



healthwatch
York

**Changes to services: The
Anticoagulation Warfarin
Monitoring Service in
York**

May 2019

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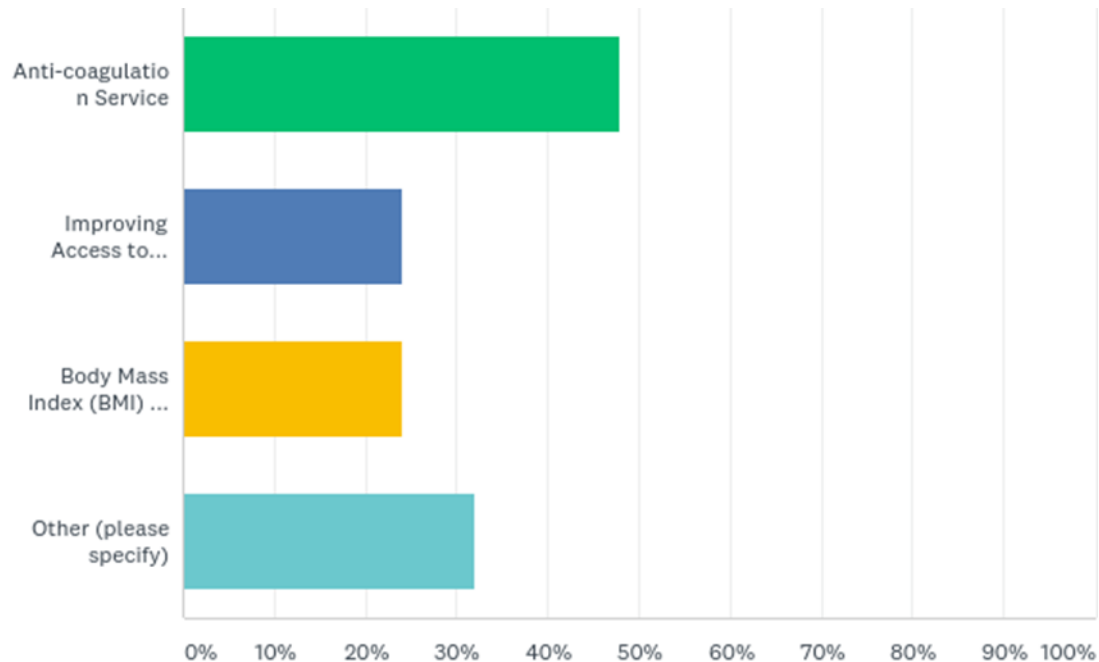
Changes to Services

Why is Healthwatch York looking at changes to the Anticoagulation Warfarin Monitoring Service in York?

In 2018, Healthwatch released a work plan survey to identify issues that people wanted us to look at. Feedback from this survey confirmed that changes to York health services were a key public concern over a number of different areas.

To find out more about what the public thought, Healthwatch York created a changes to services survey which ran from October 2018 to January 2019. This survey was available online and at events that Healthwatch York attended. The survey asked for public feedback on a number of areas outlined as a concern from the work plan survey. A breakdown of survey responses can be seen below. People were able to comment on more than one concern.

Question: Which service would you like to tell us about?



| ANSWER CHOICES | RESPONSES | |
|---|-----------|----|
| Anti-coagulation Service | 48.00% | 12 |
| Improving Access to Psychological Therapies (IAPT) | 24.00% | 6 |
| Body Mass Index (BMI) and Smoking Thresholds for Elective Surgery | 24.00% | 6 |
| Other (please specify) | 32.00% | 8 |
| Total Respondents: 25 | | |

Healthwatch advertised the changes to services survey within the York Press in December 2018¹.

In addition to the surveys, Healthwatch York continued to gather feedback via the online feedback centre on the Healthwatch York website, by email, letter, and phone or in person when people contacted us about their concerns.

In light of the feedback provided, Healthwatch York have focused on two of these areas for which we received the most evidence and have produced two small reports to summarise the findings.

These two areas of interest included:

- Changes to thresholds for elective surgery regarding body mass index (BMI) and smoking.
- Changes to the anticoagulation service, moving from York Hospital to GP surgeries.

This report focuses on changes to the anticoagulation service, moving from York Hospital to GP surgeries (primary care).

¹ Wliiers, D (2018) Healthwatch York wants to know how changes to services have affected you. York Press. Available at: <https://www.yorkpress.co.uk/news/17280912.healthwatch-york-wants-to-know-how-changes-to-services-have-affected-you/>

Summary of findings

Overall, 12 people talked to us about their experiences of changes to anticoagulation services in York. One person provided positive views relating to the new locality of the service but 11 people felt negatively towards the changes that took place. People reported on:

- A lack of consultation when changes took place
- The changes in appointment times affecting working hours
- Difficulties in accessing appointments
- Changes in INR levels and a loss of confidence in the service

This report is not a representative portrayal of the experiences of all people affected, only an analysis of what was contributed by members of the public within the small project described. These findings are a subset of a larger project on changes to services. However, the voices and stories fed back to us were able to highlight some key issues within some individual's experiences.

What are anticoagulants?

The information below about anticoagulants is taken from the NHS website².

Anticoagulants are medicines that help prevent blood clots. They're given to people at a high risk of getting clots, to reduce their chances of developing serious conditions such as strokes and heart attacks.

A blood clot is a seal created by the blood to stop bleeding from wounds. While they're useful in stopping bleeding, they can block blood vessels and stop blood flowing to organs such as the brain, heart or lungs if they form in the wrong place.

Anticoagulants work by interrupting the process involved in the formation of blood clots. They are sometimes called "blood-thinning" medicines, although they don't actually make the blood thinner (taken from NHS website). If a blood clot blocks the flow of blood through a blood vessel, the affected part of the body will become starved of oxygen and will stop working properly.

² NHS (2018) Overview: Anticoagulant medicines. Available at: <https://www.nhs.uk/conditions/anticoagulants/>

Depending on where the clot forms, this can lead to serious problems such as:

- strokes or transient ischaemic attacks ("mini-strokes")
- heart attacks
- deep vein thrombosis (DVT)
- pulmonary embolism

Treatment with anticoagulants may be recommended if your doctor feels you're at an increased risk of developing one of these problems. This may be because you've had blood clots in the past or you've been diagnosed with a condition such as atrial fibrillation that can cause blood clots to form.

You may also be prescribed an anticoagulant if you've recently had surgery, as the period of rest and inactivity you need during your recovery can increase your risk of developing a blood clot.

The Local picture: What changes have taken place?

In late 2017, NHS Vale of York Clinical Commissioning Group (VoYCCG) announced it was changing how it provides anticoagulation services.

The changes meant that patients would be seen at their GP Practice for regular anticoagulation treatment rather than going to York Hospital, Selby Hospital or Asda for their blood test. Warfarin would then be wholly monitored by the GP surgery and not the hospital anticoagulation clinic.

VoYCCG told us that patient consultation was undertaken in 2015/16. Surveys for patients to complete were provided at GP surgeries. VoYCCG's project manager at the time attended York Teaching Hospital NHS Trust clinic sites (York Hospital, Selby Hospital and Asda) to discuss the proposed changes with patients and collect people's views.

VoYCCG told us that through this consultation, patients reported wanting to have a local service, be seen near to their home, have services that are convenient and only go to hospital when they really needed to. In a letter drafted to patients from VoYCCG, a number of improvements being made to the service were highlighted. These included:

- A quick 10 minute appointment where people should not have to wait long for their blood to be taken.
- A finger prick blood test rather than blood being taken from your arm which should be more comfortable.
- Results and dosing instructions to be given at the appointment and your yellow book can be given back immediately.
- Providing the GP practice full access to all your medical records so they know how best to look after you.

VoYCCG said that initially, patients were given a choice of where they would like to attend for their anticoagulation treatment, and this led to a slow transfer of patients to the primary care service (GP surgeries). Twenty-one practices confirmed that they would provide the service. Five practices did not want to run the service. A new provider was created to offer the service to patients from these practices. York Hospital anticoagulation clinic closed at the end of January 2019.

Over this period, people have contacted us to talk about their concerns with the changes that took place.

Key themes from the people's responses

Lack of consultation

"I have never been consulted about any changes"

Five people specifically spoke about a lack of consultation they felt they received on the changes to services. One person reported finding out about the changes from seeing a sign on the window at the Anticoagulant Clinic and York Hospital and others found out in a letter. Another described it as a "shock". People described being "told" of the changes and being "forced" to go to their GP, rather than a process of consultation and engagement from the different providers.

Two people spoke more positively in regards to learning about the changes and both described pro-active forms of communication from their GP surgeries including a phone call, letters and support from nurses.

Later opening times affecting working hours

"It has removed at least 1.5 hours of my working day as the earliest appointment if it's free, is at 9:20am."

Three people discussed the changes in opening times which had directly affected their working day and in some cases, their pay. It was reported that some people's earliest GP appointments were after 9 am compared to the opening times of the service at the hospital which had started at 7:30 am. This had left people struggling to manage attending their appointments around work. This had also affected some who previously attended at 5 pm at the hospital and now could not get a later appointment than quarter past 4.

Difficulties in accessing appointments

“Why be given a certain date for the next one if it can't be fitted in because all the appointments are booked?”

Eight people reported difficulties in making appointments with their GP surgery within the time frames requested by the GP. One person said that although their appointment needed to be within 10 days, all the appointments had been taken. People said their appointments would often end up on different days each week which was difficult for some to manage and could end up taking place at different surgeries.

One person reported on the GP appointment system whereby appointments were released after 8:30 am. However, this made booking appointments more difficult for those who could not call until later in the day due to work or other reasons.

One person reported that surgeries were, at times, short of staff and another stated they were always running late, affecting appointments.

In comparison, people felt the hospital service had been very accessible and people could go at any time, to the same place and always get seen.

“I was happy with the service at hospital. It was drop in, good parking, good service.”

Some people stated they lived close and within walking distance to the hospital, whereas their GP surgery was over an hour away, or they were being sent to different surgeries to get appointments. Therefore, the changes had not supported them to access a local service.

One carer reported that they were struggling due to the different appointments at different days, the difficulties booking appointments and the changes in venue which impacted on parking as the patient had difficulties walking.

Changes in INR levels and a loss of confidence in the service

“They can never get my dose right now.”

Five people commented that since they had changed to their GP surgery, their INR levels had changed, highlighting ways the surgeries worked differently to the hospital in managing levels. One person suggested her level had been up and down and she had been unable to get an explanation. People reported a loss control over their situation. One person also mentioned that not having the yellow book meant they had nothing to carry around with them, especially on holidays.

Due to these changes and a lack of information, these patients discussed how they had lost confidence in the new service. People felt that staff at the surgeries were often unable to answer their questions.

In comparison, people felt that staff at the hospital had been able to answer their questions and give good advice. They felt the standards of care and expertise of staff had been high.

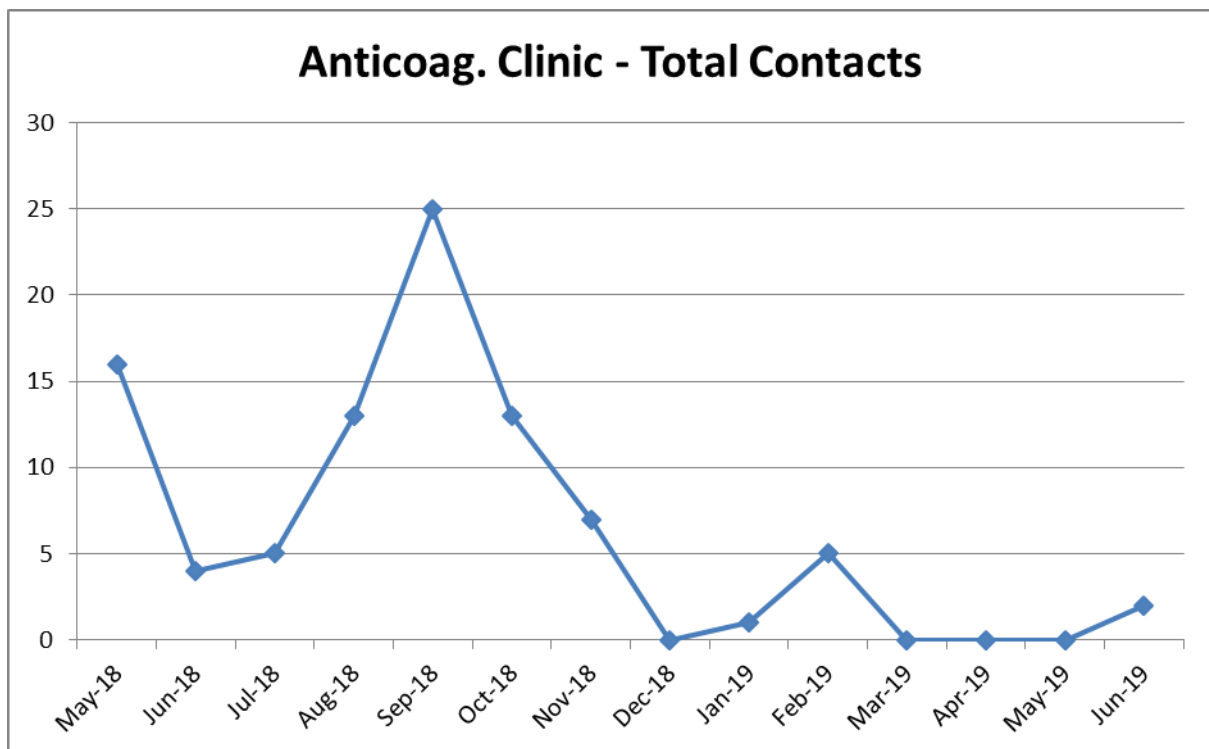
“At the hospital, the staff were there to answer any queries I might have had.”

Comments from VoYCCG

VoYCCG reported that they had received 92 contacts through the Patient Relations Team in regards to the changes made to the anticoagulation service. They highlighted similar key themes from the comments they received. These were:

- Disappointment in the service moving out of the hospital due to being pleased with this service.
- The service in GP practices running on an appointment basis rather than as a drop-in service.
- Changes in INR levels and a lack of confidence in the GP practice service because of this.

The graph below represents the number of contacts regarding anticoagulation service changes made to the VoYCCG Patient Relations Team between May 2018 and Jun 2019.



VoYCCG told us that they were able to speak to all the people who contacted the CCG and explained the service change. They had also contacted specific GP practices where appropriate. VoYCCG reported that some GP practices had been very sympathetic to patient difficulties in accessing booked appointments and were able to provide a 'bespoke' service for these particular patients.

VoYCCG stated that changes to INR levels can be expected due to the difference in the way that blood is being tested (as a finger prick test, rather than as a venous sample taken from the patient's arm). As time goes on, control should stabilise and the frequency of testing should reduce. All GP practices are using clinical software to support the warfarin management service. Clinical protocols and guidance are available in case of query.

VoYCCG stated that they were sorry to hear that a number of patients felt there had been a lack of consultation and acknowledged that further consultation with Healthwatch York could have taken place when the project was underway. VoYCCG reported difficulties being able to contact the patients affected directly, due to not holding any patient data. They were reliant on the communication from the hospital service and GP practices being effective. Just prior to the service beginning to transfer, the hospital agreed to add a sticker to the patients' yellow books, advising them of the service change and a notice was put up on the office door at the hospital. Some GP practices did send out their own letters and VoYCCG were pleased that some people within the report experienced pro-active communication.

VoYCCG were concerned to hear about a patient commenting that their yellow book is no longer in use. This should not be the case, the yellow book is a patient hand-held record and should be completed at every monitoring appointment.

Healthwatch York comments

Changing services, experienced by many as effective and supportive, causes concern and anxiety for many individuals faced with suddenly having to make quite significant changes to their routine and daily lives.

The stories people told us highlighted how staff at the hospital had often had close relationships with individuals, supporting them with their health, often over many years. People had both confidence in standards of the service being provided and familiarity. In addition to this, the service had been flexible to suit people's working days and appointment needs.

Healthwatch York understands that changes to services are needed for financial reasons. A move to local GP based services may also provide benefits to many individuals going forward, offering local and more efficient services.

However, during the changes, it is important that all services and providers involved, such as the hospital, GP practices, and the CCG work together with joint responsibility and accountability to; speak to and inform patients at the earliest opportunity, be sensitive to individuals needs and support them throughout the process. This should improve people's overall experience and reduce stress and anxiety during the transition.

Healthwatch York feels that further work is also needed to address the reported inaccessibility of appointments at GP surgeries and the inaccessibility of appointments in some GP surgeries during non-working hours for those who work. Healthwatch York are aware that only a small amount of responses are captured in this report and are interested in hearing from members of the public and carrying out further work with VoYCCG to explore whether this is a continuing theme.

Recommendations

| Recommendation | Recommended to |
|---|--|
| <p>Consider feedback to date in terms of accessibility to appointments outside of working hours and in relation to individuals' needs.</p> | <p>VoYCCG, GP practices.</p> |
| <p>Commit to co-design and co-production (in line the Social Care Institute of Excellence definition) when creating new services.</p> <p>For future service changes that involve multiple services/providers, consider ways of working together to make sure positive patient experience is at the forefront.</p> | <p>All service providers involved in changes to services (VoYCCG, York Hospital, GP practices)</p> |

Sources of support

The NICE (National Institute for Care and Excellence) website outlines sources of advice and support.

The NICE website provides a patient decision aid about anticoagulants and atrial fibrillation that gives information and provides examples of useful questions that patients can use when speaking to healthcare professionals. This is available online at:

<https://www.nice.org.uk/guidance/cg180/resources/patient-decision-aid-pdf-243734797>

Other useful sources are:

Arrhythmia Alliance

Website: www.arrythmiaalliance.org.uk

Phone: 01789 450 787

Atrial Fibrillation Association

Website: www.atrialfibrillation.org.uk

Phone: 01789 451 837 (24 hour)

British Heart Foundation

Website: www.bhf.org.uk

Phone: 0300 330 3311

Stroke Association

Website: www.stroke.org.uk

Phone: 0303 3033 100

NHS Choices

Website: www.nhs.uk

Acknowledgements

Healthwatch York greatly thank all those who took the time to contact us, fill in our surveys, give us their feedback and tell us their stories about changes to services in York.

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Contact us:

Post: Freepost RTEG-BLES-RRYJ
Healthwatch York
15 Priory Street
York YO1 6ET

Phone: 01904 621133

E mail: healthwatch@yorkcvs.org.uk

Twitter: @healthwatchyork

Facebook: Like us on Facebook

Web: www.healthwatchyork.co.uk

York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

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www.healthwatchyork.co.uk

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