



healthwatch
Milton Keynes



Gut Feelings

Supporting
NHS70

Why a Gastro group?

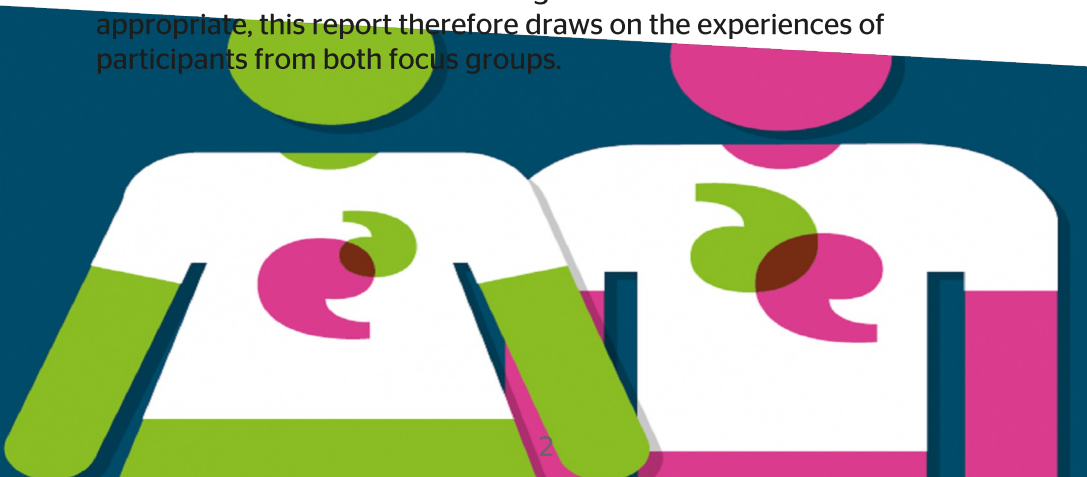
What was the issue?

Last year, Healthwatch Milton Keynes facilitated two focus groups. These were aimed at those with gastro-related conditions, with the purpose of exploring participants' experiences of gastro-related services in Milton Keynes with a view to understanding how the gastro pathway could be improved, and to explore the impact that changes to gluten-free prescribing has had on participants.

The focus groups were conducted in response to the following issues that had been raised to us:

- the concern raised by the Milton Keynes Clinical Commissioning Group (MKCCG) regarding the high number of emergency hospital admissions for gastro-related conditions in Milton Keynes, and a need to understand why this was happening.
- public concern surrounding the effects on patients of changes to gluten free prescribing, introduced by the MKCCG in 2017 following the NHS led consultation on Items which should not be routinely prescribed in primary care.

Whilst the first focus group focussed primarily on participants' experiences of gastro related services, and the latter primarily on the changes to gluten free prescribing, there was, inevitably, some crossover in the themes that emerged from discussions. Where appropriate, this report therefore draws on the experiences of participants from both focus groups.





How it was run

Focus group format

The first focus group took place in September 2018. Seven individuals attended, including four individuals with gastro-related illnesses, two representatives from Healthwatch, and one representative from MKCCG. Contributions were also made by one individual via email.

Participants' experiences were varied, with only one person telling us they felt they had been adequately supported throughout their journey through the system.

Whilst the sample was small, the issues raised were in line with similar themes identified by other groups of people living with long term conditions we have heard from, such as the MKMEG (Milton Keynes Myalgic Encephalomyelitis Group) and Diabetes UK MK. These issues include a lack of communication between health care professionals, and between patients and professionals, a feeling that professionals didn't always understand the complexities of a patient's condition and also the frustration of having to re-tell their story at each appointment.

The second focus group took place in November 2018. This group consisted of sixteen individuals, across a wide range of age groups, including two representatives from Healthwatch and two self employed nutritionists.

Healthwatch Milton Keynes invited the nutritionists to the second focus group, to help answer questions raised at focus group 1. There was a general consensus at the focus group 2 that the changes to gluten free prescribing were damaging for those recently impacted by it.

The issue is..

Communication

Communication was felt to be inadequate at several levels by all those who attended the focus groups.

In relation to the communication between doctors and patients, one participant explained that they request a speech to text interpreter due to hearing loss. However, on various occasions a British Sign Language (BSL) interpreter arrived instead. Given that the participant does not use BSL, it was very difficult for them to understand what was going on.

Other participants were also concerned that they were unable to fully understand their condition, or grasp the complexity of what diagnosis may mean, in the short appointment times provided.

Communication between departments was also felt to be problematic. Most participants had experience of being sent backwards and forwards between departments, with no one department taking ownership of the pathway or issue.

A lack of coordination between departments meant that the medication/diet regime patients were advised to follow by one consultant, failed to address co-occurring conditions that were being treated by different departments and consultants. One person told us of a diet they were put on to address one condition, but did not give them the nutrition they needed within the limitations of a co-occurring condition.

Communication between hospitals and GPs was also deemed to be lacking. For example, one participant was given fast-track services for tests when they were very ill. Months later, they had had no test results, and no-one had followed it up, despite their persistence.



Access to Care

Accessing appointments and quality of care

The focus group members identified problems both booking appointments and with the quality of the appointments once they had been booked.

With regards to booking appointments, it was highlighted that when appointments had been made through the e-referral system, they were referred to hospitals in Oxford for appointments, instead of Milton Keynes. This appeared to be an issue, experienced by the group's friends and family members, across all conditions and referrals.

Participants were also frustrated at the length of the time they were required to wait for an appointment. For example, one participant explained that they had to wait 6 weeks for what had been communicated as an 'urgent appointment'.

One participant highlighted that their appointments with their dietician were very positive. However, others were concerned that despite requests to see the same dietician each time, every appointment was with a different dietician. We were told that patients found a 15-minute slot is not long enough to explain all the existing problems/symptoms and get individually tailored advice.

It was suggested by the participants that this could be avoided by ensuring, where possible, that patients see the same dietician each visit, or ensuring that patient records are read prior to the appointment, to save time whilst the patient is there.

Managing the Pathway

Follow ups and discharge

The group told us that they felt it was up to them to ‘project manage’ their own condition.

Most participants were dismayed that check-up appointments and referrals were only made when they persisted, or once problems had arisen.

One participant with IBD described how after being discharged 25 years ago because they were able to manage their condition, they have not been offered any follow up appointment since.

This highlighted a wider concern amongst participants that once you are out of the system it is very difficult to get back into the system. Furthermore, participants felt that there was a disparity in the care provided for different conditions. It was believed that with some conditions there was a clear pathway taken by medical staff, whilst for other conditions, such as Crohn’s, the patient is required to fight for any action.





#SpeakUp

In summary

The group felt that:

- Participants told us that they felt the information they were given about their diagnosis did not prepare them well enough to fully understand their condition and the symptoms they may experience. Participants felt that this can lead patients going to A&E unnecessarily as they were often unaware if their symptoms were 'normal'.
- Focus group members also told us that issues can be overlooked or not followed through with quickly enough because there was poor communication between departments or between hospitals and GPs. This is exacerbated when patients see different medical staff each appointment
- Participants with co-occurring illnesses told us that these tend to be addressed individually, by different consultants, rather than simultaneously. We were told of their experiences of the side effects that medication/ diets prescribed for one illness had had on the co-occurring condition.
- There was a general feeling among the group that appointments/check-ups only occur when the patient persists, and usually once problems have already arisen. Potential and actual admissions could be reduced if check-ups were used as a proactive or regular means of preventing problems in the first place .



Recommendations

People told us what would help:

- A follow up appointment after diagnosis to go through support and treatment options once patient has had time to process the news
- A nutritionist rather than a dietician so that patients are given education and practical ways to ensure nutritional requirements are met through diet/supplements rather than being given a list of foods to avoid or to eat.
- Regular (perhaps annual) patient review meetings of Health Care professionals involved in the various parts of a patient's health - consultants from different departments, GP and pharmacy - and to include patient.
- Continuity of care - patients reported that seeing the same health professional would be very useful and reduce the amount of time spent bringing the 'new' person up to speed and allow more of the limited appointment time to be spent on the patient's needs.
- A follow up or 'assigned ownership' of a patient's appointments and follow ups to avoid patients having to manage the process.

healthwatch

Milton Keynes

Suite 113, Milton Keynes Business Centre
Foxhunter Drive
Linford Wood
Milton Keynes
MK14 6GD

www.healthwatch.co.uk

t: 01908 698800

e: info@healthwatchmiltonkeynes.co.uk

 [@Healthwatch_MK](https://twitter.com/Healthwatch_MK)

 facebook.com/HealthwatchMK