

Single point of contact patient experience

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1. Summary

Patients are almost entirely positive about their experiences of receiving support from single point of contact navigators. They appreciated the help with the complex logistics of cancer treatment, such as appointments and transport, alongside the quick response they were able to receive around smaller queries, and the effective triaging and referral to experts elsewhere for more significant problems. Support with the above helped to streamline their experience and reduce their stress. They also appreciated the emotional support they received, the personal connections they developed with the navigators, and that they had someone at the end of the phone who would take their requests seriously and take action, all of which helped to enhance their wellbeing. Patients also spoke of the trust they had in their navigators, which grew as the navigator effectively supported their requests or answers their questions. However, the few negative experiences shared centred on situations where navigators couldn't effectively answer questions or missed opportunities, or when there were clashes in personality.

Key themes

2. Streamlining of experience

For patients, the most mentioned benefit of the single point of contact navigator programme can be loosely grouped around the theme of 'streamlining'. This encompasses clarification of pathways, support with logistics, appointments, and transport, quick responses to queries, support with difficulties adjacent to their treatment, and signposting to other services.

Appointment scheduling was a significant concern for patients, with many mentioning that they had needed the support of the single point of contact navigator to ensure that they could attend all their consultations. Some mentioned that they would get notification of appointments late, or that the appointments they would receive were impossible to attend, due to clashing times or the need to travel between locations. In areas involving significant travel to attend appointments, such as Western Isles or Highlands, this was especially problematic. Navigators make a significant improvement to this experience for patients, as in many areas they were able to ensure that appointments were logically scheduled, minimising travel. Capacity allowing, they also had the time to proactively communicate with patients about appointments, which helpfully allowed patients to make arrangements in advance. Many patients reported feeling elevated stress around appointments, frequently mentioning that the logistics were challenging when they were already feeling tired or anxious around their treatment. Navigators provided reassurance to patients that they would be able to attend critical appointments and complete their treatment.

"It's difficult to concentrate when you're on the treatment. You have to concentrate on going up and down. Knowing it's all sorted out is so helpful. With radiotherapy, from a patient's perspective, you're really worrying that you might miss a day and not be able to complete treatment [because of transport mix ups]. It's very important to complete your treatment, it feels so important to you as a patient." Patient

“All the appointments coming through at once, some are clashing. All I had to do was ring my navigator and say I've got one for 11, another for 11.20. They'd say 'I'll sort it out' and would change it to be 45 minutes later. The last thing you want is extra hassle when you're going through all of that.” Patient

Many patients reported that they would get quick responses to questions from their navigators. Often, they would get immediate answers or call backs within 90 minutes; before single point of contact, many nurses stated that patients could wait several days for a response. Navigators will triage queries, with clinical questions often going to nurses. With experience or training, many navigators can answer questions there and then. Waiting for an answer was the most reported source of stress or anxiety for patients, and there was widespread appreciation for the benefits that the quick responses to queries offered during their treatment. For many of the patients interviewed as part of the research, this was their first experience of a significant illness, and many reported that they were worried that any new feeling or symptom could be life threatening. Navigators were often able to confirm that the symptom was normal or would know when a patient should go directly to hospital or speak to a nurse.

At the very early stages, it was a big help. I'd hardly been in hospital in my life. I've been lucky. Everything was so weird. It was good to know I could phone [my navigator] up regarding various thing. Patient

“Going through cancer, you have a good week and a bad week. You find yourself phoning [your navigator, saying] ‘I’ve got a random taste in mouth, saying this is what I'm experiencing’...’ The mind is a tremendous thing, you start over thinking, [only to] find out it’s a common issue and it'll go away. You hear horror stories about people not getting answered [in other areas of the NHS]. Longest I've ever had to wait for a call back is maybe an hour and a half. I usually get call back straight away.” Patient

For many patients in Scotland, travel is a frequently reported issue in their treatment. In areas such as the Borders and Dumfries and Galloway, patients will travel to hospitals in Edinburgh or Glasgow for treatment, sometimes every day for multiple weeks. In other areas, like the Western Isles, patients will have to fly or take a ferry for consultations and scans. Several patients spoke about the physical toll of treatment, and how they had to give up driving, or that their family or carers could only take so much time off of work to support them. In these cases, patients were grateful for the support navigators provided around transport and logistics. Many patients also spoke positively about the experience of travelling to treatment with others that had different diagnoses or were at different stages in their treatment, and the solidarity this encouraged. Navigators would often proactively identify where there were transport needs and ensure that travel was organised in a way that best supported the patient's needs.

“[Travelling] could be a challenge physically, but mainly it was mental. I couldn't coordinate it. [In the Western Isles] it's not as simple as jumping on a bus. It was nice and very reassuring to have that back up [from the navigator]. I had a few spells with infections and needed to fly to the hospital and my navigator could step in and help out. Sometimes I didn't even need to ask. [The navigator] already knew situation.” Patient

“The only time I needed to get in touch with [single point of contact service was his] big worry around organising all the transport himself. I thought I just can't go

in my current state. I thought I would have to refuse to go to appointments. It's different now [thanks to the navigator]. It's no bother." Patient

For patients, a wide network of support options is available, however it can be challenging to understand and utilise the services that are available to them. For many navigators, part of their role includes signposting patients to third sector organisations who might be able to support them with the administrative, financial, and emotional burden of cancer – something that was particularly relevant to patients without a family or support system around them. Several patients spoke of the positive effects that referrals had on them; for example, one patient spoke of the holistic massage they were referred to via their navigator, and how it helped them understand more about how cancer affected the body and reduced their stress and anxiety. With training and experience, Navigators are also able to support patients to understand where they are in the cancer pathway, what they could expect next, and putting them in contact with other services. Navigators who had experience with other relevant services and teams, such as oncology or surgery, could also use their contacts to get quick responses and keep the patients informed. This also helped to streamline patient experience and keep them focused on their treatment.

"[My navigator] was there to clarify. They were like a live signpost. You could always trust them." Patient

"I thought it was good that single point of contact could signpost and refer for holistic services. I didn't have to go through GP. I used third sector services and thought it was really good. It was nice that I was signposted [supported] instead of told to 'look at this website'. I had chemo, I didn't feel great. It was nice that someone was taking control and it was being done. You knew it was being done because they could keep you updated." Patient

3. Wellbeing

Across all the interviews that were undertaken for this work, a point that was repeatedly emphasised was the amount of stress people with cancer experience. This stress can come from the diagnosis itself, with fears around treatment and prognosis. It might come from the financial and personal implications. For others, it is related to the changes their body can undergo, via surgery or treatment. The logistics, communication, and administration are intimidating, alongside the amount of information that is shared with patients. Patients mentioned all the above when discussing how single point of contact navigators helped reduce their stress and improve their wellbeing. Having someone to support, advise, and advocate for them made a positive difference to the experience of patients, with patients almost unanimously highlighting the importance of being heard and listened to.

"I really appreciate what's been done for me in this past year. It's incredible to put it all together. Especially with waiting lists the way they are." Patient

"Cancer can be a lonely journey when you're alone at home, but you knew you could always get the navigator at the end of the phone. I felt safe and confident, if you know what I mean. I had peace of mind." Patient

"When you're diagnosed with cancer, there's so much stress. [My navigator] has taken the stress out of it. Couldn't have gotten through it without them." Patient

“Navigators are a lifeline for those who are isolated. You lose friends and family through this journey. You should have to fret around 'wasting staff time' - people will feel they aren't worthy of consultant staff time. But you'll speak to your navigator. They're not intimidating.” Patient

“[Cancer treatment] isn't the retirement I wanted. [But] I'm on the mend. On the whole it has been great. [My navigator] is lovely. So accommodating. You see how much they do to support people. They've been a wee gem.” Patient

“[My mum's navigator] was advocating and totally on the ball. Every question – they were straight on to the consultant. You just know things will be fine [with them]. It's made a difficult period great. The navigator has totally worked around what my mum wants. It's been fantastic for her, they have great relationship. Mum's doing great just now.” Patient

Patients also spoke of the profile of their navigator, and how this made a big difference to their experience. Many patients mentioned words such as “calm”, “loving”, “friendly” or “supportive” when describing their navigator. Having someone positive at the end of the line, who could reassure them and ensure they felt comfortable asking questions, had a positive benefit on patients. A few patients mentioned that they didn't always feel comfortable asking questions of their nurses, as they were very aware of their workload – this point was reinforced by comments from navigators and nurses. Thanks to the single point of contact navigators, patients could feel more comfortable asking smaller queries. Patients appreciated the extra minutes the navigator might spend on the phone with them, which helped to build good relationships and put them at ease. In areas where navigators would meet and support patients in face-to-face meetings, patients were particularly appreciative, and noted how this built trust in the navigator and patient's confidence in themselves, as they felt seen and heard.

“My navigator has a very gentle nature. Confident in their talk, and reassuring. Makes the world of difference. Just very good. Says no stupid questions. Give you the freedom to ask what you want to ask. It makes you feel as if you're their friend, on their level. Makes you feel good and that you can ask them anything at all.” Patient

[During my treatment], there was a lot of emotional support, due to fact that I had lost my daughter [to cancer] previously. [The nurse and navigator are] warm, loving people anyway. I felt very close to them. They've always been there for me. They even wished me a merry Christmas over text. It was lovely to receive such a thing from people already have so many people to attend to.” Patient

[My navigator] boosted me up. Everyone in the system - the nurses, the surgeons, all the dieticians. Knowing there's a team looking out for you [really helps]. My partner and I don't have a big circle of friends. It can be a lonely time... I can only praise it for the help they've given me.” Patient

4. Trust

Many patients spoke of their trust for their navigator, and how this helped to reduce their stress and anxiety and improve their overall experience of their treatment. A word that was used to describe some navigators was “efficient”, while many other patients using similar language to describe their navigator’s support and contributions. When patients could rely on their navigator to effectively arrange and rearrange meetings, answer queries, and signpost them to other colleagues or services, they reported positive feelings such as contentment, security, and reassurance. Several patients spoke of the advantages that single point of contact offered, such as continuity of contact. Navigators knew them and could take into consideration things they had learned about the patient and their situation.

“[The navigator] came across as really competent. They had great customer service. If they didn't know, they were up front about that but would ring and ask and would come back to me. They would give a timeline, or update me even if they didn't have an answer that day. I can't think of a time where I was sat thinking that they hadn't called. There were times where I was poorly, I had various complications [and I was having to call a lot]. There was an emergency line – the navigator was good at being proactive [for example,] suggesting I pack a bag, [just in case I need to go in]. They would give an update on what the weather was like in the area. It was little touches like that [which made a difference]. They went above and beyond.” Patient

“We had immediate trust with [our navigator]. They were confident in their work, but not over confident. It's clear that they know what they're talking about.” Patient

“The trust element is important. [The navigator was] reliable and efficient. Finding out you have cancer, you want someone reliable and efficient who is quite direct. They were sympathetic. You want most of all to know that they can do their job. [They were] completely trustworthy.” Navigator

While very little negative feedback was shared during interviews, a theme that arose in the experiences that were shared was lack of trust in the navigator. This highlighted the need for navigators to be well trained and supported, so that they could effectively triage and signpost. It also made clear the difference between services which act more like a switchboard, where patients couldn't expect the consistent support of a navigator, and where navigators cover a wide range of pathways, and therefore struggled to give specific advice. Patients would sometimes report feeling frustrated, or that they weren't confident in the information they were given, or that their request would be actioned. This could result in them asking their nurse the same question, when a navigator was in theory better placed to support them. A minority of patients clashed with the personality of their navigator, or – especially in more ‘switchboard’ style services – preferred certain navigators over others.

“The navigator could have followed up more [on the third sector referrals]. I found myself looking up the support myself. I could've used some help with the personal side – bereavement. How to tackle the emotional side of it... The navigator sometimes didn't follow up on things.” Patient

“I am so relieved when I get one of them on the phone. With others I've had problems. With one there was a language problem. Another had no empathy. I'm

not phoning up for fun, none of us are. I'm just asking for somebody to be civil, polite and say 'well, I'll look into that for you.'" Patient