| **Optional Template– Interim and Final report for Health Equity Fellowship** | |
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| **Project Details** | |
| Project Name | Living with Pain |
| Mentor | Lynette Smith |
| Start Date | April 2024 |
| **Summary/Abstract – FINAL REPORT** | |
| The summary / abstract provides the reader with an overview of all covered in the project report. Even though a summary is placed at the beginning of a project report, you can only write it once your entire report is complete. | |
| Introduction | **Overview of the project/initiative** Through the early work I have been undertaking with the NHS Scarborough & York Teaching Hospital Trust and personally, I have identified a gap in pain support services that exist in Scarborough.  My proposed project design will engage with people living with pain and long-term pain conditions that are, on the whole, silent in our growing community. Addressing opinions of their NHS acute care, emergency care and treatment from the rest of the community in their everyday lives. Therefore, finding out what is important to people, transforming care and driving positive change. The information will be collated and will be presented to Scarborough Coast Health and Care Research Collaborative (SHARC).  Chronic pain is a common condition affecting over one third of adults in the UK. It can be debilitating for some people that have a long-term effect on everyday activities, roles and routines. Causing low mood, affecting mental health with an uncertainty to their future.  Living with long term pain day to day can affect social isolation and impact on loneliness. Being unable to work with some pain conditions will have an impact on living on a low income and currently a cost-of-living crisis to contend with will mean that many will be living on the poverty line.  **Objectives**  Enabling people living with long term pain engage with organisations of support, building a network of trust and support.  Addressing opinions of their NHS acute care, emergency care and treatment.  Better address the health and care needs of **our coastal populations** through high quality collaborative research 'with community involvement'.  Empowering Scarborough’s communities to work together to improve health and wellbeing opportunities to facilitate change.  Conduct engagement and relationship-building events to raise awareness of living with Pain conditions.  Facilitate meetings with local residents and organisations, seek out community needs for addressing pain and health care.  Identify specific healthcare needs/health inequalities present in the Yorkshire Coast population that SHARC should address.  To create the best community health and wellbeing outcomes through the highest quality collaborative research  To improve the health of Scarborough through collaborative research  Deploying research into practice to make a lasting difference to the quality of clinical care that is provided to patients in Scarborough.  Field work underway regarding Pain Cafes in support of building a network of peer led support.  **Partners (List of key partners/stakeholders)**  Scarborough Coast Health and Care Research Collaborative (SHARC). GP practices, GP care coordinators, Scarborough pain community, Scarborough’s REN (Research Engagement Network) Champions. Working towards building more stakeholders.  **Approach**  Scoping & field work, personal learning, engagement through social media & events, sharing learning with SHARC to promote further future research. Identifying support in place and gaps, developing and addressing needs. Sustainability will be measured by the continuation of the support network. I have also enquired about obtaining ethics regarding questioning participants. The outcome was that I wouldn’t require ethics as the discussions would be informal and any data collected would be anonymised. This work is still ongoing.  **What will success look like?**  Valid, recognised engagement and a voice for the community to enable health services to consider their needs and requirements. A peer led support network for people living with pain and pain conditions. |
| Central aim of your project | To conduct conversations with people living long term pain. Gain insight into to peoples lives. Identify key themes. Plan for peer led pain support. |
| Methodology, results, conclusion |  |
| **Introduction: Purpose and Overview of the Project Brief – INTERIM REPORT** | |
| Provide background, context, and an outline for your chosen project | |
| Problem the idea is seeking to solve or address (if any) and population group | Identify key themes. Peer support for people living with pain. |
| Key assumptions and interdependencies | [**Assumption**](https://www.merriam-webster.com/dictionary/assumptions): Scarborough has no pain clinic or management service and people have to travel. Long wait times for Pain management services out of area.  [**Constraint**](https://www.merriam-webster.com/dictionary/constraint) Time, funding for Training.  [**Interdependency**](https://www.merriam-webster.com/dictionary/dependency): Peoples willingness to engage in conversations to drive qualitative data. Pain Café is dependent on people attending, an agenda, want not need for a Network. |
| What is the overall purpose of this project? Aims? | Through conversations and workshops, identify what support is available and wanted. To provide support for people living in pain. |
| Why it needs to be done? / Why it should be done now? | In Scarborough there isn’t a pain clinic. The nearest Pain Clinic is now York, approximately 42 miles away. The Bridlington Pain management Service (approx. 17 miles away) was closed and moved to Hull (approximately 47 miles away). There is an approximate wait time of 2 – 3 years currently to become a patient at the York Pain Management Service. For a person living with pain travelling a short distance can be problematic, a longer distance, sometimes using several modes of public transport, can be excruciating. This leaves patients with little hope when faced with this lengthy wait.  Their pain can lead to reducing responsibilities and activities such as work, occasionally having to risk unemployment through their health. This has a bigger impact on paying bills such as rent and mortgages. Fuel bills will increase as they are at home more. Food needs to be easy to cook as they may not be capable to stand for long periods of time hence their food bills increase, buying convenient, occasionally less healthy option.  At present through the conversations that have taken part so far, the majority of people have said it would to be listened too. It helps to discuss their pain. Through a peer led discussion group they will be able to use the support while they are waiting for treatment. Share ideas of what helps them with others to help them. |
| Opportunities and Challenges? | **Opportunities**  After a discussion with a colleague I was told about Pain Cafes. I had the opportunity to visit one of the Pain Café Network in Cornwall whilst holidaying there. I met some wonderful people and saw first hand how the sessions were led by Social Prescribers really supported the people attending. I met Sean Jennings, a fellow pain sufferer and founder of the Pain Café Network in Cornwall. He was on his first visit to Hayle Pain Café so you could say it was divine intervention that we were both there on the same day!  I have also had the opportunity to speak to people about how pain affects them daily.  **Challenges**  I would say one of my main challenges has been time so far. Fitting the fellowship into my time at work has been difficult as I would like to devote more time to this work.  I would also like to find funding for additional training to further support the Pain Café which so far has been unsuccessful.  Interest is there from some Clinicians and health professional however their time is precious. I understand that Bex from SeeCHANGE wanting to discuss pain may not fit into their busy schedules therefore I have had a disappointing response to scoping emails so far. |
| Desired results of the project? | Identified key themes to inform further future research. Pain Café Network established and successfully running with outside support such as clinical, health professionals, Social Prescribers. |
| Brief description of methodology used? | I am holding conversations and workshops to gain qualitive data to recognise themes that can be explored further. This information will be share with SHARC. |
| **Theory of Change – OPTIONAL: INTERIM REPORT** | |
| A Theory of Change is a way of mapping and visualising the future goals you want for your project which is fundamental to its design. It helps to set out; A clear link between the activities you want to do to achieve your goals; What needs to be in place to ensure your activities link to your goals; how you will know whether you have achieved your goals. It helps to test how plausible and feasible are your goals and provides a framework from which you gather data, learning and insight on your journey to prove how you are achieving your goals | |
| Outcomes |  |
| Inputs | Conversations with community and health professionals in pain management. |
| Activities undertaken | Created a Facebook page – What a pain in the…? Conversations (ongoing)to gather insights, identify key themes and potential input from health professionals. Planned workshops for October 2024. |
| Impact |  |
| Outputs | Ongoing - Facebook page, planned workshops, 1:2:1 conversations, For 2025 planned pain café and or potential network |
| **Body of the report INTERIM REPORT and FINAL REPORT** | |
| This section provides the detail of your work analysis, data, and graphics | |
| Provide the evidence and theory behind your project |  |
| Explain your key findings, results, | Findings  I have conducted several 1:2:1 anonymised conversations with people that have contacted me through my Community Engagement role, friends, family & What a pain in the…? Facebook page.  The majority of people I have spoken to have been women that have different long term pain conditions. Most have a diagnosis of Fibromyalgia or the potential that they may have, has been discussed with medical professional. Most have a neurodiverse diagnosis or feel that they are neurodiverse. This key theme has led me to arrange to visit a social group with solely neurodiverse members. As neurodiverse people are hypersensitive to a lot of things, making the feel and experience things in a heighten way… Is this why many pain sufferers are also neuro diverse?  Several of the people I spoke to, discussed a past trauma. I was recommended a book which I have now read on how past trauma can manifest as illness, addiction and unexplained pain. Could this be the correlation with Fibromyalgia?  I have also watched TED talks regarding people with living experience that have retrained their brains to deal with Pain differently. |
| Describe achievements, changes and difference made, impact |  |
| Provide any recommendations |  |
| **Conclusion – FINAL REPORT** | |
| This section brings the entire project report together, summarising your argument and why it is significant | |
| Restate original ambition | **Overview of the project/initiative** Through the early work I have been undertaking with the NHS Scarborough & York Teaching Hospital Trust and personally, I have identified a gap in pain support services that exist in Scarborough.  My proposed project design will engage with people living with pain and long-term pain conditions that are, on the whole, silent in our growing community. Addressing opinions of their NHS acute care, emergency care and treatment from the rest of the community in their everyday lives. Therefore, finding out what is important to people, transforming care and driving positive change. The information will be collated and will be presented to Scarborough Coast Health and Care Research Collaborative (SHARC).  Chronic pain is a common condition affecting over one third of adults in the UK. It can be debilitating for some people that have a long-term effect on everyday activities, roles and routines. Causing low mood, affecting mental health with an uncertainty to their future.  Living with long term pain day to day can affect social isolation and impact on loneliness. Being unable to work with some pain conditions will have an impact on living on a low income and currently a cost-of-living crisis to contend with will mean that many will be living on the poverty line.  **Objectives**  Enabling people living with long term pain engage with organisations of support, building a network of trust and support.  Addressing opinions of their NHS acute care, emergency care and treatment.  Better address the health and care needs of **our coastal populations** through high quality collaborative research 'with community involvement'.  Empowering Scarborough’s communities to work together to improve health and wellbeing opportunities to facilitate change.  Conduct engagement and relationship-building events to raise awareness of living with Pain conditions.  Facilitate meetings with local residents and organisations, seek out community needs for addressing pain and health care.  Identify specific healthcare needs/health inequalities present in the Yorkshire Coast population that SHARC should address.  To create the best community health and wellbeing outcomes through the highest quality collaborative research  To improve the health of Scarborough through collaborative research  Deploying research into practice to make a lasting difference to the quality of clinical care that is provided to patients in Scarborough.  Field work underway regarding Pain Cafes in support of building a network of peer led support.  **Partners (List of key partners/stakeholders)**  Scarborough Coast Health and Care Research Collaborative (SHARC). GP practices, GP care coordinators, Scarborough pain community, Scarborough’s REN (Research Engagement Network) Champions. Working towards building more stakeholders.  **Approach**  Scoping & field work, personal learning, engagement through social media & events, sharing learning with SHARC to promote further future research. Identifying support in place and gaps, developing and addressing needs. Sustainability will be measured by the continuation of the support network. I have also enquired about obtaining ethics regarding questioning participants. The outcome was that I wouldn’t require ethics as the discussions would be informal and any data collected would be anonymised. This work is still ongoing.  **What will success look like?**  Valid, recognised engagement and a voice for the community to enable health services to consider their needs and requirements. A peer led support network for people living with pain and pain conditions. |
| Summarise the key themes | 5,5 million (approximately 8%) of people are currently living with chronic pain in England.  Mandatory Pain education for medical professionals have approximately 13 hours of training over 6 years of medical training. – Pain in the Podcass, Episode 3 How much do health professionals know about pain? Published 29th January 2025 |
| Summarise your thoughts |  |
| Describe any future actions or work needed | To continue and expand the Pain Café support in Scarborough and surrounding area.  To continue with evaluation through York University and 2 supporting lecturers with potential further support with research students.  To present findings and information to stakeholders and partners.  To search out potential Pain Café funding opportunities. |