assessment and Diagnosis

Membership of Clinical Sub-Group

- Dr Rick Steeds, Consultant Cardiologist
- Ms Denise Parkin, Research Nurse (Cardiology)
- Mr Joseph Zacharias, Consultant Cardiothoracic Surgeon
- Dr Rachael James, Consultant Cardiologist

Overview

The Assessment and Diagnosis Sub-Group focused on identifying best practice in securing patient access to secondary diagnostic capabilities, including the development of a flow-chart to communicate the required actions for different types and severities of heart valve disease. Topics included the possibility of developing a rapid access valve assessment process within a valve service and the management of patients whose disease is not severe enough for a referral on to MDT or for whom treatment may not be appropriate.





the treatment pathway

Discussion

Experience and Knowledge

As with the points raised on case finding and initial referral, there is a need for a comprehensive knowledge amongst heart valve disease patients and clinicians of the various facets of the condition. As set out in the respective recommendation, this includes: required follow-up procedures and timelines; red-flag symptoms that suggest the condition is worsening; and other information around the impact of heart valve disease on a patient's life. These red-flag symptoms include: new on-set chest pain; breathlessness; dizziness; and blackouts.

Efficient Echocardiography

A key issue with echocardiography is the duplication of services that results from healthcare professionals undertaking services beyond their areas of expertise. In order to counter this, and improve efficiencies within the NHS and in line with the Getting It Right First Time initiative, it is crucial that all echocardiography is performed by appropriately accredited individuals and made available to local cardiology teams so that images can be reviewed.

Specialist Heart Valve Clinics

There are also multiple opinions on the most effective make-up of specialist valve clinics. However, key to their efficacy is ensuring guidelines are not too restrictive and ensuring those that are most experienced within the local health economy are given the opportunity to oversee service delivery. As set out in the quality statement, services must have the ability to: detect a murmur; obtain an echocardiogram; assess the report; and refer to treatment in order to reduce delays in accessing comprehensive and accurate diagnostics.

Communication, Surveillance and Deferral

As with all stages of the patient pathway, the communication between patients and healthcare professionals was seen as paramount. Patients require a clear understanding of their disease and the reasons that treatment or no treatment has been prescribed. This includes: the timing of surveillance; guidance on medication, dental care and general cardiovascular fitness; individual advice on the feasibility of exercise – based on their specific condition and their favoured activities; as well as knowledge of potential triggers to treatment and red flag symptoms. Information should be provided via a range of sources, including face-to-face communication, telephone consultation, as well as written and online materials. When treatment is deferred, it is also essential that the patient understands how to contact the relevant clinician or clinic to ensure they re-enter at the correct stage of the pathway if they have any concerns. This should avoid the need for them to present again at primary care or A&E in the event of onset symptoms.

the treatment pathway

c. Treatment

Membership of Clinical Sub-Group

- Mr Christopher Young, Consultant Cardiothoracic Surgeon
- Mr Pankaj Kumar, Consultant Cardiothoracic Surgeon
- Dr Dave Smith, Consultant Cardiologist
- Mr Malcolm Dalrymple-Hay, Consultant Cardiac Surgeon

Overview

Focussing on patients who are already under the management of a valve service, the Treatment Sub-Group examined the issues around determining the best treatment options for individual patients with the various types of heart valve disease and how this is communicated to them. This included: access to an MDT; the make-up of the MDT; the considerations of the MDT; the length of time between follow-up session; and the potential palliative care options.

Discussion

Treatment Decisions and the Multi-Disciplinary Team (MDT)

Various guidelines exist on the appropriate treatments for patients and their respective condition, including from the American Heart Association⁽ⁱ⁾ and the European Society of Cardiology⁽ⁱⁱ⁾. However it is crucial that clinicians use their own judgement and consider the specific needs of each individual patient. As set out in the Patient Perspective section, it is also crucial that patients are involved in the decision making process and empowered to discuss their options and ask questions of their respective healthcare professional.

Broadly, patients should also be referred to an MDT before a decision on treatment is made, albeit there being some cases where the clinician is beyond reasonable doubt that the patient should undergo a specific course of action. Thus, MDTs should focus on patients that lie in the “grey area” where there is no obvious course of action. In order to ensure this happens, it was suggested that patients should have seen all relevant clinicians personally before being referred to an MDT.

The make-up of MDTs is also a contested issue, but recent guidelines produced by the British Cardiovascular Society, British Cardiovascular Intervention Society and Society for Cardiothoracic Surgery (BCS/BCIS/SCTS) suggest it includes a core team, as well as optional additional members dependent on the need of the individual patient. These are set out in Table 1.

Core Team

- Interventional cardiologist with a specialist interest in TAVI
- Cardiac surgeon with a specialist interest in TAVI and SAVR
- Imaging cardiologist who specialises in echo and CT
- General cardiologist
- Clinical nurse specialist

Optional Additional Members

- Care of the elderly physician
- Vascular surgeon
- Vascular radiologist
- Cardiac anaesthetist
- Palliative care clinician

Table 1: The make-up of a multi-disciplinary team

It is crucial that MDT decisions are discussed with the patient and that the role of cardiac MDTs expands to include further administrative support to capture, support and communicate decisions. This would ensure that decisions are treated as a joint process between patient and clinicians, where the decision made would take into account wants, needs, quality of life factors and current medical evidence.

Deferral Procedures

In the event a clinician has made the decision to defer treatment, guidelines developed by the American Heart Association^(iv) on the required follow-up procedures exist. However, these can broadly be simplified as set out in Table 2.

Severity of HVD

Follow-up Procedure

Mild	Follow-up every three years with a clinical assessment +/- echocardiography if required
Moderate	Follow-up every year with a clinical review and annual echocardiography
Severe	Follow-up every six months with a consultant led clinical review and echocardiogram

Table 2: Example best practice follow-up procedures as suggested by Dr Rick Steeds

The multitude of information on what constitutes best clinical practice and what patients should expect can be complex. In order to simplify follow-up procedures, a flow chart should be developed and disseminated amongst relevant healthcare professionals and patients detailing best practice guidelines on the frequency of follow-up checks for heart valve disease patients not yet ready for intervention.

Palliative Intervention

Due to advancements in available interventional procedures, it is important that patients are not denied treatment based on their age alone. However, as set out in the quality statement, in specific circumstances, comorbidities and frailty may mean that intervention is not likely to provide benefit and is therefore not advised. Imperative in this is the communication of this decision with the respective patient and the referral to appropriate services who deal with palliative care.

d. Post-Treatment Management

Membership of Clinical Sub-Group

- Ms Karen Wilson, Research Nurse (Cardiology)
- Ms Gemma McCalmont, Specialist TAVI Nurse

Overview

The Post-Treatment Management Sub-Group looked at the follow-up procedures post-intervention. It also discussed the support of patients post-treatment, as well as communication around their treatment and long-term disease management. Whilst it was agreed by the Working Group that post-operative echocardiograms should be available to all, the frequency, location and lead-clinician of follow-ups was also discussed, as well as the prospect of self-care.

Discussion

Follow-up

Across the various stages of post-treatment recovery and management, patients require materials and guidance on what to expect. This includes the immediate post-operative recovery undertaken within a hospital setting and the long-running monitoring required following discharge. Crucial in the long-run efficacy of post-treatment management is, where possible, the existence of dedicated heart valve clinics at all tertiary centres and hospitals. There is debate as to whether it would be reasonable to require district general hospitals to also provide dedicated heart valve clinics given the resources required. However, it is argued that without such coverage, many patients would not receive the required level of care.

As mentioned previously, ensuring patients do not present back at generalist settings following treatment is essential in ensuring they receive the tailored care they require.

Frequency and Point of Delivery

Different types of heart valve disease and the different types of replacement valve used (mechanical or bioprosthetic) require different post-treatment follow-up procedures. As such, each hospital should have its own guidance on the required follow-up procedures and frequency of echocardiography for each of these different conditions and treatments.

Professional Awareness

Heart valve disease patients require tailored treatment and specific prescriptions, and in order to ensure their needs are catered for in the years following intervention, a management plan should be agreed between the specialist clinician, general practitioner and patient.

One specific issue that heart valve disease patients are at increased risk of post-treatment is endocarditis. As such, there needs to be greater awareness amongst patients and non-specialist healthcare professionals of these risks, the red-flag symptoms (which could otherwise be construed as relatively routine) and the need to refer on immediately. It must be recognised, however, that endocarditis will make up an infinitesimal proportion of a GP's workload.

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Guidelines

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