Personality Disorder Improvement Programme

End of Phase One Report

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Contents

Executive Summary

The Scottish Government commissioned Healthcare Improvement Scotland to deliver phase one of the Personality Disorder Improvement Programme (PDIP). The aim of this work was to better understand the current state of provision and access to services for those with a diagnosis of personality disorder. This report was enabled by colleagues from the third sector, those with lived experience, mental health staff and all 14 NHS boards and Health and Social Care Partnerships (HSCPs) in Scotland.

Phase one of the PDIP work included:

- Virtual visits with all 14 boards and HSCPs to understand the landscape of provision across Scotland.
- Design and delivery of a learning system to bring knowledge and facilitate learning.
- Engagement with those with lived experience to understand firsthand accounts of issues faced with accessing services etc.
- Engagement with staff to understand challenges concerning delivery of high quality care to those with a diagnosis of personality disorder.

The main findings from each of these areas of work are:

Virtual visits with all 14 boards and HSCPs to understand the landscape of provision across Scotland.	• Leadership and management challenges • Staffing challenges • Service provision limitations
Design and delivery of a learning system to bring knowledge and facilitate learning.	**Developing a learning system** provided our network with the opportunity to share learning and access expertise from others: • Highlighted snapshots of current good practice in two case studies. • Hosted 10 engaging webinars and workshops to over 1,400 attendees. • Monthly newsletters shared latest updates and upcoming events, read by over 300 people each month.
Engagement with those with lived experience to understand first-hand accounts of issues faced with accessing services etc.	**Lived experience engagement** through our third sector colleagues SRN and VOX was a crucial component of our work: • 139 people with lived and living experience took part in a comprehensive programme of engagement.

	• This work involved interviews, surveys and conversation cafes. • All work was guided by a Lived Experience Project Group.
Engagement with staff to understand challenges concerning delivery of high quality care to those with a diagnosis of personality disorder.	**Understanding barriers to high quality care** was a key feature of PDIP's engagement with staff in Scotland: • 303 staff took part in a nationwide survey. Most staff worked in adult mental health and had worked in services for more than 10 years. • 19 staff across four localities, took part in our one to one interviews.

Recommendations for phase two:

Recommendations for Healthcare Improvement Scotland	**Recommendations for local areas**
• Develop a data measurement framework. • Deliver an expanded learning system. • Produce a toolkit including case studies. • Work with three pathway boards. • Commission NES to produce educational resources. • Produce standards for delivery of care for people with a diagnosis of a personality disorder.	• Engage with the learning system. • Educational resources. • Support the development of the standards. • Support the development of the data measurement framework. • Consider volunteering to be one of the three pathway boards. • Engage with people with lived experience (PWLE) to support evaluation and development of services.
Recommendations for Scottish Government	**Recommendations for partners working with PWLE**
• Commission HIS for PDIP phase 2 (as outlined in the driver diagram). • Commission third sector organisation(s) to deliver a parallel lived experience component of the work.	• Engage with a wide range of PWLE across Scotland • Engage with existing support organisations (for example SPDN and advocacy carers groups). • Develop peer support networks. • Engage with boards to support evaluation and development of services.

Glossary

CCM	Clinical case management
CCT	Client Centered Therapy
DBT	Dialectical behavior therapy
EQIA	Equality Impact Assessment
HSCP	Health and social care partnership
ICP	Integrated Care Pathway
ICD-11	International Classification of Diseases 11th revision
MACT	Manual Assisted Cognitive Treatment
MBT	Mentalization based therapy
NICE	National Institute of Clinical Excellence
PDIP	Personality Disorder Improvement Programme
QALY	Quality Adjusted Life Year
ST	Schema therapy
STEPPS	Systems Training Emotional Predictability and Problem Solving
TFT	Transference focused therapy

Introduction

The Scottish Government commissioned Healthcare Improvement Scotland to deliver phase one of PDIP. The aim of this work was to understand the current state of service provision for those with a diagnosis of personality disorder. Colleagues from the third sector, those with lived experience, mental health staff and all 14 NHS boards and associated HSCPs contributed to this programme.

Work by the Royal College of Psychiatrists[1] (2018) and the Mental Welfare Commission[2] (2018) highlighted that there is significant variation in provision of care across Scotland for those with a diagnosis of personality disorder. The evidence suggests that there is inconsistency in the quality of services provided for a group who experience significant distress and risk, with high levels of service use. Findings from the work undertaken by PDIP indicate that there are several areas of development that will improve care. These will be explored in this report.

A note on language

The term personality disorder has been a source of discussion and debate nationally and internationally. There are a wide range of views about the advantages and disadvantages of using this term. Some PWLE and some professionals prefer to use other terminology to describe this range of symptoms. Within the PDIP programme of work, we recognise that this debate can be contentious and polarising. The aim is to respect these differences, whilst carrying out the work of reporting our findings on current services in Scotland and areas for improvement.

We aimed to write this report using language that is non-stigmatising. However we are aware that language tends to evolve rapidly and reflect societal attitude changes towards mental health. If people read this report in the far future, we hope they consider this and take into account our good intentions in using the most widely used and recognised terms available to us at the time.

Contextual Factors in Diagnosis and Development of Personality Disorders

What is meant by personality disorder?

Personality disorder is defined as a deeply ingrained and enduring pattern of behaviour and inner experience that affects thinking, feeling, interpersonal relationships, and impulse control and is associated with significant functional impairment and distress[3].

What are the causes?

Consensus around the factors which might lead to a diagnosis of personality disorder suggests a combination of biological, psychological and social influences:

- **Genetics and Temperament**
  People may inherit genetically determined vulnerabilities, including traits such as emotional sensitivity or impulsivity.
- **Early development**
  There is evidence that early life experiences, attachment relationships and experiences of trauma can impact trajectory[4]. Being subjected to abusive, insecure, unstable and invalidating environments (for example Adverse Childhood Experiences) have a significant role[5].
- **Adult experiences**
  Relationships and social factors in adulthood can contribute to these problems, for example domestic violence or severe poverty. Patterns of behaviour which may have been helpful to cope with adverse experiences, can become unhelpful in the present, and contribute to behaviours which lead to a diagnosis of personality disorder.

Diagnostic criteria

The International Classification of Diseases 11th revision re-categorised personality disorders in 2022, with the removal of discrete personality disorder subtypes. This has been replaced by a single broad category of personality disorder subdivided by levels of severity (mild, moderate, severe) [3]. Severity is determined by the degree of disturbance in the person's relationships and sense of self, the intensity of the emotional, cognitive and behavioural difficulties and the extent to which these cause distress or psychosocial impairment. The category of borderline personality has been retained, due to clinical utility (this is the personality disorder subtype with the greatest body of evidence for treatment).

Prevalence

Personality disorder is a common condition, with a prevalence of 6-10% of the general population, increasing to up to 50% of the population in contact with specialist mental health services[1]. There is also evidence that personality disorder is among the most underdiagnosed psychiatric conditions[6].

Impact on the person

There is a high rate of self-harm and suicide associated with diagnosis, with up to 80% of those with borderline personality disorder diagnosis engaging non-suicidal self-injury[7]. Lifetime suicide risk is also estimated at between 5-10%[8]. Personality disorder is associated with a higher rate of diagnosis of co-occurring mental disorders, and high rates of mortality from cardiovascular and respiratory disease. Life expectancy for those with a diagnosis can be up to 20 years shorter than for the general population[9]. There is also significant impairment in personal, family, social, educational and occupational functioning.

Management and recovery

There is evidence that interventions with specialised therapies can offer considerable improvements to those with a diagnosis. Improvements include individuals being able to self-manage the distress that can be evident with diagnosis and potentially transition away from mental health and inpatient services[10].

Core components of PDIP

What the PDIP did in phase one:

Established an Expert Reference Group (ERG), which represented a broad demographic of stakeholders from mental health services, the third sector and those with lived experience

Conducted a strategic gap analysis with all 14 boards and HSCPs to understand nationwide landscape of treatment, services and pathways

Developed and delivered a learning system to improve and share knowledge among professionals, third sector organisations, and those with lived experience

Collaborated with third sector colleagues SRN and VOX who conducted lived experience learning for the programme

Undertook detailed staff engagement work to evaluate the major barriers and facilitators to providing high quality care

Reviewed the recent relevant literature and guidelines concerning treatments for personality disorder

Throughout the duration of PDIP phase one, the Scottish Personality Disorder Network (SPDN) were at the heart of the work through our ERG. SPDN provided a chair, three rotating co-chairs with lived experience and other SPDN executive members who attended the ERG. The SPDN promoted our learning system events to their membership and wider networks.

The following sections of the report will highlight this work as well as consequent recommendations based on the programme's findings in how high quality care can be enabled for those with a diagnosis of personality disorder. This work was undertaken during COVID-19 and associated restrictions, as such considerations of and comments relating to COVID-19 are included throughout the following sections.

Evidence Reviews

To assist in informing the PDIP body of work, three rapid reviews of the literature and evidence were conducted. Due to the nature of the reviews and the scope of the evidence base, limitations on year of publication for included articles was restricted from 2017 to 2022.

The first rapid evidence review was conducted to understand the effectiveness of psychological therapies and medical treatment options for those with a diagnosis of personality disorder. The review also examined service user perceptions of psychological therapies and staff as well as improvements in function that may be attributable to psychological therapies. Staff perspectives of training and service users was also examined. Specific review questions focused on the following:

- What evidence is there as to the effectiveness of psychological therapies for the treatment of personality disorder?
- What is the evidence concerning perspectives of those with a diagnosis of personality disorder regarding the effectiveness and suitability of psychological therapies?
- What does the evidence suggest in terms of experiences of staff for those with a diagnosis?
- What does the evidence reflect in terms of staff perspectives of those with a diagnosis?
- What does the evidence suggest in terms of staff experiences and needs concerning training?
- What does the evidence suggest as to the effectiveness of medical interventions?
- What does the evidence suggest in terms of improvements in function caused by psychological therapy?

An additional rapid review of the recent literature concerning presentations in crisis for those with a diagnosis of personality disorder was also conducted. In order to assess this within the academic literature, specific crisis points were preselected to be included within the search criteria for the review. These were accident and emergency, police detention and homeless populations. The report has several sections based around what the literature suggests on the following questions:

- What is suggested on the prevalence of presentations to accidents and emergency (A&E) for those with a diagnosis of personality disorder?
- What are the re-presentations rates at A&E for those with a diagnosis of personality disorder?
- What is suggested on the prevalence of presentations in police detention for those with a diagnosis of personality disorder?

- What is suggested on the prevalence of homelessness among those with a diagnosis of personality disorder?

Presentations in crisis

Those with a diagnosis are more likely than those with other mental health difficulties to have multiple presentations in crisis to A&E, to be taken there by police or ambulance and present with suicidal ideation, mental health comorbidity, self-harm and/or drug intoxication. A&E staff report feeling unsupported in providing care. Those with a diagnosis are also more likely to be represented in police detention and homeless populations[11-23].

Effectiveness of psychological therapy

Mentalization Based Therapy (MBT), Dialectical Based Therapy (DBT), Schema Therapy and Transference Focused Therapy are the most common specialised interventions. The available literature would support effectiveness in improved symptoms, and reductions in behaviours such as suicidal and non-suicidal self-injury. These interventions also tend to have lower levels of drop out than other therapies. Prolonged duration and combination of group/individual sessions have best outcomes, but effectiveness appears to reduce with age[24-30].

Improvements in psychosocial function

There is some limited evidence that specialised psychological therapies have demonstrated improvements in psychosocial functioning. Therapies that offer skills based interventions, as well as individual autonomy and control appear to have the greatest effectiveness. This is in addition to the improvements seen in core symptoms. This evidence would also support that these improvements were seen particularly in those with a diagnosis of borderline personality disorder[12,31,32].

Lived experience perspectives on treatment

Diagnosis should be collaborative to avoid any risk of re-traumatization, with information provided on treatment options. Specialised therapies are appreciated by those with a diagnosis and are seen to be effective. The establishment of a good therapeutic alliance was also found to be effective in satisfaction with interventions and positive outcomes. Therapies of extended duration that involve individual and group sessions are preferred. However, group sessions were recommended to need careful consideration in how these are managed in a safe and supportive way[33-39].

Lived experience perspectives on staff

PWLE felt that clinicians and practitioners lack knowledge, education and training specific to personality disorder. There is also the perception among those with a diagnosis that training and education are effective tools to facilitate stigma reduction and improve staff attitudes. Trust, empathy and overall relationship building (for example the therapeutic alliance) was felt to facilitate good relationships with staff[40-42].

Staff perspectives on those with a diagnosis of personality disorder

Negative attitudes towards those with a diagnosis persist among staff, particularly nurses. Feelings of futility, powerlessness and being overwhelmed are common. These feelings are related to several factors, such as working within mental health services, staff skill level and staff perceptions on their ability to work with those with a diagnosis. Staff highlighted that there is need for more training specific to this diagnosis. Some evidence would suggest that staff who work with higher numbers of those with a diagnosis as well as receiving higher levels of training have more positive attitudes towards those with a diagnosis[41-49].

Staff perspectives on training

Evidence supports that staff would like to see greater time available for training as well as greater access to training opportunities. There is support in the evidence for training to be an effective route to reduce stigma, across a range of professional groups. Reductions seen in stigma through training have been evidenced to be most effective in the medium term, with further work needed to assess long term effects. Training is particularly effective when co-produced with lived experience and when there is access to top-up training. Staff highlight a desire for more training that is skills and psychoeducation based and specific to professional area. Training has been demonstrated to increase staff confidence, skills and knowledge[50-60].

Effectiveness of medication

Despite a lack of evidence, there are still high rates of prescribing and polypharmacy. Studies of a number of classes of medication have had small sample sizes and used varying outcome measures. Overall there is inconclusive evidence to support use of antidepressants, antipsychotics or mood stabilisers as a primary treatment. There is limited evidence on the effectiveness of antidepressant, antipsychotic and mood-stabilising medications, either on core symptom reduction or in terms of cost effectiveness. Side effects are commonly reported and evidence would suggest that specialised therapy has superior outcomes. Substantially more research needed to justify prescribing rates[61-65].

Cost effectiveness of specific specialist interventions

The evidence base for the cost-effectiveness of specific, specialised interventions is not robust. However, several NHS based studies indicate that DBT and MBT are more cost-effective than other therapies and treatment as usual. This evidence would support that savings arising from DBT being more likely to occur in the first year of treatment. Definitive conclusions are difficult to reach due to different approaches used in assessing cost-effectiveness. Furthermore, European based studies have evidenced disparate outcomes in cost-effectiveness.

Cost-effectiveness studies

There is evidence from one NHS study that DBT is more cost-effective than client centred therapy (CCT). Across four NHS based studies, the evidence that DBT is more cost-effective than treatment as usual is considerably more uncertain. However, wider international evidence is slightly more promising although it remains difficult, given differences in methods used to summarise the economic benefits of DBT in these studies. It is also difficult to conclude definitively that DBT is an efficient strategy compared to treatment as usual. Some further NHS-based evidence would imply that if savings (significant or otherwise) arise from DBT treatment these are likely to occur within the first year of treatment.

There is evidence from one NHS-based study that MBT is more cost-effective than treatment as usual, but international evidence from the Netherlands refutes this and so it remains unclear. Manual Assisted Cognitive Treatment (MACT) compared with treatment as usual was found to be unlikely to be cost-effective in one study (again with the results subject to considerable uncertainty).

One family-based intervention for parents with a diagnosis of personality disorder who have children with a mental health problem suffered from recruitment problems and it was not possible to draw conclusions from the results.

- **NHS-based cost-effectiveness analyses**
  A review of the cost-effectiveness evidence for treatments for personality disorders identified three NHS-based economic evaluations[66-68]. Two of these[66,68] were interventions specifically for those with a diagnosis of borderline personality disorder (BPD). The study population of interest in the paper by Priebe et al was participants with a diagnosis of personality disorder and at least five days of self-harm within the previous year[67]. This study had explored the effectiveness of DBT[67], which was also assessed within the economic evaluation by Brazier et al[66] whereas the study by Day et al[68] had assessed the cost-effectiveness of the Helping Families intervention for parents with BPD and their children.

The Brazier study reviewed the available economic evidence at the time of its publication in 2006, but found this was not sufficient to populate an economic model. Therefore, the authors used the existing publications but also requested further clinical trial data from the studies included in their clinical effectiveness review, and used these data to conduct separate cost-effectiveness analyses for each trial. On this basis the authors were then able to summarise economic results by treatment (DBT, MBT and MACT) compared with treatment as usual (or in the case of one study by Turner et al; DBT versus CCT) for two specific outcomes; the cost per parasuicide event avoided and the cost per Quality Adjusted Life Year (QALY) gained.

- **NHS-based cost only studies**
  Three additional studies reported NHS based costs associated with interventions for treating individuals with a diagnosis of personality disorder. One of these studies[70] examined management of adults with mental health problems (i.e. not specific to diagnosis of personality disorder) in the community. As such, it is not possible to separate the costs of those with a diagnosis of personality disorder from those who had other mental health conditions (mild-moderate depression, eating disorder, certain schizophrenia those with a diagnosis) and further conclusions can be drawn.

Strategic Gap Analysis

An integral part of the work within PDIP was to understand current service provision for those with a diagnosis of personality disorder. To facilitate this, a Strategic Gap Analysis was conducted. This analysis compares the status quo with best practice, identifies the gaps in current service provision, and outlines the suggested next steps for phase two of this piece of work.

This chapter is structured as follows:

1. A summary of existing service delivery across the NHS boards in Scotland
2. A gap analysis to identify the areas for future development
3. Proposed next steps using the Good Practice Framework for Strategic Planning to identify the key features of Phase 2 from a strategic planning perspective.

The Strategic Gap Analysis draws on the evidence and our understanding of what good services look like which is outlined in the 'What We Understand About Good Services' section of the report (page 45) to act as the comparator against existing practice.

The analysis and recommendations within this Strategic Gap Analysis are based on the evidence collected from across the programme including the following evidence sources:

- A literature review of best practice and guidelines concerning treatments for personality disorder undertaken by Healthcare Improvement Scotland
- In-depth interviews with NHS boards to map their existing personality disorder service provision conducted by Healthcare Improvement Scotland's Strategic Planning Team
- Findings of engagement with those with lived experience of a personality disorder – including individuals with a diagnosis conducted by Scottish Recovery Network (SRN) and Voices of Experience (VOX) – commissioned by Healthcare Improvement Scotland
- Survey and one-to-one interviews with staff working in services that support those with personality disorders conducted by Healthcare Improvement Scotland.

Summary of existing provision in Scotland

This section summarises existing provision across Scotland drawing on evidence and information provided by all 14 NHS boards and HSCPs.

Leadership and strategic direction

- Personality disorder is generally not explicitly addressed in mental health strategies and instead is seen as embedded within general mental health services alongside other diagnoses. A small number of board areas include it within their strategies – for example NHS Lanarkshire. While others such as NHS Greater Glasgow and Clyde and NHS Grampian have steering groups for BPD which seek to provide strategic leadership and planning for BPD conditions. Some boards have steering groups directly related to providing clinical leadership for example NHS Ayrshire & Arran have a Care Pathways Steering Group that contributes towards clinical leadership for personality disorder developments.
- A number of planned improvements and strategic developments have been delayed by COVID-19 and have yet to resume – for example in NHS Lanarkshire.
- Some boards, for example, NHS Greater Glasgow and Clyde, NHS Tayside, NHS Western Isles, NHS Lothian (specifically West Lothian) NHS Forth Valley and NHS Grampian have chosen to focus particular efforts on BPD or Emotionally Unstable Personality Disorder (EUPD) rather than personality disorders more generally. Boards stated that they felt that this focus was appropriate due to high rates of BPD or EUPD presentations to acute and unplanned care by those with a diagnosis, or with characteristics that would indicate a diagnosis.
- However the ICP for personality disorders in NHS Highland is explicitly a service for patients meeting the criteria for a diagnosis of any personality disorder rather than BPD/EUPD only. The only strand of the service explicitly for patients with the borderline pattern is DBT.
- A number of boards mentioned that they felt that lack of senior buy-in and leadership was limiting the ability of the services to develop and improve pathways for personality disorder.

Diagnosis

There are a wide variety of views on personality disorder within and between mental health teams in Scotland. Boards report that this can lead to inconsistent use of diagnostic tools and processes, misdiagnosis, and disagreements over diagnoses made. There is significant overlap with complex post-traumatic stress disorder (C-PTSD) and it is recognised that those who might attract a diagnosis of personality disorder also may have a range of comorbidities and other presentations (for example depression, anxiety, neurodiversity, eating disorders, and substance misuse). Approaches reported included multi-disciplinary and collaborative diagnostic processes but we noted that many still rely on individual clinical assessment which can vary between clinicians and services.

Ring fenced resources/specialist teams

All but two boards (NHS Greater Glasgow and Clyde and NHS Highland) do not ring fence resources for personality disorder. All support provided to people are as part of the core mental health services such as the Community Mental Health Team, general inpatient wards and crisis and out of hours services.

- NHS Highland has a specialist service for personality disorder. This service offers a stepped care approach where the specialist team provide support for the most acute and complex needs with the earlier steps of the model embedded within the Community Mental Health Team. There are some exceptions to support by the specialist team, for example where cognitive impairment makes support by them unsuitable. This team also provides consultation, awareness raising and training for professionals across other services who are supporting or engaging with people with a diagnosis of personality disorder. NHS Greater Glasgow and Clyde have pockets of funding ring-fenced for both MBT and DBT as well as having a specialist service for homelessness and personality disorders due to the complex relationship between the two.

NHS Dumfries & Galloway have a virtual team for people with a diagnosis of EUPD who provide advice, training and education for other healthcare professionals. NHS Tayside is currently considering developing a specialist clinical team for personality disorders and at the time we spoke to them, were waiting on approval to recruit the required staff to resource this.

There are four key drivers for boards’ decisions not to have a specialist service including:

- High prevalence of presentations means that it is core business for mental health teams already
- Large variation in presenting issues and need of people with a personality disorder means that it is important that skills are sitting throughout a wide range of services
- Impracticality of having a specialist and ring fenced team in an area with a small population for the smaller boards
- Availability and security of funding and resources for key staff and service developments.

Integrated Care Pathways

All boards in Scotland support people who may have a diagnosis of personality disorder through a wide range of health and social care services. Only NHS Greater Glasgow and Clyde and NHS Highland (not including Argyll and Bute) have specialist services to provide care for the most complex cases in their board area. The primary mechanism boards are using for providing for a specific diagnosis, such as personality disorder, across these services is through the development of ICP for particular diagnoses or needs. The development and use of Integrated Care Pathways is not well advanced across the boards, with most reporting that they do not have them, are still developing them, or that the ones that have been developed aren't fully operational yet.

- Some boards do not currently have an ICP or are in the stages of developing one for example NHS Tayside, NHS Ayrshire and Arran, NHS Lothian (excluding West Lothian and Midlothian who are developing and integrated care pathways (ICP)) and NHS Forth Valley. Those boards operate largely on a case by case basis for assessing need and onward service referral and may have strong informal links between some services who regularly work together. Some boards, such as NHS Fife, made the decision to not separate their trauma and BPD pathways due to the considerable overlap between diagnosis of personality disorder and complex PTSD.
- NHS Highland has a well-established ICP since 2015 which covers all personality disorder diagnoses, inpatient and out-patient treatment, psychological and other treatments. Some other boards such as NHS Lanarkshire, NHS Western Isles (pathway relates to BPD only), NHS Grampian, and NHS Borders report that they do have an ICP in place, with Lothian reporting that there is development underway for a pathway for personality disorder and complex PTSD. However boards tended to feel that the pathway isn't well implemented including feelings of their pathway being out of date, that links in the pathway have yet to be formalised or put in place, that the pathway is not well understood so inconsistency remains, that they lack the resourcing and senior buy-in to make them operational, or that it can be hard for some groups to be easily placed in the pathway – for example those who do not meet the criteria for a full diagnosis. NHS Greater Glasgow and Clyde has a pathway developed and largely operational for BPD, but other forms of personality disorder care is carried out on a case by case basis. NHS Greater Glasgow and Clyde also felt that the inpatient parts of their pathway needs further work.

Care plans

Care plans are used as standard across boards, with boards feeling that most people will have a care plan where this is needed. Some limitations in their use have been identified by boards. For example, care plans can be focused on presenting problems rather than diagnosis specific, or that care plans may not reflect the complexity of the patient's need. Some boards use the

Care Programme Approach, which provides a more organised approach when treating complex cases and working with multiple services. Within NHS Greater Glasgow and Clyde they are using an approach they refer to as Coordinated Clinical Care.

Medical management

Most boards discussed the use of medication and identified that they aim to use medication sparingly. Some such as NHS Highland and NHS Borders, have guidance, checklists and agreements that are in place to guide the use of medication. However, boards also reported that there is a diverse approach to prescribing with some professionals preferring to prescribe medication more than others.

Interventions offered

There is a large variation in interventions offered for managing and treating those with a diagnosis of personality disorder. The range and availability of interventions is often driven by resource constraints and the existing staff skills to deliver particular intervention. Some boards mentioned that it was more difficult to get buy-in and approval for the more intensive and therefore more costly interventions in the context of the current resourcing constraints and mental health service demand. The most common interventions offered in Scotland include Safety and Stabilisation, Decider skills, Systems Training Emotional Predictability and Problem Solving (STEPPS), DBT, MBT, psychotherapy, Cognitive Behavioural Therapy, Survive and Thrive, and group therapy. Interventions are largely organised around the severity of the individual's presentation and within a stepped care/matched care arrangement. There is considerable overlap in the intervention options that are available across boards such as:

- Decider skills
- STEPPS
- Survive and Thrive
- Group therapy.

However, there is disparity when it comes to provision of specialised therapies. For instance, NHS Ayrshire & Arran do not offer DBT, which is a treatment recommended for those with a diagnosis of personality disorder. Additionally, some boards noted that finding interventions for young people and older people can be a challenge as some interventions have an age criteria in their board area of 18 to 64.

Digital and virtual support

Following the pandemic, boards are increasingly trying to understand how to use virtual and digital methods of engagement within their services. Virtual engagement was noted to help improve accessibility where distance and transport were barriers to face-to-face engagement. However, it was also noted that for a large proportion of people with a diagnosis of personality disorder, face-to-face support was the most effective as the relationships with staff in one-to-one settings and with peers in group settings were vital components to engagement and success. Boards are generally in the stage of discussing ideas and asking questions rather than having defined answers around how and when to deploy digital and virtual service options.

Support for family and carers

Support for family and carers is largely provided through signposting and referral to third sector services and carers groups. NHS Western Isles provides some support on parenting and offers relationship and family counselling within some of their services. Particular interventions such as STEPPS and MBT provide sessions where family and carers participate in order to build their knowledge, confidence, and coping skills in supporting someone with a diagnosis of personality disorder. DBT has service materials that guide families with the management of the difficulties of supporting someone with a diagnosis of personality disorder. A number of boards mentioned that they are trying to use the Triangle of Care approach which places carers in partnership with the patient and service as a key partner but note that this can only happen where those with a diagnosis give consent.

Involving those with lived experience

- NHS Highland have a number of examples of where PWLE are actively involved with the PD services, such as a lived experience volunteer sitting within their specialist personality disorder service, lived experience input with recruitment, resource development, training delivery, and an established example of co-production of CAS Day Service which was the first service in Scotland to receive the Enabling Environment Award from Royal College of Psychiatrists.
- Most boards reported intentions or plans to engage more with those with lived experience to inform service improvement, redesign and delivery but weren't in the advanced stages of consistently including lived experience in planning and delivery. For example, NHS Lanarkshire are looking at opportunities for co-design and co-delivery staff of training as well as including peer navigators into mental health services. There were a few examples of where PWLE were actively involved including:
  - NHS Tayside report including lived experience individuals in designing workshops for their EUPD clinical pathway.
  - NHS Greater Glasgow and Clyde have created a service user group within their BPD work which is supported by their BPD steering group but hosted by the Mental Health Network to ensure its independence. This group have produced and

contributed content to videos used in staff training and developed leaflets, social media content and other communication materials for those newly diagnosed.

- A number of boards mentioned that they collect patient feedback but noted that they want to do more to analyse and feed findings back into service development.
- A number of boards reported strong ties with third sector organisations, such as SRN, as a service delivery partner and getting their involvement in service improvement and development. A few boards mentioned that they drew on these third sector organisations as a way to access existing panels and groups of lived experience.
- Some boards mentioned that they are seeking to involve family and carers more in service design and planning and are trying to use the Triangle of Care approach. This is not currently happening but some boards identified that they hope to be able to do this in the future.

Data availability and usage

- Data is not systematically and comprehensively captured in a planned way with very few boards identifying management and performance data. Where data is available, diagnosis specific data can be difficult to isolate. This impacts the ability to understand need and service use for those with a diagnosis of personality disorder. There are some examples of the following data being collected in some boards:
  - Prevalence of diagnosis
  - Patient feedback
  - Service use, such as inpatient bed use and use of crisis and out of hours care
  - Management data including wait times, complaints, and disengagement
  - Impact/performance data including audit, evaluation, and clinical outcomes
  - Funding requirements
  - Staff attitudes
  - Staff training and skills
- There are concerns amongst boards about the reliability of the data they hold as differing views on this diagnosis can skew diagnostic estimates and intervention data.
- A number of boards identified that without a clear Integrated Care Pathway they are unable to develop a robust estimate of the resourcing requirements needed to adequately fund services.

Staff skills, knowledge, and capacity

- All boards mentioned staff skills as a key challenge in providing a wide range of interventions suitable for treating and supporting people with a diagnosis of personality disorder. There are wide spread reports of staff, across specialised and general mental health services, not feeling that they have the confidence to work with people with a diagnosis of personality disorder. This was particularly true for more complex presentations. Furthermore, specialist interventions such as DBT require specific training that is not common amongst staff.

- Those with lived experience reported that they felt that the stigma associated with a diagnosis of personality disorder was regularly present amongst health and social care staff. Those with lived experience also reported that they felt they were treated differently once their diagnosis was made or became known to staff. This view was echoed by many of the boards we spoke to. Boards also felt that staff can often feel helpless when it came to working with people with a diagnosis of personality disorder. This was due to the persistent nature of the difficulties those with a diagnosis experience, long timeframes for improvement and a need to focus on management and recovery based approaches to treatment. They felt that this can often contribute to how staff feel when engaging with those with a diagnosis.
- Most boards reported issues with high staff turnover and a challenge to recruit suitable permanent staff when advertising positions. A number of boards, including NHS Tayside and NHS Shetland report relying on locum psychiatry staff as they are unable to fill positions.
- Funding available for staff is limiting the boards desire to provide a wide range of interventions suitable for treating people with a diagnosis of personality disorder. This is resulting in training requests being declined and lack of investment in time spent by staff on coordinating training.
- Boards are struggling to adequately train staff. Almost all boards reported that they do not have a policy and/or plan for training staff in relation to personality disorder. Staff turnover and the creation of specialist teams in other fields of mental health meant that those they do train are unavailable to continue services – particularly specialist services where boards reported that they had to stop interventions like DBT and MBT.
- Trauma related training, most commonly Trauma Informed Practice, was regularly reported by boards as being in place or will be in place for all relevant staff. Where boards reported challenges in accessing Trauma Informed Practice training for all staff they noted that this was inhibiting their ability to improve their services for personality disorder.

Funding

- All boards reported stretched services and limited financial resources contributing directly to a reduction in the range and intensity of support available for people with a diagnosis of personality disorder as well as impacting on timely access for people when they need the support. Many boards reported that they were unable to offer particular specialist interventions that have evidenced positive clinical outcomes for people with a diagnosis of personality disorder, such as STEPPS and DBT, due to funding constraints. Wait times for interventions and to see specialist staff exist across almost all services in all boards in Scotland. Some wait times are within national and local targets, while others can be significantly beyond these – particularly for psychiatric and psychological therapies/input. Most boards also mentioned that funding constraints directly impacted the ability to train their staff as it is a challenge to release staff from delivery to participate in training.

- All but two boards (NHS Greater Glasgow and Clyde and NHS Highland – excluding Argyll and Bute) do not ring fence funding specifically to personality disorders so support provided is balanced across a wide range of diagnoses and mental health needs where they are consistently seeing an increase in demand and reduction in resources.
- A number of boards mentioned the availability of third sector support for signposting and onward referral has been a challenge across many areas of Scotland. This has been particularly acute where the number of services available from the third sector reduced during the pandemic and hasn’t yet reached pre-pandemic levels again.

Learning and sharing

- There appear to be very few regular structures in place to learn and share learning to inform service improvement amongst boards and appears to be driven by both a lack of strategic buy in as well as stretched resources and staff. One example of learning and sharing identified by boards is that the development of the NHS Greater Glasgow and Clyde ICP was informed by similar pathways for learning disabilities and older adults.

Gap analysis

Drawing on a comparative analysis of good services and the existing provision in Scotland, key gaps and challenges are:

- A lack of shared and accurate understanding of personality disorder diagnosis across staff, services and organisations leading to inconsistency in diagnosis and treatment
- Limited senior buy in and leadership required to operationalise service improvements
- Under-developed or newly developed ICP leading to inconsistent treatment and reducing the ability for those with a diagnosis to access the right support regardless of where they present
- Under resourcing of mental health and other health services limiting the range, intensity, quality and timely access to the services for people with a diagnosis of personality disorder
- Limited access for those with a diagnosis to evidenced based interventions and treatments due to the availability of resources to fund the services and skilled staff to deliver the services
- Limited meaningful involvement from those with lived experience in the design and delivery of services
- Staff turnover and recruitment challenges leading to loss of knowledge and specialist personality disorder skills and a stretched workforce to deliver services. Staff continuity is also of particular importance when supporting people with personality disorder as trusted relationships require constant and reliable engagement over an extended period of time to develop

- Limited opportunity for personality disorder specific training for staff across relevant services due to resourcing constraints and absence of detailed staff training plans which could help with addressing stigma, confidence and skill gaps
- Inconsistent and incomplete data collection and limited use of data to inform future service design and improvement
- Limited opportunities and evidence of learning within services and sharing learning with others to improve services
- Unclear role for digital and virtual service delivery
- Inconsistent approaches to transition arrangements between services for those transitioning from children and adolescent mental health services (CAMHS) and learning disability services to adult mental health and from adult mental health to older adults. The National Institute for Clinical Excellence (NICE) guidelines stipulate that services should have suitable transition arrangements in place for these interfaces. NICE guidelines recommend that individuals within learning disability services, who attract a diagnosis of personality disorder should be treated in adult mental health services where appropriate.

It is also worth noting that boards identified a range of contextual factors which were impacting on service delivery including:

- In smaller boards and smaller communities there were reports of issues around patient confidentiality and hesitancy accessing services due to confidentiality concerns by those with a diagnosis
- Dispersed populations in rural areas and poor access to transport (in both rural and urban settings) were both reported by boards to pose accessibility issues, in particular making group work harder
- Remoteness, for example in the Western Isles, can make crisis support more challenging due to the geographical distance and travel between islands required.

Lived Experience Learning

Engagement with people with lived and living experience was led by the SRN and VOX and was integral to the work within PDIP. SRN and VOX delivered a comprehensive programme of engagement and co-design over 2022/23 called ‘With Us, For US’, guided by input from their Lived Experience Project Group and involving 139 people with lived and living experience. The full lived engagement report is available in our programme resources. Key summarised themes identified through this work, and quotes from those with lived and living experience are shown below.

Language, stigma, discrimination and diagnosis

During our engagement people shared many experiences of stigma and discrimination resulting in devastating effects on both their mental health and their relationship with services. People stated that they often feel treated as a diagnosis, not a person.

‘See me as a person, not just my diagnosis. Realise we are all treated the same, but the diagnosis doesn’t affect us all the same way.’

Many feel the wording of the diagnosis and descriptions of symptoms should be changed, as it often causes misunderstanding and contributes to negative attitudes. There is a consensus that the language used effectively blames the person for the behaviour and doesn’t acknowledge the impact of trauma and life experiences.

‘There’s attitudes that because it’s a personality disorder, there’s something wrong with my personality. But actually, it’s a result of things that have happened to me in my past, such as trauma.’

Many people we engaged with strongly believed that their physical and mental health care was adversely affected by their personality disorder diagnosis. Due to the stigma surrounding personality disorder, people are often dismissed with legitimate concerns around their mental and physical health. People felt that the problems they experience are not primarily about individual poor practice but are systemic. This means that even where practitioners are trying hard to meet people's needs it is very difficult for them to do this.

'It's the system that is broken. You can have the best staff in the world but with a broken system they cannot help.'

Some people told us that getting a diagnosis could be validating as it helped them to understand and process their emotions and behaviours. However, many people talked of receiving a diagnosis as being a difficult experience. Part of this is due to the stigma surrounding personality disorder. However, many people also expressed concerns about the accuracy of their diagnosis and that they experienced a lack of transparency in the process.

'My experience with PD diagnosis was just a label that was treated negatively. They come with negative bias and judgements and I felt that every single day, every appointment.'

People emphasised that ensuring people are given the right diagnosis required time and consideration and a compassionate approach which recognises how difficult this experience can be. It is clear there are issues around poor experiences of receiving a diagnosis which must be addressed.

'You become your diagnosis instead of being a person. It's dehumanising and invalidating.'

Role of trauma and trauma responsive services

During our engagement many people talked of experiencing a lack of understanding of trauma and how it impacts on people's behaviour. They emphasised that everyone experiences trauma and distress differently and there is not an extensive list of what classifies trauma as it is unique to each person. Although many services claim to be trauma-informed, this knowledge is not reflected in their practice. Many shared that trying to access support has contributed to their complex trauma.

'Getting a diagnosis has been another trauma for me…I just felt like it was pass the parcel, every service I went to they said they couldn't help me.'

The experience of using NHS services has been re-traumatising to some, whilst many others have been negatively impacted when seeking support. Even where there are specialist services, these are not necessarily working for people seeking support. There is a need for a change in thinking and for significant service redesign which is truly informed by lived experience.

“It’s like having a key that doesn’t match the lock. The services are not equipped to deal with trauma.”

To create services that meaningfully support people living with trauma, we must start with moving away from what feels to people like an overly medical or diagnostic approach to focusing on what would help people to live their lives. This would provide a basis to develop the services and flexible care pathways that people believe would support their recovery.

Components of good services – relational, compassionate, flexible

People told us that good services are those which are based on relationships, show compassion and are flexible and adaptable to their needs and preferences. There is a need to be more open about what we mean when we talk about person-centred services. What is important to people is a focus on **relationships** and building the trust that people need if they are to recover. Good relationships are those where the person feels listened to, and where their experiences, feelings and ideas are validated and valued. Through this they can develop the trust needed to embrace new ways of thinking and adopt new coping and self-management strategies. Underpinning this is a requirement to have some consistency of practitioner over a period of time.

‘Taking the time to create that relationship builds trusts, and when you have trust in a person it can continue.’

A **compassionate** approach helps people to understand and process their emotions and behaviours, rather than being turned away due to these behaviours. Validation and empathy are important aspects of a compassionate approach. Services need to invest more in providing the time and structured space for people to process their experiences and find their own ways of living. Services delivered with compassion recognise how hard it is for people to build trust and engage, so will invest in relationship and trust building. Compassion from clinicians will help people feel safer when accessing support and particularly when receiving a diagnosis.

‘All that people want or need is compassion and treated like a human being. All the fancy practices and techniques in the world, but that’s all it boils down to really, just wanting to be met with compassion and to be understood.’

Good services are **flexible and adapted** to what the person needs at time rather than being dependent on someone’s diagnosis or history. Services would be treating the person, not the diagnosis. Having lived experience at the heart of services will help achieve this. Central to this is that access to support should not be time limited from the outset, as this can put pressure on people to feel they must be ‘fixed’ by this time, and if they aren’t then they will be left with no support. This flexible and adaptable approach means people will feel in more control of their care and better able to collaborate on decisions about their support.

‘Person-centred means taking the lead from the person and allowing them to be in control and decide what they want to do.’

Taking a whole person whole system approach

Taking a whole, person, whole systems approach means services would look to provide holistic support to people living with trauma and/or a diagnosis of personality disorder. A whole person approach means that they would be connected to other services which can provide financial, social and emotional support. It would also focus on what people need to live a life of their choosing. At most, diagnosis, is only one factor in this process.

‘The people providing the service would get to know me as a person, not a diagnosis. They would seek to understand my whole-life context, not just my symptoms.’

A whole system approach means that people will have a supported journey and will progress through different types of supports as required. Taking a more holistic approach to support means a range of treatment options will be offered. Moving away from ‘fixing’ people and instead supporting people to live well and be accepted. The role of supporters (families, friends, carers) should also be considered, as they are an integral part of a whole person whole system approach but are often overlooked.

“Support would be truly person-centred and tailored specifically to my needs and situation. There would be a range of supports to pick from –not just one “personality disorder pathway.”

People were very clear that diagnosis is only one part of the process of identifying the range of supports needed to help them live a life of their choosing. Therefore, we propose a shift to whole person, whole system care pathways, which mean people will be offered clinical and community-based support in the same care package. People will be able to collaborate on the development of their care pathway and be full decision-makers on their own journey.

Developing peer support

Developing peer support is key to achieving whole-person, trauma responsive and recovery focused support based on empathy, compassion, and the power of shared experiences. Peer support is validating, people feel they can talk openly with no judgement. This type of support can help people to understand their experiences and embrace change. Reflecting with peers can help people gain insight on how they want their care and support to look. More organic forms of peer support are created by coming together, therefore investment in peer roles needs to take place so there can be effective, timely and meaningful support for people.

> ‘Peer support feels like there is a place for me. It’s acceptance, opportunity, hope. You need support to find where you belong.’

There are two key areas where people have identified peer support would make a difference; peer practitioners within services, and peer led support groups in the community. Within services there should be more investment in peer roles, such as peer practitioners who are part of clinical services and can support people before, during, and after therapies and/or therapeutic courses. Additionally, people will be supported to find and join peer support groups in their community which will assist their ongoing recovery and minimise future crisis.

> ‘There would be an increased presence of peer support workers and they wouldn’t be separated from mainstream mental health provision.’

For the mental health system to meaningfully support people living with trauma and/or personality disorder, we must create spaces where people can feel a sense of acceptance and belonging and recognise the value of peer support.

Staff Engagement

Engagement with staff was a key area of our work. Staff engagement took place from June to October 2022 with staff across the country invited to take part in the survey, with a smaller group of staff self-selecting for one to one interviews.

Survey outcomes

The staff survey comprised a mixture of scale based and open response questions. 303 staff took part, with the most common professional group being nursing.

Psychiatry (6%)
Nursing (48%)
Psychology (25%)
Occupational Therapy (8%)
Other (13%)

Most staff reported working in adult mental health services (86%) and had worked in services for more than 10 years (69%). Most felt that they had the knowledge (91%), skills (82%) and empathy (93%) to work well with individuals who have a diagnosis and felt that individuals could be supported to manage their distress and improve their lives (94%). However 76% reported limitations to their service and 96% reported challenges to working in this area, with challenge identified as:

- **Challenges to supporting clients**
  Effectively establishing and managing the ending of relationships
  Helping those with a diagnosis take ownership of their recovery
  Providing wider support to clients
  Managing risk.
- **Consistency in team approaches to treatment**
  ‘Splitting’ of teams, with a lack of agreement in approaches to support those with a diagnosis
  Lack of positive risk taking
  Lack of shared understanding of diagnosis between services and professions.
- **Attitudes towards diagnosis**

Negative perceptions among staff of service users, wider service based stigmatisation and misconceptions of those with a diagnosis.

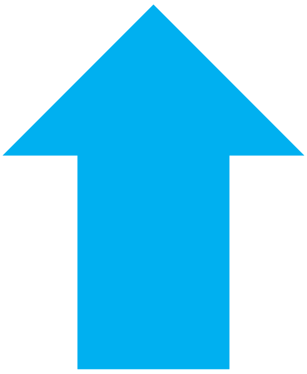
- **Service based challenges**
  Lack of specialist and dedicated services, poor country-wide access to interventions, lack of communication between services, lengthy waiting lists for treatment.
- **Staff wellbeing**
  Emotional impact of working with individuals considered to be high risk for self-harm and/or suicide, concerns around being 'good enough' as a practitioner, lack of resources such as wellbeing and supervisory support, managing 'revolving door' clients, staff shortages, lack of training opportunities.

Despite perceived challenges and limitations staff did express that they had adequate access to supervision (83%), opportunity for reflective practice (79%) and had good wellbeing support (75%). Additionally, staff found their service to be good (73%) and that their work was rewarding (75%). However, it should be noted that approximately 10% of staff found no rewards from working in this area. Areas of reward were described as:

- **Seeing positive outcomes for those with a diagnosis**
  Reductions in risk and distressing symptoms, seeing clients move on from services or needing less contact and support. Seeing recovery, skills building and changed perceptions of services. Improvements in self-understanding and improved relationships with family, friends, and so on.
- **Seeing services and service access improve**

Increased prevalence and access to dedicated services and improvements underway for personality disorder specific pathways. Reductions seen in stigmatisation of personality disorder diagnosis and seeing negative attitudes challenged in services. Having effective care planning and time to dedicate to those with a diagnosis in addition to having access to training.

- **Building relationships and enjoying the work**
  Enjoyment of working in a challenging environment that challenged professional skills and abilities, and enabled professional growth. Being able to help others, having time to building good therapeutic relationships and being able to engage and collaborate with those with a diagnosis. Having clients express gratitude.



Areas of reward

- Seeing positive outcomes
- Seeing services and access improve
- Building relationships and enjoying the work

Interview outcomes

One to one interviews took place with 19 staff, across four localities (NHS Greater Glasgow and Clyde, NHS Ayrshire & Arran, NHS Lanarkshire and NHS Fife). These localities were thought to best represent the demographic makeup of Scotland, and included a range of professions. Staff involved had varying degrees of time spent working in mental health services (between 1 to 37 years). Below represents areas of engagement across professional groups.

Psychiatry (N=3)
Nursing (N=6)
Psychology (N=6)
Occupational Therapy (N=3)
Physiotherapy (N=1)

The aim of the interviews was to understand staff perspectives on barriers to high quality care. Interviews generated four main themes:

- **Challenges around diagnosis and diagnostic language**
  Staff felt that language around diagnosis is stigmatising and there is a lack of collaboration and shared understanding in current approaches to diagnosis. Staff also reflected that a medication-based approach to treatment of personality disorder is common, with overreliance on medication and frequent polypharmacy. Misdiagnosis and comorbidity with other mental health presentations is also felt to be common, which can complicate approaches to treatment.

  "…if it's a diagnosis that is sort of slapped upon someone, it isn't thought about or explained…it isn't used in a sort of shared language type way, I think that can be quite damaging"

  "…my concern is that that might not really change the stigma that may go along with the difficulties these patients come seeking help with. So it's not perfect, but actually although a lot of people feel they don't like the diagnosis, patients I have worked with, a lot of people also have said they now understand what's wrong…and I think depending how you say that to someone can influences the action"

- **Service design challenges**
  Staff disagreed in the need for specialist or dedicated services. Staff reflected that there is a lack of country-wide access to interventions and that there is considerable time taken in the development of services and pathways. Staff expressed that there is a lack of parity in how mental health is viewed as opposed to physical health. Additionally, staff felt there is a lack of flexibility and adaptability in service design to cater to needs of service users. There was also the feeling that there is an over-reliance on targets and practices of disengagement-discharge. Some staff also considered the appropriateness of current approaches to crisis and inpatient care for those with a diagnosis, with most feeling that this care (whilst well intentioned) could be harmful.

  "…the duty system often doesn't work for this group of people when they are in crisis and, and I suppose it could be said for anybody that when you're in crisis, you would like to speak to somebody who you know and somebody who knows you. But for this group of patients in particular, I think they find it very hard to speak to a duty worker"

  "…a dedicated service would be optimum but how would that be designed? How it would interact with psychiatrist services? I don't know because there is such a crossover between the two and I don't think that you could discriminate against people either by putting them to a dedicated service. Um yeah, I don't, I don't know how it can be resolved, to be honest"

- **Access to training and job satisfaction**
  Staff felt that there is inequitable access to training and supervision across professional groups, particularly in low-intensity interventions. It was reflected that there is a lack of early career, personality disorder specific education and training. Staff also expressed that there is a considerable personal emotional impact when working in this area. It was felt by many that there is a lack of positive risk taking, which can inhibit being able to move forward with clients.

"It's been explicitly said we're prioritizing adult mental health services here, so my colleagues CPNS, OT's in our MDT have been rejected from that training because the priority is focused on adult mental health"

"…the lack of consistency of approach and I absolutely am not suggesting that there's a one-size-fits-all, but there are things to me that are really important. Risk management is really important but so is, but so is risk management that is not risk averse, it's really important.

- **Stretch on staff and managing relationships**
  It was reflected that there are considerable staff shortages and issues recruiting new staff, with impacts seen on service provision, staff and on the wellbeing of those with a diagnosis. Communication and information sharing between services was also felt to be lacking. Some staff expressed that there is a lack of one team vision to treatment approaches with this client group. Staff also reflected that negative attitudes and perceptions remain among staff groups towards those with a diagnosis. Difficulties managing therapeutic relationships were discussed, as were further considerations to risk and managing professional team relationships.

"Whereas now it's just about existential, you know how do we keep the service running? Rather than what can we do extra or what can we do to change the services actually, you know, just at the moment, we're just saying how can we provide a service to these people with what amounts to roughly about 50% staffing?"

"…the biggest challenge, I think is that our services are set up in a very modularised way and it's artificially modularising how we might work with this patient population. And it's very easy to see the resources as the source of all problems, but I think it's

> even how we distribute those resources that we've currently got as well and communicate between us”

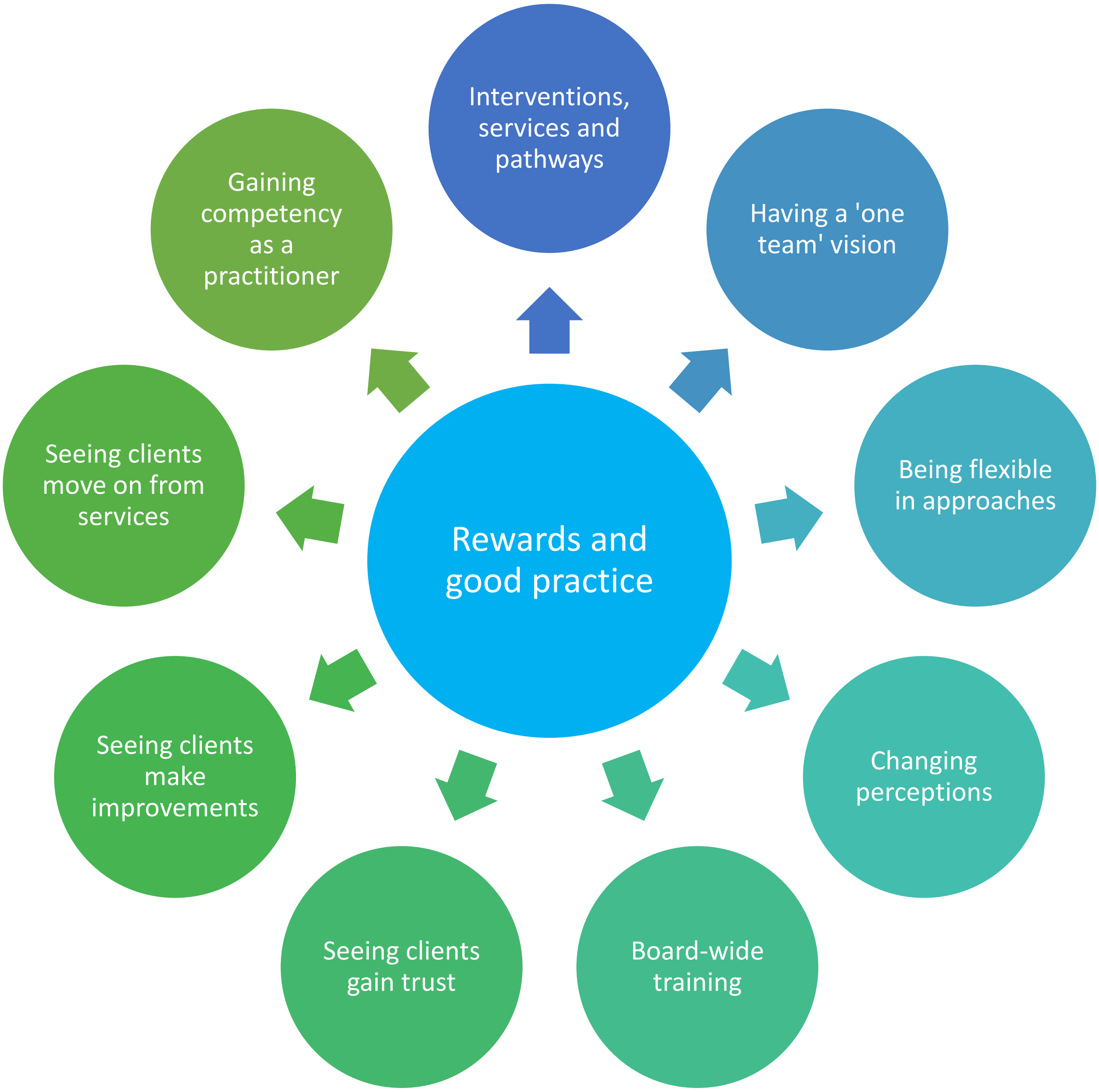
Barriers to high quality care

- Diagnosis and diagnostic language
- Access to training and job satisfaction
- Stretch on staff and managing relationships
- Service design challenges

Whilst not a theme from the analysis, it was expressed that there were areas of perceived rewards and strengths within services, such as:

- Increased provision of interventions and dedicated services and pathways
- Being part of a team that was supportive and shared the same vision
- Having the ability to be flexible in approaches
- Seeing changing perceptions concerning diagnosis and reductions in stigma within services
- Specific to NHS Ayrshire & Arran; the board wide roll out of Decider skills training for staff
- Seeing clients gaining trust in the therapeutic relationship
- Seeing clients make improvements in their life and these improvements impacting their other relationships
- Clients being able to move on from needing the input of services
- Improvements in practitioner’s skills as and confidence.

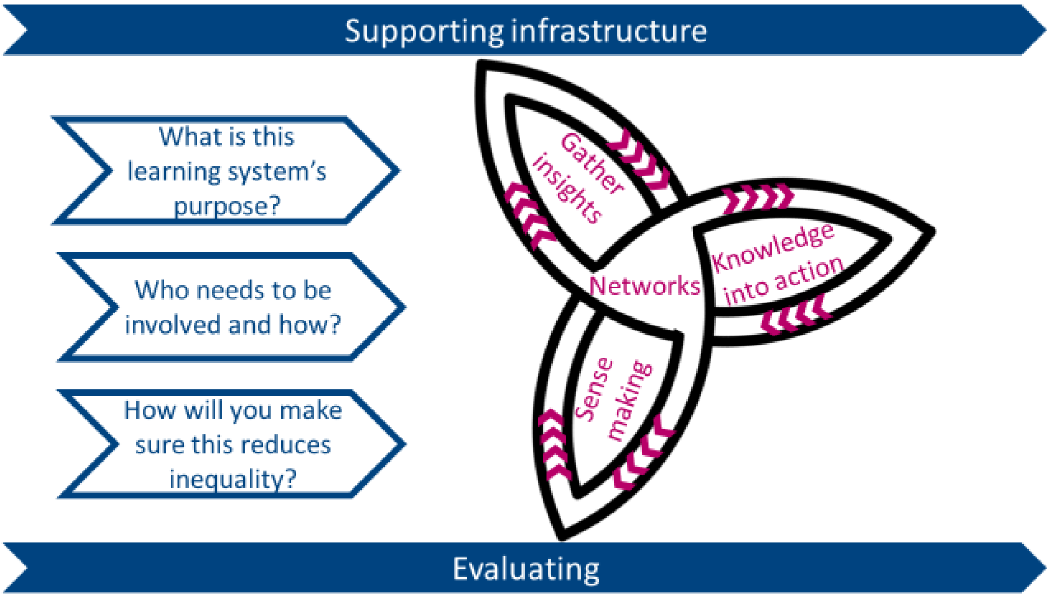
> “…this is 10% of the population you know realistically, and this 10% get an incredible burden and the 90% turn around and say to them sort yourself out…This is about us as the 90% recognizing that that's not feasible and we need to find a way to be better”


Rewards and good practice
Interventions, services and pathways
Having a 'one team' vision
Being flexible in approaches
Changing perceptions
Board-wide training
Seeing clients gain trust
Seeing clients make improvements
Seeing clients move on from services
Gaining competency as a practitioner

Learning System

A key deliverable for the PDIP was to develop and deliver a learning system. One of the goals for the learning system was to provide opportunities for people to learn together and access the expertise of others, to support improvements in services. This was the ethos behind the series of webinar and workshop events that ran from May 2022 until March 2023.

The PDIP learning system was established on principles of equality and inclusion. Events and activity planning followed the Participation, Accountability, Non-Discrimination, Empowerment and Legality (PANEL) principles as a human rights based approach. We completed an Equality Impact Assessment (EQIA) to ensure we considered the rights and access of people engaging with our work. The EQIA was regularly reviewed to ensure that we addressed actions and learning from new and emerging evidence. For example, in practice this included improving accessibility to our virtual events by providing clear guidance on how attendees could join sessions and make the most of Microsoft Teams tools to communicate in ways they felt safe and comfortable with (such as anonymizing their presence).



The programme has captured and synthesised examples of innovation and good practice in established personality disorder services and pathways through the learning system. PDIP has produced two case studies showcasing snapshots of current good practice. The first case study shared learning on working in partnership with lived experience and third sector organisations to design services, with SRN and NHS Lanarkshire. The second case study illustrated an example of innovation on flexible training model implementation for staff development with NHS Greater Glasgow and Clyde.

The webinar and workshop series launched on the 31st of May 2022 with ten events over the course of phase one. The approach taken to the learning system was an iterative one, where attendee feedback was fed forward to inform upcoming events. By doing this, PDIP aimed to actively listen to stakeholder voices and used these to ensure an open approach that was responsive and collaborative. PDIP continuously reviewed and refined the topics of all the events, reflecting on attendee feedback. The topics we covered were:

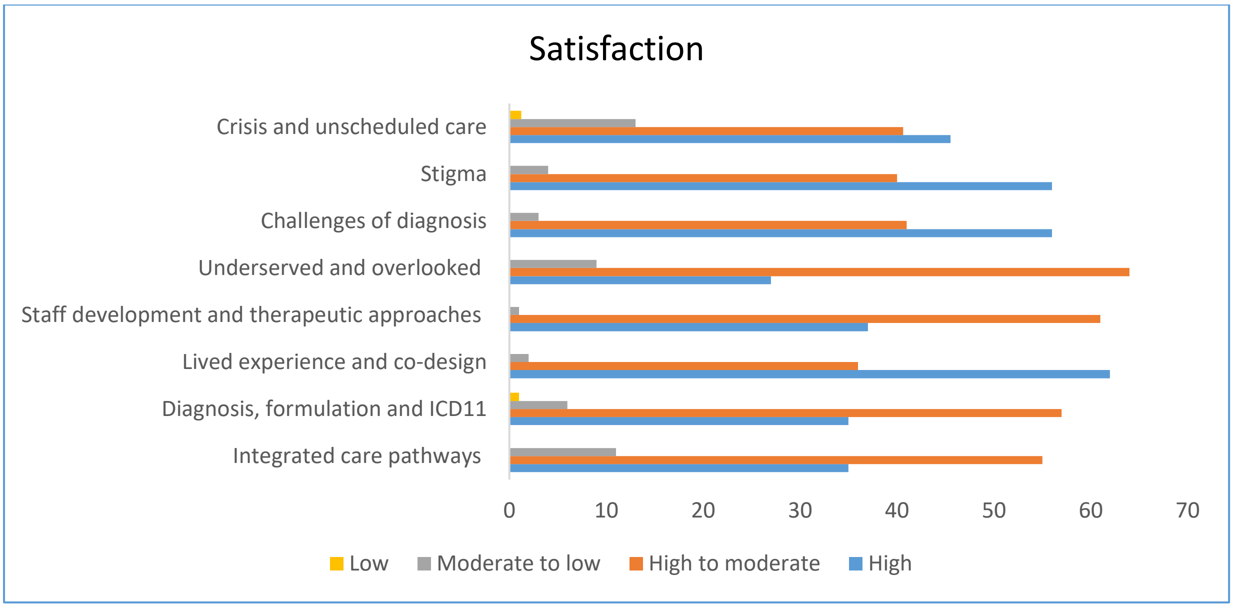
1. Programme launch webinar taking place in May of 2022
2. Integrated Care Pathways and specialist services
3. Under-served and often overlooked groups
4. Diagnosis and formulation
5. The challenges of diagnosis
6. Lived experience and co-designed services
7. Staff development and therapeutic approaches
8. Stigma
9. Unscheduled care and out of hours
10. End of phase one webinar.

Each event was evaluated with questions being posted live using Microsoft Teams. Key outcomes are described below. Evaluation focused on six key areas, specifically area of interest from attendees (for example professional practice, lived experience, third sector, other), satisfaction with the event, knowledge and understanding gained and impact going forward. The evaluation also assessed attendee experience of the events with open response questions on key take away messages and what could improve future sessions.

There was considerable interest and engagement with the webinars and workshops, with significant numbers registering for each event. For most of the events across the series, approximately 50% of those who registered attended. Outcomes indicate that the most common attendees were those from professional practice. This was consistent across all events. The event for staff engagement and therapeutic approaches garnered most engagement from professional practice (94%). Lowest levels of professional engagement came from the event for underserved and often overlooked. Greatest lived experience engagement came from the underserved and often overlooked event (12%) and lowest levels came from the events for staff engagement and therapeutic approaches and diagnosis, formulation and ICD-11 (3%).

There were considerable levels of participant satisfaction across events, with attendees rating their satisfaction with the content of the webinar/workshop as being either high or high to moderate. See figure 1 for attendee satisfaction across events.

Figure 1. Attendee satisfaction with event content



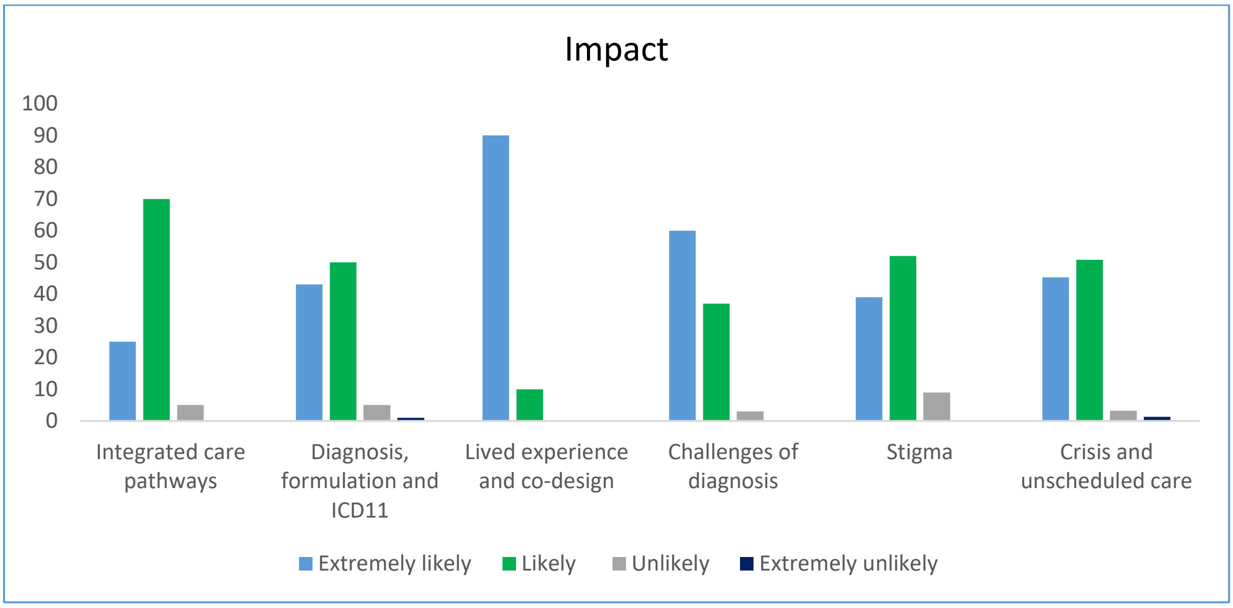
A key feature of the webinar and workshop series was sharing knowledge and information. There was considerable agreement across events that knowledge and understanding was increased due to attendance. Attendee disagreement concerning increased knowledge and understanding was low. Figures below highlights rates of disagreement across events:

- Challenges of diagnosis – 3%
- Underserved and overlooked – 12%
- Staff engagement and therapeutic approaches – 4%
- Lived experience and co-design- 1%
- Integrated care pathways – 4%
- Crisis and unscheduled care – 1%.

The event for Diagnosis, Formulation and ICD-11 evidenced the highest rates of participant disagreement. Approximately 27% of attendees strongly disagreed that attendance had increased their knowledge and understanding. However, to provide some context, most attendees across events were from professional practice. It is reasonable to assume that many of those who attended this event would have prior knowledge and understanding of diagnosis, formulation and the changes made to the categorisation of personality disorder within ICD-11.

Impact of knowledge gained going forward (either professionally or personally) was an additional area of evaluation. Again, most attendees rated that the knowledge and understanding that they gained through the event would have future impact for them, with considerably low levels of disagreement.

Figure 2. Impact of knowledge going forward



Attendees at each event were offered the opportunity to give their views on the key take away messages and what they believed could improve future events in open response questions. This feedback involved descriptions of events including: informative, enjoyable, interesting. It was also felt that events highlighted the importance of understanding and empathy. Attendees were also asked what they felt would improve future events, with suggestions ranging from more time and interaction, to more lived experience input and information on services.

The events on staff development, stigma and crisis and unscheduled care contained targeted questions on what could assist in achieving improvements in these specific areas of interest. Attendees suggested the following improvements:

Staff

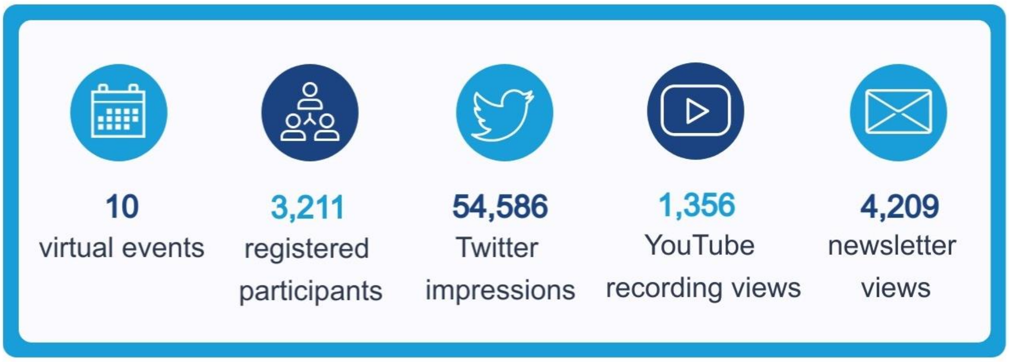
- More education
- More supervision
- More training
- More funding
- More staff.

Stigma

- More education
- More training
- More collaboration with those with lived experience.

Crisis and unscheduled care

- Continuity of staff
- Continuity of care
- Training
- More staff
- More funding
- Empathy and understanding.



10 virtual events

3,211 registered participants

54,586 Twitter impressions

1,356 YouTube recording views

4,209 newsletter views

Evaluation of the webinar and workshop events has shown that there is considerable interest and appetite for engagement, particularly for those from professional practice. Attendees of these events felt that they contributed towards improved knowledge and understanding in specific areas relating to diagnosis, available treatment, treatment access, lived experience and stigma. Those who attended also felt that what they gained from the events would have impact for them going forward, either in a professional or personal capacity. This was a key aim of the learning system, to share knowledge so that learning could be facilitated and that this learning would have benefits beyond the events.

Outcomes suggest that events were found to be interesting, engaging, and informative whilst at the same time providing clarity and highlighting areas for future consideration. Specific areas for improvement were also noted, which map well to the findings of the lived experience and staff engagement, particularly around language, staff training and education as well as the importance of lived experience voices and input in improving services.

Board reflections on impact of COVID-19 on service provision

COVID-19 presented significant challenges in providing care across mental health services, however there was also opportunities to explore and implement different ways of working. Our work aimed to understand what opportunities and challenges boards faced during this unprecedented time.

Opportunities

- Most boards (NHS Greater Glasgow and Clyde, NHS Forth Valley, NHS Tayside, NHS Lothian, and NHS Lanarkshire) reported that COVID-19 enabled the use of remote access for services (e.g. Access Anywhere, Near Me). This facilitated and created equitable access for those from more remote and/or rural locations (NHS Highland, NHS Dumfries & Galloway, NHS Orkney, NHS Western Isles, NHS Borders, and NHS Argyll & Bute).
- NHS Highland reported that STEPPs was particularly successful when delivered remotely.
- Remote working increased ‘joined up’ working (NHS Forth Valley) and increased access to staff (NHS Shetland).
- It was felt that group sessions worked well when delivered remotely (NHS Tayside, NHS Lothian).
- Adaptation to new working procedures meant there was more positive risk taking and avoidance of hospitalisation (NHS Lothian).

Challenges

- COVID-19 ceased all face-to-face contact in services, with a detrimental impact seen in higher intensity therapeutic interventions that require enhanced relational contact (NHS Forth Valley, NHS Shetland, NHS Fife, NHS Grampian, and NHS Argyll & Bute).
- COVID-19 delayed areas of planned improvement work within services, such as NHS Lanarkshire’s work on their ICP.
- Wait times for service assess were also significantly impacted by COVID-19, creating a backlog that some boards (for example Lanarkshire) are still working through.
- Increased pressure on staff due to additional needs throughout services during the pandemic (NHS Fife).
- Loss of links with the third sector (NHS Fife).

- The need for careful consideration in use of remote facilitation to ensure that those with a diagnosis do not feel negatively impacted (NHS Greater Glasgow and Clyde).
- Careful consideration needed in terms of access to technology, technological knowledge and access to private spaces for remote facilitation (NHS Greater Glasgow and Clyde, NHS Lothian).

What We Understand About Good Services

This section outlines what we understand good services look like for those with a diagnosis of personality disorder. It is based on the work completed during this programme including:

- The two rapid evidence reviews and one economic review
- In-depth interviews with NHS boards to map their existing personality disorder service provision conducted by Healthcare Improvement Scotland's Strategic Planning Team
- The lived experience learning - findings of engagement with those with lived experience, conducted by SRN and VOX
- Survey and one-to-one interviews with staff working in services that support those with a diagnosis of personality disorder.

Overall, the available evidence does not support one single model of delivery over others. Instead a variety of delivery models are suitable for supporting those with a diagnosis of personality disorder. Within the various models there are a range of key features that are important to ensure that the services and support provided match what we would consider to be good practice. These features are the highlighted below.

Strong leadership with:

- A clear and coherent strategic plan for how to plan, organise and deliver services
- Buy-in and commitment from senior leadership through to front-line
- A shared understanding of issues, objectives and approaches including a system-wide breadth of focus
- Good communication within and across organisations and services
- Clear and accountable joint governance structures that encompass all the relevant stakeholders and organisations
- Led by those using a collaborative and transparent leadership style that enables distributed leadership, innovation and appropriate risk taking across boundaries

Models of care which:

- Are informed by a clear understanding of need and evidenced based approaches
- Contains a stepped match care model which matches severity with appropriate treatment, interventions and support, whilst also allowing for reasonable patient choice

- Models that actively engage people in their treatment and promote self-management in a collaborative therapeutic relationship
- Ensures services are embedded in secondary care and that structured clinical assessment and care planning happen here
- Provides access to a range of evidence based interventions that are right for the person and at the right time[*]
- Peer support is available and fostered
- Support is available for family and carers
- Medicines are prescribed with care, especially antipsychotic and sedative medicines, and that comorbidity is treated
- Interventions also focus on longer term goals in education and employment
- Models of care/treatment should consider partnership(s) with third sector organizations to expand ICP beyond the offer of standard or specialised interventions to those that take a more ‘whole’ person approach
- Transitions and endings are carefully managed with structure and a phased plan
- Coordination between different elements and professional groups to ensure access to the right support is enabled no matter where in the system people turn up
- Services that have strong relationships between staff and those with a diagnosis including consistency, trust, respect and compassion and use trauma informed practices
- Adherence to best practice guidelines (for example NICE, Psychological Matrix) such as the use of Care Programme Approach, with consideration given to enhancing equity in provision across society (for example those with protected characteristics such as ethnic minorities, LGBTQIA) and use of interventions with durations of greater than 12 weeks.

Involvement of lived experience which:

- Ensures diagnosis, interventions and ongoing engagement with services incorporate choice by the person as key to the person-centred care **for their own care**
- Ensures that those with lived experience are able to meaningfully input into service design, delivery and review to **inform wider service delivery**
- Makes best use of existing local user, carer and advocacy groups and national representative bodies to provide supported, structured and efficient ways of involving lived experience.

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[*] Evidence-based interventions for those with a diagnosis of Personality Disorder include Structured Clinical Management (SCM), STEPPS, Dialectical Behavioural Therapy (DBT), Mentalisation Based Therapy (MBT) and Schema Focused Therapy (SFT). For those who may or may not meet full diagnostic criteria for a diagnosis of personality disorder, a range of interventions are agreed by expert opinion to be useful, for example: Emotional Coping Skills, Survive and Thrive, Decider Skills and interventions aimed at improving social and occupational functioning.

Adequately trained and supported service staff through:

- Regularly and robustly assessing staff skills, experience and confidence to conduct training needs assessments
- Having a clear, comprehensive and planned out approach to staff training across relevant services
- Provision of high quality training in specialist therapies, trauma, unconscious bias, and other required skills required for diagnosing, treating and supporting people with a diagnosis personality disorder
- Consistent and shared view of evidence based approaches to diagnosis, interventions, treatment, and support for people with a diagnosis personality disorder
- Putting in place structures and dedicated time to enable staff to implement and further develop their new skills and knowledge
- Putting in place structures that support staff in their wellbeing, safety, performance, development, and contribution to a healthy working culture and environment.

High quality data including:

- Collecting data that matters, not just what is available, to be able to understand performance, impact, challenges, and improvement opportunities
- Collecting consistent, comprehensive and accurate data that is quantitative and qualitative data from a variety of sources including statutory services, community and third sector services, staff and user engagement.

Adequate and well deployed funding through:

- Robust understanding of budget requirements drawn from high quality analysis
- Clear articulation of current spending
- Adequate resource to meet need that is allocated efficiently to achieve impact.

A focus on learning and sharing by:

- Regularly reflecting on experience to generate and curate learning including identifying enabling factors, barriers and future opportunities to do things differently
- Using data and learning to inform understanding of trends, assessing performance, and informing service improvement
- Establishing, joining and regularly using networks of relevant stakeholders to share learning to inform others.

Recommendations and Proposed Structure of Phase Two

A key outcome for phase one of PDIP was to draw on the combined knowledge and experience gained through the programme and produce recommendations to deliver improvement activity in phase two. The sections above in this report detail extensive engagement with PWLE and the staff who work with them and health and social care services across the length and breadth of Scotland.

Across all sectors there is a clear consensus that improvements are essential and that people with a diagnosis of a personality disorder deserve better. A diverse range of participants at PDIP workshop events shared the following perspectives:

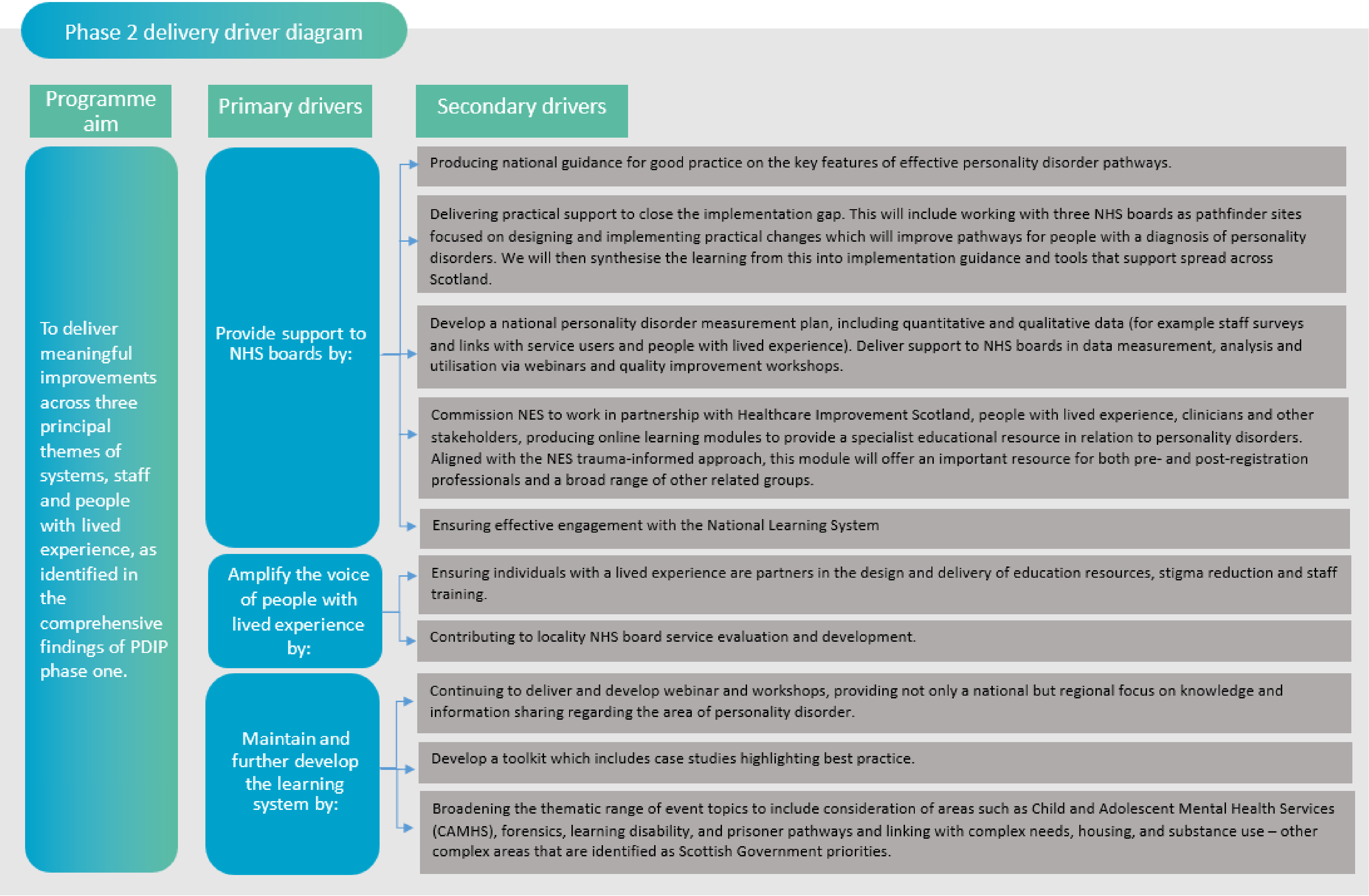
> "We need to ensure we are looking at the person as a whole not just a diagnosis..."
>
> "It's their care, not mine – we should give options on where they can go and what they can do…"
>
> "[I] have found negative attitudes can breed negative attitudes. We need people to feel confident to challenge stigma…"

As a result, the overall aim of phase two of the project is to deliver meaningful improvements in services and supports for people with a diagnosis of personality disorder as identified in the phase one recommendations. These are:

- Supporting NHS boards in the development and implementation of improved care processes.
- Amplifying the voice of people with lived experience to ensure services are co-designed and co-produced with people with lived experience.
- Supporting staff development through development of specialist training modules and resources.
- Maintaining and further developing a national learning system to support a focus on capturing and sharing learning to accelerate the practical work of improvement.

Longer term, the aspiration remains that people who may attract a diagnosis of personality disorder presenting to mental health services anywhere in Scotland will have timely access to effective care and treatment. We believe that there is great opportunity to learn from PWLE to inform training, service evaluation and development, and expanding the role of peer support. Healthcare Improvement Scotland are currently engaging with our colleagues in the Scottish Government about future work. We are presenting the case for funding of a two and a half year phase two that will focus on:

Recommendations for Healthcare Improvement Scotland	Recommendations for local areas
• Develop a data measurement framework. • Deliver an expanded learning system. • Produce a toolkit, including case studies, to support service improvement. • Work with three pathfinder sites to design and implement practical changes improving pathways for people with a diagnosis of a personality disorder. • Commission NES to produce educational resources. • Produce guidance for delivery of care for people with a diagnosis of a personality disorder.	• Engage with the learning system. • Engage with the production and roll out of specialist educational personality disorder resources. • Support the development of national guidance. • Support the development of the data measurement framework. • Consider volunteering to be one of the three pathway boards. • Engage with people with lived experience (PWLE) to support evaluation and development of services.
Recommendations for Scottish Government	**Recommendations for partners working with PWLE**
• Commission HIS for PDIP phase 2 (as outlined in the driver diagram below). • Commission third sector organisation(s) to deliver a parallel lived experience component of the work.	• Engage with a wide range of PWLE across Scotland • Engage with existing support organisations (for example SPDN, advocacy and carers groups). • Develop peer support networks. • Engage with boards to support evaluation and development of services.



Phase 2 delivery driver diagram

Programme aim

To deliver meaningful improvements across three principal themes of systems, staff and people with lived experience, as identified in the comprehensive findings of PDIP phase one.

Primary drivers	Secondary drivers
Provide support to NHS boards by:	Producing national guidance for good practice on the key features of effective personality disorder pathways. Delivering practical support to close the implementation gap. This will include working with three NHS boards as pathfinder sites focused on designing and implementing practical changes which will improve pathways for people with a diagnosis of personality disorders. We will then synthesise the learning from this into implementation guidance and tools that support spread across Scotland. Develop a national personality disorder measurement plan, including quantitative and qualitative data (for example staff surveys and links with service users and people with lived experience). Deliver support to NHS boards in data measurement, analysis and utilisation via webinars and quality improvement workshops. Commission NES to work in partnership with Healthcare Improvement Scotland, people with lived experience, clinicians and other stakeholders, producing online learning modules to provide a specialist educational resource in relation to personality disorders. Aligned with the NES trauma-informed approach, this module will offer an important resource for both pre- and post-registration professionals and a broad range of other related groups. Ensuring effective engagement with the National Learning System
Amplify the voice of people with lived experience by:	Ensuring individuals with a lived experience are partners in the design and delivery of education resources, stigma reduction and staff training. Contributing to locality NHS board service evaluation and development.
Maintain and further develop the learning system by:	Continuing to deliver and develop webinar and workshops, providing not only a national but regional focus on knowledge and information sharing regarding the area of personality disorder. Develop a toolkit which includes case studies highlighting best practice. Broadening the thematic range of event topics to include consideration of areas such as Child and Adolescent Mental Health Services (CAMHS), forensics, learning disability, and prisoner pathways and linking with complex needs, housing, and substance use – other complex areas that are identified as Scottish Government priorities.

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