



# Impact of a Patient-led Helpline on NHS Services

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## Background to Project

COVID-19 has caused unprecedented strain on the Scottish National Health Service (NHS) resulting in patients having to wait longer than usual for access to specialist pain services. In response to this Pain Concern received Scottish Government Funding to enhance the support options available to people with pain on waiting lists for these services.

Pain Concern created a National Telephone Helpline with a dedicated telephone number for pain patients in Scotland. The Helpline was manned by paid Helpline Operators, recruited out of Pain Concern's existing pool of trained volunteers, and they received bespoke training to support callers and evaluate the service.

The project ran from January to the end of March 2022, and intended to achieve the following outcomes – to enable waiting list pain patients to:

- Feel empowered to tackle the broader problems of daily living
- Feel empowered via self-management advice, understanding pain, activity management and dealing with emotional distress to prevent further decline in function
- Be better able to make the best use of NHS pain services when they are seen

## Intervention

Helpline Operators, experienced in taking calls from people in pain, took a standardised approach to dealing with conversations; they provided emotional and practical support to callers explaining Pain Concern's *Self-Management Navigator Tool*, sending them a copy of the tool and directing them to other pain management resources.

## Methods

Study Design comprised of feedback and comments obtained from patients during calls, observations made by the operators and a survey of clinicians supported by Evaluation Support Scotland. Contemporaneous data during calls were collected by the Helpline Operators and classified into 'service and user feedback', 'observations during calls' and 'capturing casual moments'. The Helpline Operators were required to complete their record and documentation for each caller immediately after calls and data were summarised in an 'after contact' survey record. Common themes were identified. An 'evaluation survey' was sent to 14 clinicians to obtain feedback about the service from healthcare professionals' perspectives.

## Results

Thirty-eight records were completed by Helpline Operators. In terms of "service and user feedback" 17 (45%) said that they felt better / more positive having spoken to the Helpline Operators, 17 (45%) callers felt better prepared for their healthcare appointments after speaking with Pain Concern.

Typical feedback is represented by

*"I feel much more confident in how to discuss medication and treatment with both my GP and the care home"*

For "Observations during calls" 20 patients (52%) were noted to sound more positive and hopeful, with a noticeable improvement in their tone of voice by the end of the call. In terms of "capturing casual moments" callers expressed the struggle they had with healthcare appointments and the challenge around remaining focused on what they wanted to talk about.

Six clinicians responded (42%). Five rated the service highly with the lower rated response having no significant waiting list. Comments were very favourable about the support and resources, highlighting patients needed them at point of referral. However, there is currently no mechanism to do this.

## Conclusions

Patients waiting on lists for specialist pain service had a positive experience of the skilled support and resources of Helpline Operators manning a Telephone Helpline with their lived experience of pain management and use of Pain Concern's *Self-Management Navigator Tool*. Overall their confidence to manage their appointment and be better equipped to manage pain seemed to improve. A longer duration would enable confirmation of these findings.

The work also revealed that most Regional Health Administrations (Health Boards) do not have a mechanism to communicate with patients on their 'pain' waiting lists. Pain Concern intends to explore what can be done in future to improve lines of communication.