| **Optional Template– Interim report for Health Equity Fellowship** | |
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| **Project Details** | |
| Project Name | **Pip Pop and a Pandemic – exploring the inequalities and the gap in life expectancy for people with a serious mental illness** |
| Mentor | Bal Athwal |
| Start Date | May 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 | This project builds on the work of Tracy Willits, a senior lecturer in media production at York St John University, who produced a documentary titled ‘Pip, Pop and a Pandemic,’ exploring the inequalities and the gap in life expectancy for people with severe mental illness (SMI) through the lived experience of people with schizophrenia. The film follows two couples from the Northeast before, during, and after the pandemic. The result is a raw and emotional insight into the many serious problems that exist in our mental health care system. Two of the participants have since died, backing up research that says people with SMI conditions have a life expectancy 15 to 20 years shorter than the general population. The film was shown in Parliament in 2023 with a call to action and panel discussion. A link to the documentary is provided. [Pip pop and a pandemic (youtube.com)](https://www.youtube.com/watch?v=JlEo6IEiZRU)  Building on the initial documentary findings, Tracy is now working with Dr Spencer Robinson (Deputy Director at the Institute for Health and Care Improvement @ York St John University) on a project aligned to the Humber and North Yorkshire ICB Health Equity Fellowship Programme to further explore health inequalities experienced by people with SMI. |
| Central aim of your project | The overall aim of the project had several facets, firstly, utilising the findings from the SMI documentary to support thinking for strategies or interventions to reduce inequalities with people with severe mental illness. Areas of exploration and focus included:   * Examine the current literature related to SMI pts, health inequalities and physical annual health checks. * Gain an understanding of SMI pts experience of physical annual health checks. * Gain an understanding of primary and community care staff experiences who support and interact with SMI pts and complete the physical annual health check. * Explore and understand current primary care safety netting practice and what interventions are used in primary care to support stronger adherence for SMI physical annual health checks. * Consider interventions or strategies involving specialist bookable appointments for SMI with staff trained in helping complete necessary forms such as PIP and carers allowance. * Gain an understanding of the community advisory workforce that support people with long-term mental illness. |
| Methodology, results, conclusion | **Methodology**  Various methodologies were used to support the development of this project. The team embarked on an NHS QI discovery phase which included a rapid literature review and engaging and presenting at several meetings with system stakeholders involved in SMI. These included engaging with experts from Bradford VCSE in relation to incentives with GP and SMI health checks, meeting with colleagues from Bridlington and East Coast communities involved with pts with LD and annual health checks. The team also attended and presented the project and some early findings for discussion at ICB system level SMI meetings that included VCSE, ICB system leaders and local NHS providers. In addition, also presenting at an NHS MH and community provider NHS Trust to further understand current climate and professional perspectives. The project also had abstracts accepted at an International Royal College of Psychiatry Conference in Belfast (October 2024): Faculty of General Adult Psychiatry Annual Conference: Future Directions for Adult Psychiatry, and the Institute of Health and Care Improvement Annual research conference at York St John. Building on the early engagement and system discovery phase the team then developed a qualitative phase which involved the design and implementation of 2 focus groups with SMI pts: one held at North Shields in the Northeast, the second in Durham City. The location and access to pts was due to previous relationships held by a project team member.  **Results**  Literature review  Explored the barriers and blocks to people with SMI attending their annual health check. Findings included lack of awareness of physical health check provision, lack of understanding of the reasons for the check and why it is important (including the relationship between their mental and physical health), difficulty engaging with invitations sent via traditional routes (for instance, not opening post), previous poor experiences of the health check, concerns about the check itself (that it will only provide ‘bad news’) and what it will involve (e.g. fears about blood tests, being weighed), poor mental health at the time of being invited (e.g. low motivation, psychosis, anxiety), Diagnostic overshadowing’ often occurs in patients with SMI – physical health concerns put down to a mental health diagnosis, Primary care staff not always confident working with people with SMI, The problem of stigma: self-stigma and the internalisation of a negative stereotype applied to oneself, and social stigma imposed by society.  Explored the evidence and concept of ‘quality’ in a physical annual health check. Findings included, people coping with SMI need personalised support to self-manage their physical health, and that recognises the challenges they face (from NIHR), Telephone invitations, text message reminders and opportunistic verbal invitations improve uptake (more effective than letters), Two-way communication rather than rigid referral processes, Bridging the gap between primary and secondary care, Mental health professions and GPs working closely together.  Cancer prevalence amongst SMI patients  The literature highlighted some stark findings in relation to cancer prevalence and SMI mortality. Findings suggest people with SMI pts are less likely to be screened for cancer and more likely to die from cancer despite the incidence being similar (Perini et al., 2013) Adults with SMI 2.1 x more likely to die from cancer and is one of the leading causes of premature mortality in people with SMI (above CVD, respiratory and liver diseases). This is likely due to reduced screening uptake, delayed diagnosis, treatment choices and adherence. Wynnychuck (2023) argues people with SMI often present with more advanced cancer at diagnosis, experience poorer quality of care, receive fewer treatments, have higher disease mortality and are less likely to receive timely palliative care (Wynnychuk 2023). The screening gap is high for women with schizophrenia with half less likely to receive breast cancer screening compared to women in the general population. Patients with schizophrenia were more likely to receive a delay in diagnosis, present at late-stage disease and often delay or refuse treatment/therapy (Farasatpour, 2013). As well as poor screening uptake, delays in diagnosis may be due to physical illnesses more difficult to detect due to overshadowing of psychiatric symptoms (Kisely & Siskind, 2021)  SMI pt focus groups  11 participants were recruited from a mental health support charity. All participants viewed health checks as important as there was a tendency of people to neglect their health. People described sometimes not having the capacity to express their physical symptoms. Physical issues being missed due to ‘diagnostic overshadowing’ i.e mental health symptoms are overshadowed by physical systems by health professionals. Barriers to attending AHCs appointments were explored highlighting the anxiety around negative past experiences of dismissive attitudes – ‘it’s all in your head’, anxiety and paranoia around waiting for test results, difficulty getting GP appointments, unable to see the same GP as most participants felt it important to see the same doctor each time, who understands their circumstances and history. *“It's so hard to discuss mental health with a stranger. Going into everything again with someone who doesn't know you can be very traumatic. You’d just rather not do it.”*  Inability to bring along a person of choice e.g. a partner and rushed GP appointments with no time to discuss symptoms.  The interactions with and perceptions of health professionals (HPs) were varied with participants describing difficulty expressing symptoms, especially with HPs they don't know or trust – and recognising the importance of building relationships and continuity of care. Poor integration and communication between services e.g. psychiatrists, GPs, MH professionals, pharmacists and not feeling listened to – physical symptoms attributed to or overshadowed by mental health symptoms. Those who had positive experiences with HPs described them as being empathetic, patient and supportive.  Participants discussed their experience of what additional support was offered. Offers of support e.g. nutritional advice and lifestyle support were often reactive and not proactive. Only one participant was aware of the reasonable adjustments available when attending appointments – this participant had requested these adjustments in the past and had been denied. There was a view that more confidence was needed to request these adjustments in the presence of a support worker.  Focus groups with health professionals:  This work is still ongoing and will continue beyond the programme. Factors that influence this include challenges in recruiting focus groups with health professional from primary and secondary care due to various factors such as access, availability and current capacity challenges and industrial action. However, we are currently engaging with the primary care in the Teesside area due to support from our mentor Bal Athwal signing posting us to potential interested GPs. We are also recruiting secondary care colleagues via the local mental health trust based across NY and Teesside.  Discussion  Based on our current understanding and observations supporting patients with SMI is complex and continues to be a challenge across the health system involving primary and secondary care and VCSE. Our journey started with a documentary which gave us a unique lens into the SMI pts and prompted many areas for development and focus including safety netting, system improvements and better communication. However, throughout our discovery phase and engaging with system thought leaders, VCSE and clinicians involved in SMI it became apparent that the system had lots of variation regarding provider delivery. Some basic assumptions such as who ‘owned’ the SMI pts and was best placed to deliver support was unclear amongst professionals from differing providers when exposed to regional meetings.  The findings from our pt focused groups echoed the literature which involved recommendations such as a proactive approach to provision of information for people with SMI with additional adjustments and lifestyle support made available. The recognition to further improve GP/ HP training and awareness of mental health conditions to combat clinical anxiety managing SMI pts and combat perceptions around dismissive attitudes and diagnostic overshadowing which could put patients at risk of delayed diagnosis of other significant disease. Recognition of the importance of cultivating a relationship and building trust with people with SMI to allow for open and honest communication regarding their physical and mental health and finally improving the integration and communication between different healthcare services e.g. mental health services, primary care and pharmacy to avoid confusion, delays with diagnosis and medication. |
| **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 | Pip, Pop and a Pandemic is a documentary about the lived experience of schizophrenia. The film follows two couples from the Northeast before, during, and after the pandemic. The result is a raw and emotional insight into the many serious problems that exist in our mental health care system.  Whilst attitudes to mental health have significantly improved in the last ten years, this documentary proves that the problem of stigma and discrimination against people with severe mental illnesses like schizophrenia still exists. The call to action advocates a required change in the current system to one that truly supports the vulnerable living on the fringe of society. This is especially important with the announcement of plans to get more people off disability benefits and back into work. In terms of mental illness, a forceful approach could put vulnerable people at risk.  The findings from the documentary have helped shape early thinking and supported further scoping and discovery conversations amongst the SMI professional community over the last 6-12 months. This has led to the development of research to examine and the potential of interventions to further explore and consider. These include:   1. Examine the current literature within SMI and the annual physical health checks. 2. Explore with SMI patients their understanding and experience of the physical annual health check. 3. Explore with medical and clinical staff in primary care their experience in supporting and the delivery of annual physical health checks involving SMI patients. 4. Develop and test potential interventions within primary care looking at robust safety netting mechanisms for SMI patients to attend their annual physical health checks. 5. Explore the potential of bookable appointments in appropriate locations with staff trained in helping to fill out the necessary forms such as PIP and carers allowance. 6. Explore the potential of providing a trained and accessible Welfare support role to work with people with long-term mental illness to support them with regular PIP and benefit appointments. |
| Key assumptions and interdependencies | The film gives an insight into the health inequalities that exist in our mental health care system. Two of the case studies have since died supporting the literature and research that says people with serious mental health conditions have a life expectancy 15 to 20 years shorter than the general population. |
| What is the overall purpose of this project? Aims? | Building on the documentary insight the overall aim is to address the health inequalities of patients with SMI and improve life expectancy through regular uptake of the physical annual health checks, improve access to primary care including robust safety netting and support patients with PIP and benefit assessments. This involves:   * Focus groups involving SMI patients (North Tyneside and Durham) * Focus groups involving primary care staff, including GPs, practice nurses and HCA’s (York and Teesside) * Rapid literature review * Analysis of annual physical health check and quality of health checks using Pts PMH and ‘RightCare physical health and severe mental illness scenario’ ( October 2023). * Explore and test potential safety netting mechanisms in primary and secondary care to encourage patients with serious mental health conditions to attend their annual check-up and make it easier for SMI patients to attend appointments. * Examine and understand current primary care practice involving annual physical health checks and the quality of annual health checks and explore the potential improvements. * Potential of primary care education sessions to reduce clinical bias of ‘overshadowing diagnostics’ of wider health issues such as cancer due to SMI related symptoms. |
| Why it needs to be done? / Why it should be done now? | As highlighted previously there remains a significant health inequality regarding life expectancy for people diagnosed with severe mental illness who tend to die on average 15-20 years younger than the UK population. The factors that influence this are multifaceted and complex ranging from patient and lifestyle factors, access to services and treatment and delayed diagnosis. Recent findings from the literature review highlighted adults with SMI are 2.1 x more likely to die from cancer and this is the leading cause of premature mortality in people with SMI (above CVD, respiratory and liver diseases).  This work also builds on the governments RightCare physical health and severe mental illness scenario (October 2023), which states  “For people with SMI, 2 in 3 deaths are from physical illnesses that are preventable. This highlights the urgency of early intervention and supporting people to engage with regular physical health checks in order to identify and treat risk factors, and prevent longer term complications.  Cancer, cardiovascular disease, liver disease and respiratory disease accounted for around 60% of all deaths of adults with SMI before the COVID-19 pandemic ([Office for Health Improvement and Disparities](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Ffingertips.phe.org.uk%2Fprofile-group%2Fmental-health%2Fprofile%2Fsevere-mental-illness&data=05%7C02%7Cs.robinson2%40yorksj.ac.uk%7C24215cde40ad44f3ed3b08dd5fccaa48%7C5c8ae38ef85b4309b7ec862815a37aee%7C0%7C0%7C638772055094332824%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=z91EAAQzFk2GOdHsDW4Q6N%2BBbBHitGlCtMRHTV%2FUXj0%3D&reserved=0)).  Cardiovascular disease (CVD) is the single largest cause of a widening mortality gap, and far more common than suicide, yet disorders like CVD and diabetes are predictable and potentially preventable ([World Psychiatry](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fonlinelibrary.wiley.com%2Fdoi%2Ffull%2F10.1002%2Fwps.20420&data=05%7C02%7Cs.robinson2%40yorksj.ac.uk%7C24215cde40ad44f3ed3b08dd5fccaa48%7C5c8ae38ef85b4309b7ec862815a37aee%7C0%7C0%7C638772055094361785%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=vi02q%2FKV%2FzxTuhW%2BOIN9poxNgnuv0fX3ld3EpcldTyg%3D&reserved=0)).  There are more than 500,000 people in England living with an SMI but at local level numbers are small – a typical practice will have 60-100 patients with SMI on their register ([NHS England](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.england.nhs.uk%2Fstatistics%2Fstatistical-work-areas%2Fserious-mental-illness-smi%2F&data=05%7C02%7Cs.robinson2%40yorksj.ac.uk%7C24215cde40ad44f3ed3b08dd5fccaa48%7C5c8ae38ef85b4309b7ec862815a37aee%7C0%7C0%7C638772055094378676%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=m382TKi%2BoBIgU1ZXLVt180NPcSGCaWkyKK6FCgBSZWs%3D&reserved=0))”. |
| Opportunities and Challenges? | Based on the findings from the documentary there are several opportunities to explore further and gain a deeper understanding of SMI patients and primary care staff using a qualitative approach to help inform improvements. There are also opportunities to test potential interventions within primary care improving safety netting and increase the uptake of annual health checks. Findings from the recent lit review highlighted people with SMI are less likely to be screened for cancer and more likely to die from cancer despite the incidence being similar (Perini et al., 2013) which suggests there is an opportunity to consider how cancer screening and a physical annual health check could be combined or co-delivered simultaneously.  We have presented and discussed our project to various stakeholders across the health system including a poster at the TEWV research conference and presented via the ICB SMI steering group led by Dr Stella Morris and meeting senior leaders at ‘Place’ and ICB colleagues delivering localised interventions involving the annual health check in Bridlington and the East coast and Bradford in West Yorkshire.  Tracy has recently met with Rachel Maskel MP for York to further highlight the inequalities and share the HE fellowships project building on the original documentary.  Tracy has also shown the documentary at the Royal College of Psychiatry Conference in Belfast: Future Directions for Adult Psychiatry followed by a Q&A discussion (Oct 24).  The challenges are the potential size and breadth of the piece of work as our scoping and discovery conversations across the health system have unearthed variation and differing views around ownership and the delivery of health checks. Potential access and pilot testing within primary care will stretch beyond the initial timescales within the HE fellowships programme. |
| Desired results of the project? | 1. A deeper understanding of SMI patients experiences of the annual health check. 2. A deeper understanding of primary care staff and their experiences in delivering physical annual health checks within SMI pts. 3. Recommendations of potential improvements and interventions in the delivery of the annual physical health checks and national cancer screening programmes. 4. Insight that can support the testing of interventions that reduces premature mortality within the SMI community. |
| Brief description of methodology used? | Currently the project has undergone a rapid lit review and has delivered two focus groups to SMI pts from Tyneside and Durham. The intervention is to recruit a primary care professional focus group and deliver a further pts focus group. We are currently liaising with a Lead GP Dr Dan Cottingham to arrange a focus group in York with Primary Care staff. This approach involves qualitative methodology.  Unfortunately, due to capacity issues and longterm sickness Dr Dan Cottingham was unable to support this work which has led us to collaborate and engage with another GP Dr Jonthan Slade from Teesside. This connection was created via our mentor Bal Athwal. |
| **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 |  |
| Activities undertaken |  |
| Impact |  |
| Outputs |  |
| **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 | Please see methodology, results and discussion section |
| Explain your key findings, results, |  |
| Describe achievements, changes and difference made, impact | Key achievements include developing new relationships with key stakeholders from across the health care system who were supportive of our project ideas and direction. Having several abstracts accepted for local and international conferences and research forums to present our ideas and research findings. Supporting the development of a narrative which explores and examines SMI pts and inequalities within the system. Generating insights and findings from the documentary and the pt focus groups to support a robust framework for future academic research involving health professionals within primary and secondary care and a framework for testing and implementing interventions in primary / secondary care. |
| Provide any recommendations | It is difficult to conclude final recommendations without us gaining the differing health professional perspectives. Initial recommendations based on the outcomes and interpretation of the documentary, literature and the patient focus groups would consider:  Recommendations overview:   * Proactive approach to provision of information for people with SMI and annual physical health check (AHCs), being proactive with offering additional adjustments and lifestyle support. * Ensure provision of reasonable adjustments for people with SMI and ensure all practice staff and HPs are aware of current guidance. * Improve GP/ HP training and awareness of mental health conditions to combat dismissive attitudes experienced by people with SMI. * Recognise the importance of cultivating a relationship and building trust with people with SMI to allow for open and honest communication regarding their physical and mental health. * Improve integration and communication between different healthcare services e.g. mental health services, primary care and pharmacy to avoid confusion and delays in diagnosis and medication.   SMI participants highlighted they would find it beneficial to:   * Be able to bring along a person of choice to appointment. * Request longer appointments (20-30 mins) at later in the day * Request a quiet waiting area. * Request more home visits. |
| **Conclusion – FINAL REPORT** | |
| This section brings the entire project report together, summarising your argument and why it is significant | |
| Restate original ambition | This project builds on the work of Tracy Willits, a senior lecturer in media production at York St John University, who produced a documentary titled ‘Pip, Pop and a Pandemic,’ exploring the inequalities and the gap in life expectancy for people with severe mental illness (SMI) through the lived experience of people with schizophrenia. The film follows two couples from the Northeast before, during, and after the pandemic. The result is a raw and emotional insight into the many serious problems that exist in our mental health care system. Two of the participants have since died, backing up research that says people with SMI conditions have a life expectancy 15 to 20 years shorter than the general population. The film was shown in Parliament in 2023 with a call to action and panel discussion. A link to the documentary is provided. [Pip pop and a pandemic (youtube.com)](https://www.youtube.com/watch?v=JlEo6IEiZRU)  Building on the initial documentary findings, Tracy started to collaborate with Dr Spencer Robinson (Deputy Director at the Institute for Health and Care Improvement @ York St John University) on a project aligned to the Humber and North Yorkshire ICB Health Equity Fellowship Programme to further explore health inequalities experienced by people with SMI.  Evidence suggests there remains a significant health inequality regarding life expectancy for people diagnosed with severe mental illness. SMI patients die on average 15-20 years younger than the UK population. The factors that influence this are multifaceted and complex ranging from patient and lifestyle factors, access to services and treatment and delayed diagnosis.  Findings from the original documentary unearthed several areas for further exploration ranging from the potential of pragmatic interventions to gaining a deeper understanding of health system factors, patients experiences and health professional perspectives and views.  Areas of early focus drawn from the documentary and at the start of our fellowship journey and prior to our discovery process are outlined below for context.   * Introducing specialist bookable appointments with staff trained in helping to fill out forms such as PIP and carers allowance. * Explore and test potential safety netting mechanisms and nudge GPs and mental health professionals to encourage patients with severe mental health conditions to attend their annual check-up and make it easier for these patients to book afternoon appointments. * Examine and understand current primary care practice and explore the development of change interventions which could involve, educational and training sessions. * Considerations of a GP education and awareness to support wider health issues such as cancer, CVD, etc which maybe masked due side effects of the medication or presume symptoms are caused by anxiety due to mental illness. |
| Summarise the key themes | As described in the results and discussion and initial recommendation section |
| Summarise your thoughts | The project will continue to move forward as we draw on colleagues’ expertise both within academia and across the health system. Our area of focus within an SMI health inequalities context continues to energise Tracy and I and our wider colleagues who have been drawn in to contribute to the project. The SMI inequalities agenda is complex and fraught with challenges and variation from varying experience, opinion and delivery which we did not expect. However, this complexity creates opportunities for future collaborations and research. For example, Tracy is collaborating with colleagues from the Royal College of Psychiatry to develop an article for ‘the conversation’ and build on previous collaborations with the Big Issue. In addition, it is hoped a further meeting with Rachel Maskell MP and sharing our current research findings would lead to a parliament debate around the inequalities and early mortality rates of people with SMI.  Reflecting on our own experiences within the programme we would both recommend the HEFP to wider colleagues both in academic, NHS, and the wider health sector. Whilst both Tracy and I have greatly underestimated the capacity required to move this project on at preferred pace and have limited access to the organised meeting and wider discussion forums the process has allowed us to be exposed to a much wider network of professionals and differing narratives that we were not previously sighted. This exposure has been a positive experience as it has helped shape our thinking throughout the discovery phase via our conversations and the wider literature. The support from our mentor Bal Athwal has been excellent and she has kindly helped signpost us and give us access to her differing forums/networks and relevant people within the SMI agenda. |
| Describe any future actions or work needed | The project will continue beyond the fellowship programme as we start engaging and work with primary and secondary care with an aim to conduct several focus groups to understand their views and perspectives. It is hoped that some small, piloted interventions in primary care involving appointment adjustments, safety netting and communication strategies would be tested and measured in the future. |