

# Experiences of patients requiring strong opioid drugs for chronic non-cancer pain: a patient-initiated study

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## ABSTRACT

### Background

Chronic non-cancer pain is an increasing problem in health care. This study was initiated by a patient wanting to discover more about the experiences of other patients requiring strong opioid analgesia for such pain.

### Aim

To determine the attitudes and experiences of patients receiving long-term strong opioid medication for chronic non-cancer pain in primary care.

### Design of study

Qualitative study using interpretative phenomenological analysis.

### Setting

A semi-rural general practice in southwest England.

### Method

The study data came from a focus group and 10 individual patient interviews. A patient researcher was involved in the design, conduct, and analysis of the project.

### Results

The impact of pain affected participants in every aspect of their daily lives. Attitudes to strong opioid medication were both positive and negative. Concerns about starting medication usually centred on fears of addiction, being seen as an addict, or that the patients may have a more serious condition than they had previously thought. However, these fears were tempered by an appreciation of the benefits that strong opioids brought in terms of pain relief and consequent gains in a nearer-to-normal existence. The data did not produce any evidence of addictive behaviour or of tolerance despite these initial fears. Patients adopted a trade off approach, balancing pain relief with medication side effects, accepting more pain for a reduction in sedation and nausea. All patients described coping strategies they developed themselves and learned from outside influences, such as pain clinic courses and support from the GP. There was realism that total pain relief was not possible, but that a balance could be struck.

### Conclusion

Chronic non-cancer pain is associated with high levels of distress and psychosocial impairment. Patients in this study appreciated the benefits of strong opioid medication, having come to terms with fears of addiction and learned coping strategies. These findings should encourage GPs to consider strong opioid medication for patients with severe chronic pain in line with published evidence-based guidelines.

### Keywords

chronic pain; opioids; primary healthcare; qualitative research.

## INTRODUCTION

Despite the recent publication of reviews<sup>1,2</sup> and evidence-based guidelines for the appropriate use of strong opioids for persistent non-cancer pain,<sup>3,4</sup> there is little work published about the experiences of patients with chronic non-cancer pain receiving opioid drugs in a primary care setting. One UK survey<sup>5,6</sup> indicated that chronic pain is widespread in the population; particularly in those aged over 50 years where long-term pain is more common. A survey of patients with chronic non-cancer pain attending a UK pain clinic, indicated that around three-quarters reported benefit from strong opioid drugs, with a similar proportion reporting opioid side effects.<sup>7</sup> Doubts have been expressed about the use of strong opioids for chronic non-cancer pain, but a recent review<sup>8</sup> stated that the evidence base was insufficient to allow conclusions concerning problems such as tolerance and addiction.

User involvement in research is currently being promoted in health services research.<sup>9,10</sup> As part of the development of user involvement in research, the Honiton Research Practice in Exeter hosted an information evening for interested patients. This was designed to explain research currently being conducted and to see whether they would like to become involved. One patient present at the meeting revealed that, as a sufferer from chronic pain, he had concerns about the effects of long-term opioid

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## How this fits in

Chronic pain is a significant health burden in our society. Although guidelines exist for the use of strong opioid medication, fears remain among patients and doctors about long-term use. This study shows that these medications can give effective analgesic benefits and patients adopted strategies for trade-off between pain control and side effects of medication. Coping strategies and a positive GP-patient relationship were also regarded as important.

medication. He expressed an interest in finding out something of the experience of other people in a similar position to himself and whether they also had concerns about the effects of long-term medication. A research project was developed from this original idea with the aim of describing the experiences of people with chronic non-cancer pain receiving strong opioid analgesia.

### METHOD

A search of the Honiton Group Practice database (population 16 000) revealed 35 patients without cancer taking regular strong opioid drugs (search terms: morphine, buprenorphine, MST Continus® [Napp], Zomorph® [Link], fentanyl, Durogesic DTrans® [Janssen-Cilag], Temgesic® [Schering Plough] and Sevredol® [Napp]). All were over 18 years of age and 19 (54%) were female. Each patient's GP was approached and asked to confirm the diagnosis, the use of strong opioids, and whether or not it was appropriate to include the patient in the study. GPs excluded four people from the study because of cognitive impairment, physical frailty, or psychological problems.

Patients received a letter asking if they would participate in either a focus group or an individual interview in their own homes. Recruitment ceased when sufficient participants were recruited for the qualitative research methodology of interpretative phenomenological analysis, which was used for the study. The number of participants required for interpretative phenomenological analysis is usually between five and 15, as the methodology is concerned with the experiences of small homogeneous groups and is not looking for variations and extremes, such as in grounded theory.<sup>11</sup> After consultation with the local research ethics committee, it was agreed that the patient researcher, who proposed the research question, could join the focus group as a participant. The following areas were covered in the focus group:

- the type of pain experienced;
- its duration and the impact of the pain on the participants' lives and relationships; and
- the positive and negative aspects of using strong

opioid medication and types of health care received.

From the initial analysis of this transcript a more detailed schedule was constructed for use in the interviews. Interviews were audiotaped with the participants' permission and confidentiality was assured. The names given to the participants have been changed, apart from the patient researcher's, to provide anonymity and to protect confidentiality.

Tapes were transcribed from the focus group and interviews. The research group members individually read and re-read the transcripts to gain a general sense of the overall accounts. Preliminary notes were made. The research group met regularly to discuss and develop the analysis. As the texts were re-read, emergent themes were identified and discussed. This process was also informed by the experience of the interviews. As the themes emerged they were developed and refined into major themes by a continued returning to the raw data to produce a meaningful narrative based on the participants' own words. In interpretative phenomenological analysis the focus is the participants' experiences of the topic under investigation and, as such, it does not claim to produce objective statements. It is an attempt to unravel the meanings in the participants' accounts through a process of interpretative engagement with the interviews and transcripts.<sup>12</sup>

The overall aim of interpretative phenomenological analysis is to translate the themes into a narrative account attempting to find interesting and essential information to communicate to an audience. The account presented here may not be the only possible interpretation, but it can be justified from the raw data. The verbatim extracts provide the evidence base for the thematic account and their inclusion provides a means of validation.<sup>13</sup> Although not primarily concerned with testing a hypothesis or generating a theory, it may be possible to move towards a tentative 'grounded' theory, which may be transferable to other people and settings.<sup>14</sup>

### RESULTS

Four patients took part in the focus group. Ten individual interviews were conducted (four in the presence of a spouse who was free to contribute). Details of the participants are summarised in Table 1. Strong opioid medication had been used for a median of 15–28 months (range = 8–108 months) and was initiated by the GP in 10 of the 14 cases. Four major themes emerged from the data.

#### *Impact of pain*

Chronic pain had made a profound impact on the lives of all the patients in the study and their partners and families. All participants consistently

reported social isolation, limitations in activities of daily living, loss of a previous lifestyle, and perceived stigma. The pain made them miserable and unsociable and they were constantly frustrated by the things that they could not do and that others had to do for them:

*'It restricts my life to a great extent, socially I don't go out. Obviously walking is out of the question and I don't drink, well I never have done, but if I wasn't in pain I would drink. But generally taking part in activities, normal family life, I find that everyone else can go off and I'm left to mind the house, dogs, whatever.'*

(Brian, focus group)

*'It's [the pain] made it bloody miserable, unsociable. That was the worst when I couldn't get out and walk or stand up, I couldn't do anything in the garden, or any damn thing, so that was one thing I'd lost.'* (Douglas, interview)

*'I live a different life really now you know, I just manage to get out to the kitchen and wash the plate and that's about all I can do you know now.'* (Alice, interview)

*'I want to decorate, because this place needs decorating, but if I start, as the wife just pointed out this morning, I'll end up in pain. I'll probably, no I will do, but at least I'll get a start and then as she said again, she will be the one that suffers, not me, it's her that will worry.'* (Ian, interview)

As well as feeling different participants thought they were often viewed differently because of their problem and that there was a stigma attached to that, or they were not valued as they would have been before:

*'But why do people assume that if you can't move or you're in a wheelchair or something, they think there's something wrong with your brain. There's nothing wrong with my brain. I mean I'm quite the ticket. [Laughs] We're here laughing, but people treat me as though I'm something out of Mars I think, they don't think I've got any brains but I have, it's not my head [laughs] ... it's the bottom part of me that don't work, it's not my head.'* (Frances, interview)

The effect of the condition on their life was often an influence when it came to considering medication. This led to the consideration of taking stronger medication for the pain.

### **Attitudes to strong opioid medication**

Three aspects of attitudes to strong opioid medication emerged from the data. The first was participants' initial reaction when offered the medication. When first offered strong opioid drugs the patients had mixed emotions. Some thought that it was a strategy of last resort and that they must be at the end of the line with their own illness:

*'So that's when the doctor said to me, what about morphine and I thought it sounded so end of the road – morphine, and he said, "no, don't be afraid of it a lot of people think this is the final thing to be on", but he said it wasn't.'* (Laura, focus group)

*'It's a frightening word, isn't it? When you see it in the media, when you see it on the television, you think if you're taking regular morphine you must be in a pretty bad way, you know.'* (Katherine, focus group)

For others this was even more pronounced and they either thought that they must have another illness that the doctor had not mentioned, or that they had reached the final stages of their own condition and that morphine and its counterparts were only prescribed for dying people:

*'The first thing I thought about was, you only get given morphine if you're dying, umm, I used to be a carer like to cancer patients and I thought I haven't got cancer, so I was a little wary.'* (Belinda, interview)

*'When I was first offered it I, when it was first mentioned, I thought well I made the comments, but I thought they [opioid drugs] were for people that are terminally ill. I said, 'now you're not telling me that this is terminally ill or have I got something else I don't know about that you've not told me.'* (Charles, interview)

One of the other common concern participants had was that they might become addicted to the drug. This was often influenced by what they had heard and seen in the media:

*'I don't want to become addicted, if I'm going to become addicted then as far as I'm concerned I'm a druggie, so I might as well not be here anyway, so I don't want to become addicted. You see what it does to people on the television, you know drugs, being addicted with cocaine and all that other stuff. I don't want to get into it like that and I assume you can from medical*

drugs, well you can because you see the programmes on the telly. You can get addicted by that, I don't want to get to that state.' (Charles, interview)

'I was afraid of becoming addicted ... I thought if I take morphine and I become addicted to it, I'm going to be taking more and more and more and I don't want that to happen, because I fear once you become addicted to something you can't cope with normal life, you're not being fair to your family or anyone else if you do that. But fortunately so far I'm not that way ... I try to take as few tablets as I possibly can.' (Grace, interview)

The second aspect was the beneficial effect of the medication. All participants had reached a point where they were willing to try anything that might help. They also found that once they started the treatment the positive aspects often countered the negative first emotions as they experienced relief from pain and the newfound ability to resume a more 'normal' existence:

'No just as long as I got rid of the pain, that was all I was interested in. Because I was getting a lot of pain then, a real lot of pain, well I do now but I'm lucky I've been alright so far.' (Ian, interview)

'Oh I was all for it, I mean anything to stop this awful, these terrible spasms I was getting in my

legs. It was almost as though somebody had taken all the muscles and pulled, oh it was horrible, and I mean I was delighted to get anything to relieve, you know even a little bit. I would be very very upset if these were stopped you know, I dread to think. I just don't think I could survive without them, they really do help.' (Alice, interview)

Some expressed their appreciation for opioids even more strongly and did not see any problems with it once they started taking it:

'To be quite truthful it's the best thing I've ever taken and I'm glad really that I was allowed to take it because I know normally its only given to people that umm, are umm, seriously ill and I wouldn't put myself down as seriously ill. I just put myself down in chronic pain I suppose.' (Charles, interview)

'I didn't really have any views because I was suffering from pain so I was quite glad to have any tablets that helped to reduce the pain.' (Harry, interview)

'No, as far as I am concerned it's all good points because it's helping with my pain, so you know I can't see any bad points in it, because it does help with the pain.' (Harry, interview)

While others still had reservations, but appreciated the drugs for what they were able to do:

**Table 1. Participants, their conditions and medication usage.**

Name	Age (years)	Condition	Duration (years)	Medication/ current dosage	Initiator	Laxatives	Pain clinic	Adjuncts
<b>Interviews</b>								
Alice	73	Multiple sclerosis	5	Fentanyl 100 mcg/hour	GP	No	No	SSRI, AE
Belinda	34	Chronic back pain	6	Morphine elixir 60 mg/day	GP	No	Yes	SSRI, TCA, NSAID, AC
Charles	63	Chronic back pain	12	Morphine S/R 60 mg/day	GP	No	Yes	SSRI, TCA, NSAID
Douglas	74	Spinal stenosis	2	Fentanyl 75 mcg/hour	Consultant	No	No	TCA, AE
Edwina	70	Chronic back pain	1	Morphine S/R 60 mg/day	GP	Yes	No	Nil
Frances	69	Chronic back pain	14	Morphine S/R 60 mg/day	Consultant	Yes	Yes	Nil
Grace	63	Chronic back pain	12	Morphine S/R 30 mg/day	GP	Yes	Yes	TCA
Harry	61	Complex regional pain syndrome	3	Morphine S/R and Morphine tablets 30 mg/day	Consultant	No	Yes	Nil
Ian	71	Chronic pancreatitis	28	Fentanyl patch 50 mcg/hour	GP	No	No	Nil
Julian	61	Chronic shoulder pain	10	Morphine S/R 100 mg/day	GP	No	Yes	NSAID, TCA
<b>Focus group</b>								
Katherine	51	Chronic neck pain	9	Buprenorphine S/L 1200 mcg/day	GP	No	No	TCA, NSAID
Laura	76	Rheumatoid arthritis	25	Morphine S/R 60 mg/day	Consultant	Yes	No	TCA, NSAID
Brian	56	Chronic back and ankle pain	20	Morphine S/R 80 mg/day	GP	Yes	Yes	SSRI
Mike	47	Chronic back and ankle pain	15	Fentanyl patch 50 mcg/hour	GP	No	Yes	SSRI

AC = Anticonvulsant. AE = Anti-emetic. NSAID = Non-steroidal anti-inflammatory drug. S/L = sub lingual. S/R = slow release. SSRI = Selective serotonin reuptake inhibitor. TCA = Tricyclic antidepressants.

*'It's a bad thing (morphine), but I think it gives you back your independence.'* (Belinda, interview)

The third aspect was dealing with side effects and developing a balance. Constipation was an infrequently mentioned side effect and only five of the 14 participants were taking regular laxatives. The more challenging side effects appeared to be sedation, nausea, and impaired mental functioning. Participants described a trade-off between getting 'good enough' pain control and an acceptable level of medication-related side effects:

*'It's, it's got a good and bad side, morphine. Umm, the advantage is, I only take it if its severely, severe pain where I cry. When I take it, it works really, really well but it makes you feel rather sick, umm, rather spaced out and thinking wise, umm, it outcomes more on the other, do I want to be sick or do I want to cry with pain? So I'd rather be sick but it is a very, very good painkiller.'* (Belinda, interview)

*'The side effects of it, and it did have side effects, for oh, a good 2, 3 weeks, I sweated, I was hot I was cold, I flushed, I couldn't rest, you never did see hot flushes like I had with those tablets, and I said to him [the GP] I've got to persevere and I did but they did have side effects. I'd read it in the book, in the thing, that once you take them you don't come off it unless you see your doctor first and then he will take you off them. But even now I get sweats now and again, I don't know if it's the tablets or what it is, but I get sweats.'* (Frances, interview)

The relatives of participants also noted the benefit of improved pain control:

*'Well since you've got the morphine down a bit and you can get about a bit more, well you do get about a bit more, you're all, I mean OK it still hurts, but you do make the effort.'* (Wife of Julian, interview)

However, the participants also were keen to reduce medication when at all possible to decrease side effects and to show they were not addicted to it:

*'I've been able to reduce my morphine which has cleared my head, because I was so drugged up I was very near to committing suicide.'* (Julian, interview)

*'I don't want to do that [take more morphine]. I*

*want to stay on as little as I possibly can because there might come a time when I need more and I don't want to be on high doses. I've always tried to keep it at a minimum amount of tablets each day. But if it gets beyond what I can cope with then yes, I will give in and I'll take extra tablets.'* (Grace, interview)

At times though they were reconciled to needing to take the dose that helped and not to worry too much about the side effects:

*'Take the stronger pain killer to get rid of the pain, and don't worry about the side effects and it hasn't been too bad, but I do find if I don't take them then it's a wasted day because you just sit in agony.'* (Katherine, focus group)

### Coping strategies

All participants described coping strategies that they developed themselves that they learned from outside influences, such as pain clinic courses and support from the GP. One of the most commonly used techniques was of distraction and trying to occupy themselves to forget the pain:

*'Yes, being involved, at least even in your worst state there's something you can get out of reading and learning about something else.'* (Laura, focus group)

*'I'll do what I can when I can and that's how I'm going to live. And I've done that since. Once I was able to accept that then that was it, I was a lot better afterwards.'* (Grace, interview)

Of the seven patients who had attended a specialist pain clinic, all but one were appreciative of the service. Learning that others were in the same situation, that pain itself does not always equate with physical damage, and that pain and depression often co-exist were seen as helpful concepts. Learning relaxation techniques and the concept of 'pacing' also helped:

*'Like I say, the best thing to come out of it for me was learning how to relax because I couldn't relax. I was very tense, very, very tense, so if something was to go wrong I was always tense. I used to sit all tense and at least I can relax now, which I couldn't before, so yes, the pain clinic was really, really good.'* (Charles, interview)

*'It did make me realise that pain and depression do work together.'* (Belinda, interview)

### Relationship with the GP

Another major theme that emerged from the data was of the importance of the relationship of the patient with their GP. All participants were in regular contact with their GP. They placed particular importance on ease of access, the doctor having time available, and the ability to listen and explain as well as continuity of care by the same doctor. Being able to have time to explain themselves and to be made comfortable was one of the first preferences:

*'I always find she (my doctor) will make time, it doesn't matter whether she's running late or not, she will make time to sit and listen to what you've got to say.'* (Katherine, focus group)

*'Yes it is important because I feel that I can go up to him and I can speak to him, and I can ask him different things, and I can tell him. You know what is wrong — its embarrassing sometimes but if you don't tell him he's not going to know and I've come to the conclusion that if I want him to know anything I've got to tell him, because otherwise he's not going to know what he's treating me for is he? But I think he's wonderful, I really do.'* (Frances, interview)

This was also reflected by some of the relatives participating in the interviews:

*'We find that we can talk to him and he talks back softly to you and he explains things.'* (Husband of Frances, interview)

Being understood as a person as well as knowing about the condition was considered important:

*'Well, if you have a GP who knows you and knows what you're like as a person, I think they can understand better how you're feeling.'* (Grace, interview)

The GP was also seen as being the professional who was always around even when they had been through other clinics:

*'I mean really, when you have finished with all the specialists and the consultants your GP is your main contact, he is your back up really. Yes it is important.'* (Harry, interview)

Although the participants generally described good relationships with their GPs and a feeling of being understood and cared for, they sometimes felt they could not tell their doctor all that was troubling them. At times they concealed the severity of their

pain and did not want to be seen as wasting the doctor's time:

*'I don't break down in front of him, I can't, I can't. As I say I put on a brave face, but he just really doesn't know what I'm going through, he really doesn't. But I can't tell him. There's no way I can say to him how I am, I can't tell him.'* (Frances, interview)

*'I always try to make out that I'm better than I actually am. I think it's a mistake to do it, but I don't want to give in.'* (Grace, interview)

## DISCUSSION

### Summary of main findings

The impact of living with chronic pain that affects every aspect of daily life is a familiar theme in the area of chronic pain research. For all the people in the study the pain had taken over so much of their lives that, although they may have had reservations, the offer of stronger pain relief was usually welcomed.

Concerns about starting strong opioid medication usually centred on fears of addiction or being seen as an addict, or worries about having a more serious condition than was previously thought. Some described it as being at 'the end of the road'. However, with reassurance these fears were tempered by an appreciation of the benefits that strong opioids brought in terms of pain relief and consequent gains in independence, and a nearer-to-normal existence. The data did not produce any evidence of addictive behaviour or of tolerance of medication despite the initial concerns. Patients developed trade-off strategies, especially regarding the balancing of pain relief with medication side effects, by accepting more pain for a reduction in sedation and nausea. There was realism that total pain relief was not possible, but that a balance could be struck.

Participants also described coping strategies which had evolved from within themselves and were also learned from outside influences, such as pain clinic courses and support from their GP. An open relationship with the GP marked by continuity, openness, and the ability to listen and give advice was valued, although a reluctance to fully reveal the extent of their pain was also found.

These findings would indicate that for certain patients with chronic pain prolonged strong opioid medication can produce appreciable levels of pain control balanced against acceptable levels of side-effects. Patients had an awareness of potential problems of tolerance and addiction and were keen to keep opioid doses to a minimum.

### Strengths and limitations of the study

The strength of a qualitative research methodology, such as interpretative phenomenological analysis, comes from the deep personal insights of a few people as opposed to large quantitative survey data. The study was small in numbers to try to understand something of the participants' experiences. The findings will not be generalisable, but they may be transferable to other settings and have the potential to generate a theory and act as a starting point for further research.<sup>14</sup>

The project was inspired by and carried out with help of a patient researcher; this may be viewed as both a strength and a weakness. The personal experience of the patient helped the health professionals develop interview schedules and to think outside their professional 'boxes'. The possibility of bias by the patient being too close to the data is a potential weakness. Rather than follow the more usual route of using a patient advisory group the researchers felt that involving the patient fully in the research process was innovative and gave the patient a greater sense of involvement and ownership. Another model of patient researcher involvement in the field of migraine management has been published<sup>15</sup> and principles of good professional-patient partnerships have been refined.<sup>16,17</sup>

The local research governance and management systems and local research ethics committee found the issues of confidentiality and active patient participation in the research process challenging. There appeared to be no set guidance to help them in managing the actual involvement of a patient/researcher, despite the desire for more patient/user participation in research.<sup>9,10</sup>

This study only included patients who were established on strong opioid medication and provides no information on those who may have started opioids, but discontinued for reasons such as side effects and ineffective pain relief.

### Comparison with existing literature

The literature concerning chronic non-cancer pain management has predominantly come from specialist pain management services and consensus statements from expert bodies. In the UK the Pain Society published its recommendations for the appropriate use of opioids in persistent non-cancer pain. This acknowledged the lack of data in many important areas of clinical practice, such as primary care.<sup>4</sup> In the US, particular attention is also being given to this area by the Opioid Management Society, which is developing a certification programme to inform prescribers on all aspects of opioid use.<sup>18</sup>

The experiences of the participants in this study compare with other studies looking at patients with

chronic pain in terms of impaired wellbeing, social withdrawal, stigmatisation, and 'not being believed'.<sup>13,19</sup> Patients' fears regarding addiction and the association of opioid use with terminal illness have also been found elsewhere.<sup>20</sup> The observation that patients try to balance therapeutic benefits and side effects from medication has also been found in a pain clinic survey in the UK. In that study around three-quarters of patients reported benefits and the same proportion had opioid-related side effects. A certain level of side effects was acceptable for the resulting reduction in pain.<sup>7</sup>

The benefits of behavioural and relaxation approaches to chronic pain have been described<sup>21</sup> and were similar to the experiences of patients in this study who had attended a pain clinic.

The importance of the doctor-patient relationship and continuity of care to the participants highlights the value of this therapeutic relationship in primary care.<sup>22</sup> However, the reluctance of patients to share fully the extent of their pain may contribute to inadequate pain control due to the GP underestimating pain intensity, which has been reported in other primary care settings.<sup>23</sup>

### Implications for future research

The prevalence of chronic pain is likely to increase with an aging population and the use of strong opioid medication in primary care may increase. There is a need for further studies examining the potential barriers to initiating prescribing of strong opioids by GPs and the degree of confidence and comfort they have in monitoring patients receiving long-term opioids for chronic pain.

The difficulties of conducting patient/user research in the NHS and the interactions between research ethics committees and researchers require further exploration if such research is to flourish.

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### Ethics committee

North & East Devon LREC Study (2003/9/183PCT0047). All participants gave their informed consent

### Competing interests

Brian Ruel is a patient of the Honiton Group Practice and is registered with David Seamark

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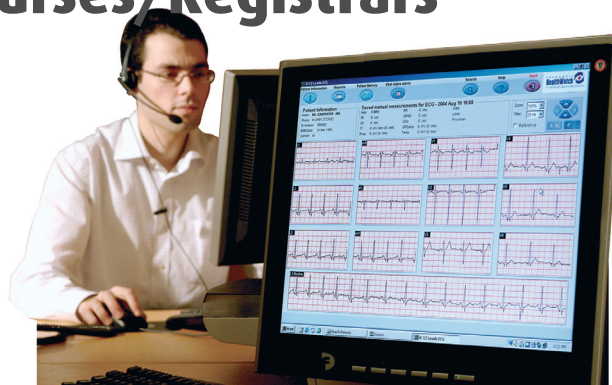
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