

# Community Action on Health

**Any Qualified Provider (AQP) – Patients' experiences of Anti-coagulation services**

**March 2012**



Community Action on Health is a charity working within Newcastle to tackle health inequalities through patient, carer and public involvement.

We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective services.

We have vast experience and expertise in gathering the views and opinions of patients, carers and the general public in relation to health services. For example:

- locating new GP surgeries
- services to include in new community health facilities
- visibility of existing health services
- changes to care pathways

We employ various quantitative and qualitative data collection techniques:

- Questionnaires – paper-based and online
- Participatory appraisals
- Drop-in events
- Face-to-face interviews
- Focus groups
- Informal group discussions

We also provide guidance on:

- how services can engage with patients, carers and the public
- developing patient-friendly services
- a patient-focussed approach to delivering health services

For more information about the services we can provide please contact Kieran Conaty on 0191 2263450 or email [kieran@caoh.org.uk](mailto:kieran@caoh.org.uk). Visit our website at: [www.caoh.org.uk](http://www.caoh.org.uk)

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# Section 1- Introduction

## 1.0 Introduction

### 1.1 Community Action on Health

Community Action on Health (CAOH) is an independent charity based in Newcastle upon Tyne. We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective services.

### 1.2 Topic context

#### 1.2.1 Extending patient choice

In July 2010 the Government White Paper, 'Equity and excellence: Liberating the NHS' outlined proposals to reform the NHS in England. At the heart of these proposals was giving patients more control over their own healthcare through an 'information revolution' and greater choice. Patients would be able to choose which organisation provides their healthcare, which consultant-led team treats them, what actual treatment they receive and which GP practice they register with.

From April 2012 patients will be able to choose a named consultant-led team. In addition, GPs will be able to set larger practice boundaries and in some pilot areas patients who move house, will be able to stay with their current practice and commuters will be able to register with a practice near their work.

#### 1.2.2 Any Qualified Provider (AQP)

April 2012 will also see the phased introduction of Any Qualified Provider. The White Paper states that:

"Whenever people need healthcare they should be able to choose from any organisation in England that offers a service that is clinically appropriate for them, meets the quality standards expected from providers of NHS-funded services, and can deliver services within NHS prices".

When patients are referred by their GP they will be able to choose from NHS, independent and voluntary sector organisations to provide their care, where available, enabling them to choose a provider that best meets their needs.

Opening healthcare provision up to any qualified provider also aims to improve the quality of services, reduce gaps in services and improve patients' access to services.

The Department of Health suggested eight potential services that would be appropriate for priority implementation, based on consultation with national patient groups, commissioners and providers. These community and mental health services are:

- Musculo-skeletal services for back and neck pain
- Adult hearing services in the community
- Continence services (adults and children)
- Direct access diagnostic tests
- Wheelchair services
- Podiatry services
- Venous leg ulcer and wound healing
- Primary care psychological therapies (adults) ('talking therapies')

In addition, PCT clusters and Clinical Commissioning Groups are able to choose other services as deemed appropriate and a priority in their locality.

### 1.2.3 AQP services in NHS North of Tyne

Working together, NHS North of Tyne and the Clinical Commissioning Groups based in Newcastle upon Tyne, North Tyneside and Northumberland are considering the following three services to offer AQP:

- Adult hearing services in the community
- Direct access diagnostic tests
- Anti-coagulation services

### 1.2.4 Anti-coagulation services

Anti-coagulant medication reduces the ability of the blood to clot. People at risk of blood clots may be prescribed anti-coagulant drugs, including those who:

- Have artificial heart valves
- Have had a heart attack
- Have had a stroke caused by a thrombosis or a clot
- Are at risk of deep vein thrombosis or pulmonary embolus
- Have atrial fibrillation
- Are undergoing orthopaedic surgery
- Have angina
- Are undergoing procedures to coronary arteries

The two most common types of anti-coagulant medication are:

- Warfarin, which is taken orally in tablet form
- Heparin, which is given as an injection or through a drip

In order to ensure that a patient's blood is clotting at the desired speed, they are regularly monitored. This measurement is called the international normalisation ratio (INR) and requires patients to attend a clinic to have their INR checked. The frequency of this monitoring depends upon how long a patient has been taking the medication and ranges from daily to quarterly.

In Newcastle, anti-coagulation services are currently provided by the Newcastle upon Tyne Hospitals NHS Foundation Trust, via clinics at:

- The Freeman Hospital - Monday to Friday 9:00 - 11:30am
- Royal Victoria Infirmary (New Victoria Wing Outpatient Department) - Monday, Tuesday and Friday mornings

There is also a Community INR Service which operates through the following GP practices:

- Falcon Medical Group
- Grove Medical Group
- Kenton Medical Centre

### **1.3 The project**

CAOH was asked to assist NHS North of Tyne in gathering people's experiences, perceptions and preferences of anti-coagulation services. This information will be used to develop guidance for commissioners if AQP is approved for anti-coagulation services in the future.

#### **1.3.1 Aim**

To explore people's experiences, perceptions and preferences of anti-coagulation services.

#### **1.3.2 Objectives**

The key objectives of the project are to:

- Explore patients' experiences of anti-coagulation services
- Explore patients' information needs around their anti-coagulant medication



# Section 2 - Methodology

## 2.0 Methodology

To enable the objectives of the project to be met, one methodological process was employed to gather people's views.

## 2.1 Questionnaires

This project had a tight timescale of three weeks from planning to delivery of the report. In order to reach the largest number of people within these timescales questionnaires were identified as the most appropriate data collection method.

Where possible, CAO staff carried out interviewer-administered questionnaires. This facilitated the gathering of more in-depth information, enabling interviewers to talk through their responses with participants, clarify any points and draw out additional information where appropriate.

Self-completion questionnaires with freepost return envelopes were also used where administered questionnaires were not appropriate.

## 2.2 Participants

Patient's currently accessing the city's anti-coagulant monitoring services were targeted for this project through various community settings.

<b>Group</b>	<b>Recruitment method</b>
Age UK	<ul style="list-style-type: none"> <li>• Sent electronic copies of flyers inviting people to take part, to distribute to members</li> </ul>
Ashfield Lodge Sheltered Housing scheme	<ul style="list-style-type: none"> <li>• CAO staff attended to speak to residents</li> </ul>
Benwell Hall Knit and Natter group	<ul style="list-style-type: none"> <li>• CAO staff attended group meeting to speak to group members</li> </ul>
Carers Centre Newcastle	<ul style="list-style-type: none"> <li>• Sent flyers and posters inviting people to take part, to distribute to people attending sessions and visiting the building</li> </ul>
Caring Hands Charity	<ul style="list-style-type: none"> <li>• Sent flyers and posters inviting people to take part, to distribute to people visiting the building</li> </ul>
Community Action on Health E-news	<ul style="list-style-type: none"> <li>• Electronic flyer distributed to 270 inboxes via CAO's E-news</li> </ul>
Community Cardiac Care Team	<ul style="list-style-type: none"> <li>• Lists checked to identify any anti-coagulant patients to approach</li> </ul>
Different Strokes North East	<ul style="list-style-type: none"> <li>• CAO staff attended group meeting to speak to members</li> </ul>
Elders Council of Newcastle	<ul style="list-style-type: none"> <li>• Sent electronic copies of flyers inviting people to take part, to distribute to members</li> </ul>
HealthWORKS Newcastle	<ul style="list-style-type: none"> <li>• Sent paper flyers and electronic copies inviting people to take part, to distribute to users in general and also patients attending the Exercise on Referral sessions. Flyer was also displayed on the electronic screen.</li> <li>• Attended several progression classes (Next Steps)</li> <li>• Directly mailed flyers and questionnaires to 40 identified anti-coagulant users</li> </ul>
High Moor Court Sheltered Housing scheme	<ul style="list-style-type: none"> <li>• CAO staff attended Chatterbox session to speak to residents</li> </ul>
Search Project	<ul style="list-style-type: none"> <li>• Sent flyers and posters inviting people to take part, to distribute to people attending sessions and visiting the building</li> </ul>
Stepping Stones Cardiac Support Group	<ul style="list-style-type: none"> <li>• 67 flyers inviting people to take part were sent directly to the group members (the group meet monthly but the meeting this month was outside of the project timescales)</li> </ul>

A number of other community groups were approached to take part in the project but unfortunately none were meeting within the three week project window.

Twenty-two people gave their views.

# Section 3 - Findings

## 3.0 Findings

This section documents the findings of research carried out with people residing within Newcastle or using the city's anti-coagulant services.

### 3.1 Participant profile

Twenty-two people took part in the research. Fourteen participants were male and eight female. Their ages ranged from 45-54 years old and 75+. Twenty-one were White British and one participant identified themselves as 'Human'. Fourteen people considered themselves to have a disability as follows:

Factor	No. of responses
Physical impairment	11
Mental health problem	1
Longstanding illness	5
Sensory impairment	0
Learning disability	0

One participant took their anti-coagulant medication due to atrial fibrillation; the remainder had had strokes, or had other heart problems.

### 3.2 Anti-coagulation monitoring

#### 3.2.1 Location

Participants were initially asked where they go for their INR monitoring. Three go to the clinic at the Freeman Hospital and five to the clinic at the RVI. Three patients go to their own doctor's surgery for their monitoring and a further five participants attend other GP practices in the city, namely Prospect Medical Group, Parkway Medical Centre, Adelaide Medical Centre and the West Road Medical Centre.

Two participants use the Community INR Service at Kenton Medical Centre although one patient had been to Grove Medical Group when they could not get an appointment at Kenton.

A further one person has their own monitoring machine at home and three people are seen by a nurse in their own home.

The vast majority of participants (90.9%) felt that the location of their INR testing venue was either very or fairly convenient with one patient stating that going to their

GP surgery was “much better than going to the RVI”. One participant who felt that the Freeman Hospital was a ‘very convenient’ location for them actually mentioned that they had to get two buses from their home to get there. For some, two buses may be seen as inconvenient, but this patient was retired and happy to have the opportunity to “get out of the house”.

One patient who attended the RVI clinic described the location as ‘not very convenient’ because “I walk with crutches and parking at the hospital is expensive, I have a blue badge and still have to pay”.

A further one participant carried out their own monitoring at home but went to the RVI for a check-up every six months. They started home monitoring in 2007 but before that attended their own GP practice.

“The machine was free on a month’s trial but then I had to pay £400 for my own. It allows me to monitor the impact of other medications on the warfarin”

### 3.2.2 Decisions about location

Participants were also asked what three things were most important to them when deciding where their INR monitoring should take place. They were given the following options:

- Distance from home
- Access to information and advice from a clinician
- Being able to receive enough support to manage your condition yourself
- Car parking
- Public transport
- Facilities
- A ‘one stop shop’ – being able to get testing advice and treatment at the same venue on the same day
- Advice from doctor
- Other

As can be seen from the table overleaf, distance from home, access to information, car parking facilities and a one stop shop are the most important factors to patients when choosing where patients go for their INR monitoring.

Factor	No. of responses*
Distance from home	20
Access to information and advice from a clinician	9
Car parking	8
A 'one stop shop'	8
Being able to receive enough support to manage your condition yourself	4
Public transport	6
Advice from the doctor	3
Facilities	1

\* Several participants did not choose three factors

### 3.2.3 Results

Three-quarters of participants (77.3%) received the results of their INR monitoring at the same time as the appointment for the test. A further one said that they were not specifically told of their results but believed that their 'doctor would phone me up if anything was wrong'. The participant who carried out their own monitoring was obviously able to access it there and then and took their machine to be calibrated every six months and the three people who were monitored at home received their results in the post.

### 3.2.4 Admission to hospital

Participants were also asked whether they had ever been admitted to hospital because of problems with their anti-coagulation and four had.

"I had internal bleeding, I was passing blood, I became seriously anaemic. They couldn't find the cause and I had cameras put up and down"

"I got a blood clot after I had a hip replacement, I was rushed straight back in"

"I passed out 2 or 3 years ago due to a blood clot"

## 3.3 Information about anti-coagulation monitoring

The second section of the questionnaire explored patients' views around the type of information they have received about their anti-coagulation testing.

### 3.3.1 Verbal information

Six participants felt that they received too little verbal information, although one said “but by now I feel I have picked up most of it”. Others said:

“Unless you ask for it you don't get anything, they assume you understand but the nurse is happy to answer my questions”

“I was in hospital drugged up and felt it was very hazy. I only knew I had to take it”

“Not a lot, especially about what I can eat – I've been on warfarin 13 months now). I got the basics about the time I should take the tablet and told I couldn't eat blueberries and kale”

The remainder were satisfied with the verbal information they received.

“I was put off by the fact it is rat poison and it seemed daunting. But they explained it in detail that the amount was so small that it wouldn't do me any harm. And I have been told what the side effects are”.

“It seems to depend on your bloods how much information you are given”

“I receive all the information I need relating to my results, any adjustments I need and they make an appointment for me”

“I have a good rapport with my blood doctor; he can answer any of my questions”

“I am kept fully informed; everyone is friendly and talks to you”

However, one participant, despite indicating that they had received enough information said “I only get what I ask for, nothing is ventured” and one said that they received too little information.

### 3.3.2 Written information

Responses to this question varied more than the verbal information although again the majority of people (63.6%) felt that they had been given ‘the right amount’ of written information.

“In hospital I was given information and when I went to the clinic I was given additional information and it was good”

“Up to now everything seems spot on”

Two participants had not received any written information at all and another two felt that they had received too little.

“I found my own information, found some in a newspaper”

“I received a small leaflet but would have liked more information around diet”

“I’ve not received anything for a year; I only got stuff at the beginning”

A further one patient said that they had received too much information, another two could not remember and one patient did not want any.

### 3.3.3 Additional information

Participants were also asked what other information they would like to receive and in particular:

- The reasons for taking prescribed medicines to manage their condition
- How drinking alcohol can affect their condition

Five patients felt that they would like additional information, three requested information about reasons for taking the medication and four wanted information about drinking alcohol.

The others had already received the information from a clinician or had found the information themselves.

“I was given some information about drink, but I don’t drink”

“I already know about why I am taking this prescription and how to manage it. I also don’t drink, only when I am on holiday but I am very sensible with it”

“I am adequately informed around alcohol and all packs have a leaflet with them. I was given plenty of information around these”

“I know the reasons for my prescription and how alcohol can affect my condition”

“I know why I take warfarin - that was explained to me and I know about alcohol”

Patients were also asked whether they knew enough about what they should eat to help them manage their condition; five people felt that they did not, stating:

“I would have liked to have known the side effects at the beginning in hospital, but you won’t question the doctor, not if you have just had a stroke”

“I can manage but I don’t know enough about what I can eat. I wish someone would write a recipe book. The only specific foods I was told to avoid were blueberries and kale - I would like to know more. What I know has just come from reading magazines”

“I would like to know more, I was told by a family member not to drink cranberry juice but never by a nurse or doctor”

“I only know you should avoid cranberry juice and blueberries”

Another participant stated that they knew enough but had not been given anything by clinicians; it was “only because I researched it myself”. Others who were satisfied that they knew enough said:

“I have been to health sessions at hospital and they have informed me about this”

“I was well informed from the beginning”

“My consultant gave me the most information. He told me I could have broccoli but as long as it was always part of my diet”

“I know that broccoli, pineapple and cranberry can affect you. But I was told I could have one floret - it's alright in small doses”

“I get a monthly magazine from The British Heart Foundation which includes recipes and menus”

Finally, participants were asked whether there was any other information they would like to receive about their treatment. One said that they simply went online for any additional information they needed. However, one person did request more information about the difference in procedures between monitoring at the GP surgery and the hospital monitoring.

“When I go along to my six weekly check, the machine they use just pricks my finger. At hospital they insist on taking a vile full of blood, why is this? It's hard for them to find my veins and they just end up collapsing and leaving me bruised”

Another requested information about medication that could affect their INR levels, this patient has atrial fibrillation and requires six readings within range before being referred for their cardioversion operation.

“I went for my monitoring and I was out of range. The nurse asked if I'd taken any medication and I had some paracetamol this morning, she said this will have affected my levels. No one has ever told me this; it is very frustrating as I need to keep my levels in range before I can have my op!”

One other participant said that they “would like more general information about warfarin and how it would affect me”.

### 3.4 Appointments

The questionnaire also covered appointments and enquired as to whether patients had been unable to attend their monitoring appointment at any time. Almost one third of the participants (31.8%) had been unable to attend their appointment at one time or another and for three people this was due to being unwell.

“I only missed some appointments when I was in hospital”

One patient had had to rearrange their appointments because they were on holiday but stated “they are very flexible with the appointments” whilst another said they might miss one if it scheduled at the same time as another appointment. Simply forgetting was the reason one patient gave and the final participant had “missed a couple through misunderstanding the appointment time and date”.

### 3.5 The Service

#### 3.5.1 Good points about the service

Participants were also asked whether there was anything particularly good about the service they receive. Those who visited the hospital clinics for their monitoring felt that they were offered a very efficient and friendly service.

“Can’t knock the Freeman, it’s excellent”

“What we get at the clinic is ideal, I am very happy with the service”

“Staff are always pleasant”

“It’s good, the staff are friendly”

“They have excellent communication skills in the clinic”

“They are friendly and efficient”

“Rapid testing and the pharmacist is great”

The participant who had their anti-coagulant monitoring at their own surgery stated that “I am able to ask questions, and they also ask me questions”, whilst those who were monitored at Kenton Medical Centre said:

“Although I get given an appointment, they will squeeze me in before so I can stop off on the way to work. The nurses are very helpful”

“It is very organised - I have not had any problems”

At other GP practices patients were equally complementary:

“It’s very efficient and I have a phone number I can ring to ask questions”

“It all works well”

“The Newcastle community staff are excellent”

Those who are seen at home were also happy with elements of the service:

“There are three girls in the team and they are all very good, they are good at taking blood”

“All the staff are brilliant and I get a letter two days after my bloods are taken”

### 3.5.2 Improvements to the service

Eight people (36.4%) put forward suggestions to improve the service they received for their anti-coagulant monitoring. One felt that the waiting times could be improved; another suggested that the computer system should be more reliable, a third believed that the NHS should provide home monitoring machines for patients who will be taking the medication for the rest of their lives and a fourth wanted information about how to improve their INR levels.

“The waiting times, although they are not too bad”

“The central computers often crash, could they not write the results on paper instead of having to wait for ages?”

“I am on lifelong warfarin, so the machine was the best £400 I have spent, but it should be free for people”

“They could tell me what to do to help my results”

Another requested a specific appointment date and time for being seen at home whilst another wanted the nurses to talk to them about their results more.

“I get a letter but it has no day or time on it, it says that the phlebotomist is going to come - they come any day at any time. The letter just says they will be here sometime this week”

“When they take my blood they could talk to me more about it”

The patient who has atrial fibrillation suggested being able to book in appointments up to six weeks in advance, having more information about the telephone service and more timely provision of the card that tells people that the patient is taking an anti-coagulant.

“The telephone service is sporadic - it only seems to be answered during clinic times and it's just an answerphone the rest of the time. This was frustrating in the beginning when I wanted to ask questions. It would be good to know when it is actually manned so I can ring at these times”

“It would be good to have 6 weeks of appointments booked in, in advance instead of getting a new one each week as sometimes the appointments are full for the next week”.

“I have asked the nurse three times for a card to say I'm taking warfarin in case anything happens to me, they keep saying they'll send something but I'm still waiting”.

Finally, a patient who had been admitted to hospital due to problems with anti-coagulation asked for information to be relayed to them about why it happened so that they could avoid it happening again.

“When I was admitted for the blood clot they never told what caused it, I thought it may have been down to dehydration but I was never told”

### **3.6 Any other comments**

Finally, participants were offered the opportunity to give any other comments about their experiences of the anti-coagulation service they received. The majority of comments were positive.

“I was confused about the service and how it works initially. It was unsettling in the beginning but once in the routine of it staff are quite reassuring”.

“I have taken warfarin for 5 years and had no problems”

“I am pleased with the services I receive and they answer all my questions”

“They are doing a good job, I have always been able to ask for advice”

“It does what I expect it to do”

However, one patient commented on the medication schedule.

“It's irritating that my doses change throughout the week and it can be a faff coordinating it with other medication”

A further two mentioned new developments in anti-coagulant medication.

“I was twice approached at hospital to have a vitamin K trial. They have been so good to me at the hospital I was keen to get involved and give something back, but my travel insurance company would not cover me while I was on it so I could not go through with the trial.

“I saw a new wonder drug in the paper the other day but the hospital staff said the papers were just 'bigging' it up and it would not be coming into the NHS”

“I look forward to a new anti-coagulant that is due to be released and makes monitoring easier”

### **3.7 Summary**

#### **3.7.1 Location of anti-coagulant monitoring**

As can be seen from the findings above, all but one patient was happy with the location of their INR monitoring. When choosing where to go for their monitoring, distance from their home, access to information and advice from a clinician, car parking availability and having a one stop shop where they could get testing advice and treatment was most important to patients.

#### **3.7.2 Information about anti-coagulant monitoring**

In terms of the information they are given about their anti-coagulation testing the majority of people felt that they received the right amount. Four participants asked for more or more timely verbal information and two stated that they only received verbal information if they asked for it directly. Two participants had not received any written information at all and a further two asked for more.

The majority of patients felt fully informed in terms of the reasons for taking their medication and how alcohol and various foods can affect their INR readings. However, three people wanted more information about the reasons for taking the medication, four wanted information on alcohol and two wanted more information about eating.

In addition, one participant requested information about why procedures at the GP surgery differ from the hospital and another wanted information on how other medication can affect the INR reading.

#### **3.7.3 Appointments**

Less than one third of participants had been unable to attend their monitoring appointments at any time due to being unwell, on holiday, or simply forgetting to go. One person did however miss some appointments due to misunderstanding the appointment date and time.

#### **3.7.4 The service**

Across all monitoring locations participants were generally happy with the service they received. They felt it was efficient, flexible and staff very friendly and open.

However several improvements were suggested:

- Reducing waiting times
- Being able to book up to six weeks of appointments in advance
- Ensuring that a date and time is given to patients who are monitored at home
- Telling patients when the telephone service will be manned

- Improving the reliability of the computer system
- Providing home monitoring machines free of charge
- Providing more information about how to improve INR levels
- Passing on information about the causes of patients admissions to hospital
- Providing patients with a card saying they are taking warfarin at the initial appointment

