Personality Disorder Improvement Programme

Working to understand the current service provision for people with a diagnosis of a personality disorder.

The Scottish Government commissioned Healthcare Improvement Scotland to deliver phase one of the Personality Disorder Improvement Programme (PDIP).

This report summarises the work PDIP has carried out in phase one to understand the current state of provision and access to services for those with a diagnosis of personality disorder.

This report was enabled by the cooperation and generous engagement of a wide range of stakeholders and colleagues from the third sector, those with lived experience, mental health staff and 14 territorial NHS boards and 31 Health and Social Care Partnerships.

Contents of this report

This summary will highlight:

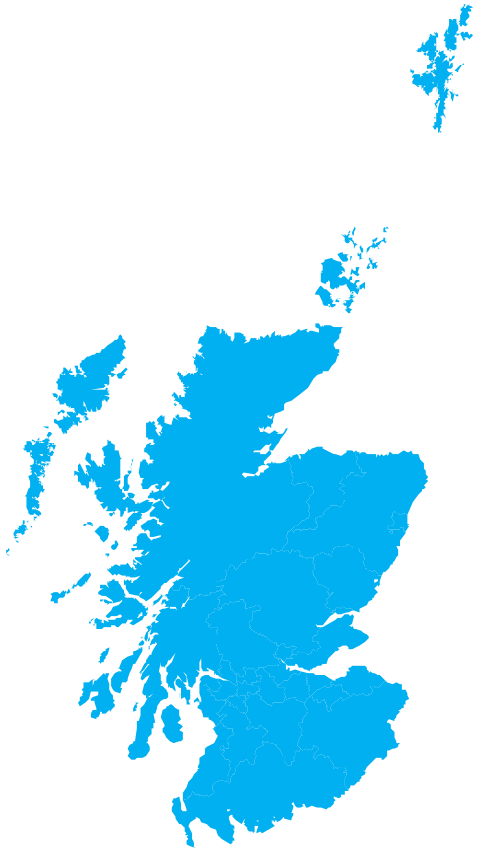
- Scope of work
- Contextual factors
- Evidence review
- Strategic Gap Analysis
- Scottish Recovery Network (SRN) and Voices of Experience Scotland (VOX)
- Learning System
- Recommendations and Phase Two

Scope of the work

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 and access to services for those with a diagnosis of personality disorder. This report was enabled by partners from the third sector, those with lived experience, mental health staff and colleagues from 14 NHS boards and 31 HSCPs.

Work by the Royal College of Psychiatrists (2018) and the Mental Welfare Commission (2018) highlighted that there is significant variation and disparity in provision and access to care and services across Scotland for those with a diagnosis of personality disorder.

The evidence suggests that there is an 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

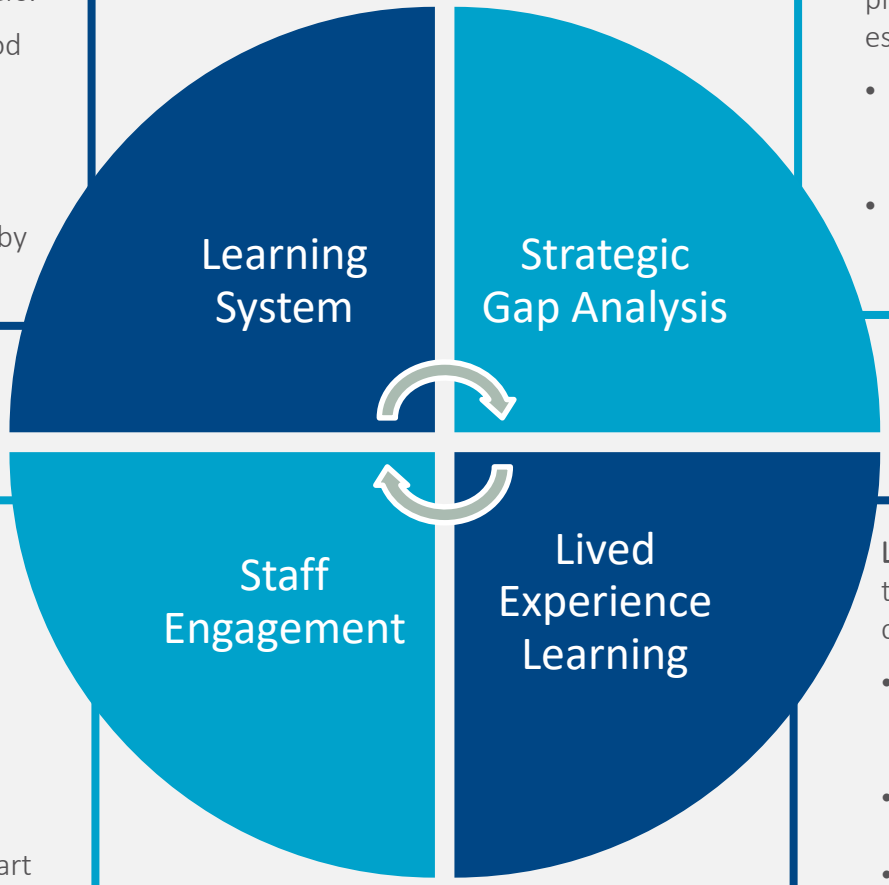
The term personality disorder has been a source of discussion and debate nationally and internationally. Some people with lived experience and some professionals prefer to use other terminology to describe this range of symptoms. Within the PDIP programme of work, we recognise that this debate can be 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.

Core Components of PDIP

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 1,800 attendees.
- Monthly newsletters shared latest updates and upcoming events, read by over 300 people each month.



Understanding the landscape of current service provision played a key role in the programme's activity. PDIP worked to establish connections across professions:

- Virtual locality visits with all 14 NHS Scotland health boards and associated health and social partnerships.
- Gap Analysis report completed by Strategic Planning colleagues.

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.

Lived experience engagement through our third sector colleagues SRN and VOX were 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.
- In addition our ERG was chaired by members of the Scottish Personality Disorder Network.

Contextual Factors in Diagnosis and Development Personality Disorder

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. It is associated with significant functional impairment and distress.

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.

For example, there is evidence that early life experiences, attachment relationships and experiences of trauma can impact trajectory. Genetic vulnerability, temperament and adult relationships can also contribute.

Diagnostic Criteria

- The International Classification of Diseases 11th revision (ICD-11) re-categorised personality disorders in 2022, with the removal of discrete personality disorder subtypes.
- It has been replaced by a single broad category of personality disorder subdivided by levels of severity (mild, moderate, severe).
- A borderline pattern qualifier has been retained due to clinical utility.

Impact on the person

- A high rate of self-harm and suicide is associated with diagnosis, with up to 80% of those with borderline personality disorder diagnosis engaging in non-suicidal self-injury.
- A higher rate of diagnosis of co-occurring mental disorders is found, with significant impairment in personal, family, social, educational and occupational functioning.

Prevalence

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

Management and recovery

- Interventions with specialised therapies and good team-based care 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.

Overview of recent literature

Presentations in crisis

Those with a diagnosis are more likely to have multiple presentations to A&E, be taken there by police or ambulance and present with a range of additional difficulties such as suicidal ideation, self-injury and/or drug intoxication. Those with a diagnosis are also more likely to be represented in police detention and homeless populations.

Effective therapies

MBT, DBT, ST and TFP are the most common and effective interventions, with improved symptoms; reductions in suicidal and non-suicidal self-injury and less attrition than other therapies. Prolonged duration and a combination of group and individual sessions appear to have the best outcomes.

Impact of effective therapies

Specialised psychotherapies, that offer skills building and autonomy, suggest some improvements in psychosocial/ social function in addition to fostering improvements in symptoms, particularly in those with a diagnosis of borderline personality disorder.

Experiences of treatment

Diagnosis should be collaborative, with information on options. Specialised therapies are appreciated as are good therapeutic relationships. Therapies of greater duration, involving individual and group sessions are preferred with careful consideration on how group sessions are managed in a safe and supportive way.

Experiences with staff

Perception that clinicians and practitioners lack knowledge, education and training specific to diagnosis. Training and education are felt to be effective tools to combat stigma and improve attitudes. Trust, empathy and overall relationship building were felt to facilitate good relationships with staff.

Staff experiences

Negative attitudes towards those with a diagnosis persist, particularly among nurses. Feelings of futility, powerlessness and being overwhelmed are also common, with staff perceiving that they do not have the necessary skills nor training to work with service users.

Staff training

Training is felt to be an effective route to reduce stigma, across professions. Particularly effective when co-produced with lived experience and when there is access to top-up training. Staff highlight desire for more training that is skills and psychoeducation based and specific to professional role.

Medication

The evidence base for the use of medications is lacking and there are high rates of prescribing and polypharmacy. Side effects are common, and evidence suggests that specialised therapy has superior outcomes. Substantially more research needed to justify prescribing rates.

Cost-effectiveness of specialist interventions

Several NHS based studies indicate that DBT and MBT are more cost-effective than other therapies and treatment as usual. Definitive conclusions are difficult to reach due to different approaches used and the wider evidence base (Europe) showing disparate outcomes in cost-effectiveness.

Strategic Gap Analysis

All 14 NHS boards provided information about their current service provision through interviews . They highlighted their approaches and challenges, describing significant variation across Scotland.

The following gaps between current provision and population need were identified from the Strategic Gap Analysis.

Leadership and management challenges

- A need for a shared and accurate understanding of personality disorders across staff, services and organisations leading to inconsistency in diagnosis and treatment.
- Greater senior buy in and leadership is required to operationalise service improvements.
- More meaningful involvement from those with lived experience in the design and delivery of services is needed.
- There is limited use of data to inform future service design and improvement driven by concerns around data completeness and availability.
- Currently limited evidence of learning within, and between, services to improve services.

Staffing challenges

- Staff turnover and recruitment challenges are currently 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.
- There is 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.

Strategic Gap Analysis

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The following gaps between current provision and population need were identified from the Strategic Gap Analysis.

Service provision limitations

- Resourcing of mental health and other health services is limiting the range, intensity, quality and timely access to the services for people with a diagnosis of personality disorder.
- Under-developed or newly developed Integrated Care Pathways leading to inconsistent treatment and reducing patients' ability to access the right support regardless of where they present.
- There is a desire to offer a wider range of evidenced based interventions and treatments which is currently limited due to funding and staff skill shortages.
- Currently working through the role for digital and virtual service delivery with the added complexity that face-to-face services can be of particular benefit to building the trust and long-term relationships required to support people with a diagnosis of personality disorder well.
- There are examples in of combining trauma and personality disorder care pathways, and of keeping them as separate pathways.

"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."

Shared by staff member as part of the PDIP Staff Engagement work.

Learning from Lived Experience

Our third sector colleagues SRN and VOX completed a comprehensive programme of engagement work with people identifying as having lived or living experience. This work has highlighted important topics for future improvement activity.

Language, stigma, discrimination and diagnosis

- Current language is felt to be stigmatising, discriminatory and in need of change.
- Diagnosis can be validating to some but difficult for others.

Role of trauma and trauma responsive services

- Services need to move from being trauma informed to being trauma responsive.
- Avoiding re-traumatising people accessing support, informed by lived experience.

Components of good service

- Truly person-centred services focus on relationships that build trust.
- Flexible and adaptable services that focus on compassion and the person's needs.

Taking a whole person, whole systems approach

- Connected services that provide social, financial, and emotional support.
- Consider the role of supporters (family, friends) in recovery

Developing peer support

- More investment in peer roles within services, such as peer practitioners.
- Support to find and join peer support groups in the community.

"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."

"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."

Shared by lived experience participants.

Staff Engagement

Survey and interview outcomes

Staff engagement took place from June to October 2022. 303 staff took part in an online survey and 19 self-selecting for one to one interviews. Staff who took part represented primary, secondary and crisis care from psychology, psychiatry, nursing, occupational therapy, physiotherapy, etc.

Survey outcome revealed that most staff were nurses (48%) from adult mental health services (86%) and felt they had the necessary knowledge (91%), skills (82%) and empathy (93%) to support those with a diagnosis. Most staff (94%) felt that those with a diagnosis could be supported to manage and improve their distress.

Whilst staff reported that working with those with a diagnosis was rewarding, significant numbers also report that there were limitations to their service (76%) and challenges to working in this area (96%).

Rewards

Staff highlighted that whilst working with those with a diagnosis of personality disorder was at times difficult and challenging, there were also considerable rewards:

- Seeing services and access to services improve
- Seeing positive outcomes for those with a diagnosis following working with services
- Building relationships and enjoying working with those with a diagnosis
- Being part of a team with one vision
- Having the ability to be flexible in service/approaches used
- Reductions in stigma in staff and services
- Seeing people move on in their recovery and needing less service involvement
- Growing skills and confidence as a practitioner

Challenges

Staff also identified significant barriers to providing high quality care for people with a diagnosis of personality disorder:

- Attitudes around diagnosis and diagnostic language, which can be pejorative and stigmatising
- Issues with how services are designed (lack of communication between services, arbitrary treatment targets and practices of disengage-discharge)
- Limited access to services and interventions nationwide
- Inequitable access to training across staff groups and lack of training places
- Service wide pressures on staff and impacts on staff wellbeing
- Managing relationships with clients and teams
- Consistency in approaches and a lack of one team vision

PDIP Learning System

The PDIP Learning System was launched **to provide opportunities for people to learn together and access the expertise of others**, to support improvements in services for people with a diagnosis of personality disorder. It promotes equality and inclusion in its activity.

We hosted a series of **10 virtual webinar and workshop events** that ran from May 2022 to March 2023. All available resources including recordings are shared on the PDIP webpage.

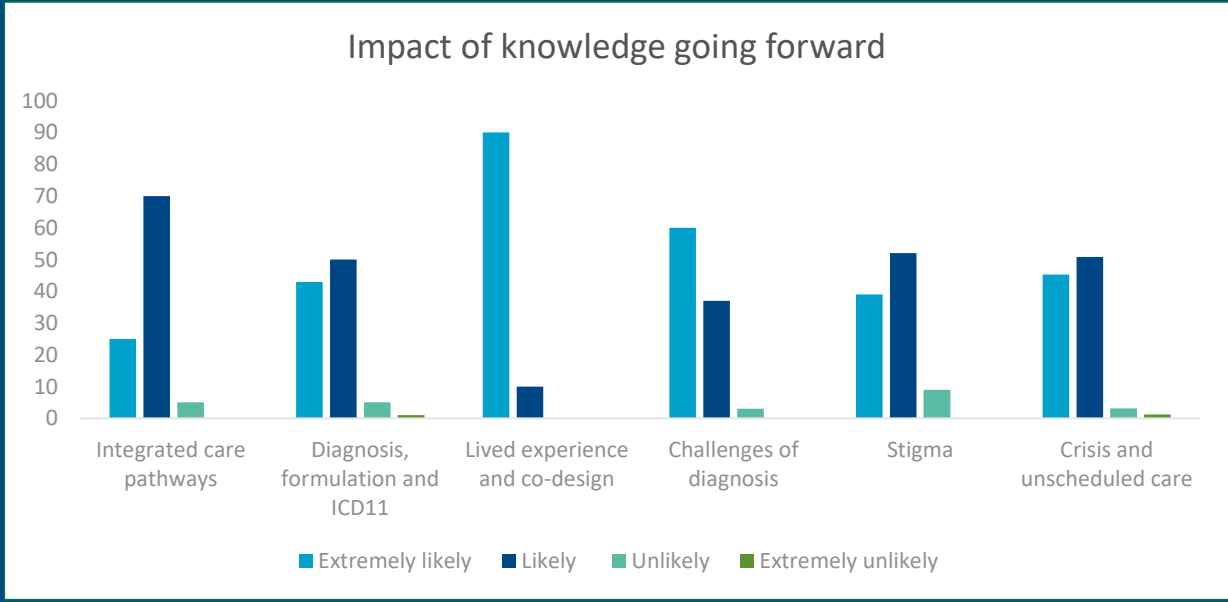
Our **monthly newsletters** kept our network up to date with the latest programme information. We showcased learning from our events, useful resources, and ways to get involved in our work. We also shared snapshots of current good practice in **two case studies**.

3,211 registered participants

54,586 Twitter impressions

1,356 YouTube recording views

4,209 newsletter views



Evaluation of the webinars and workshops has shown considerable interest and engagement, detailed in our companion report.

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 noted such as **language, staff training and education**, and the importance of **lived experience voices and input in improving services**.

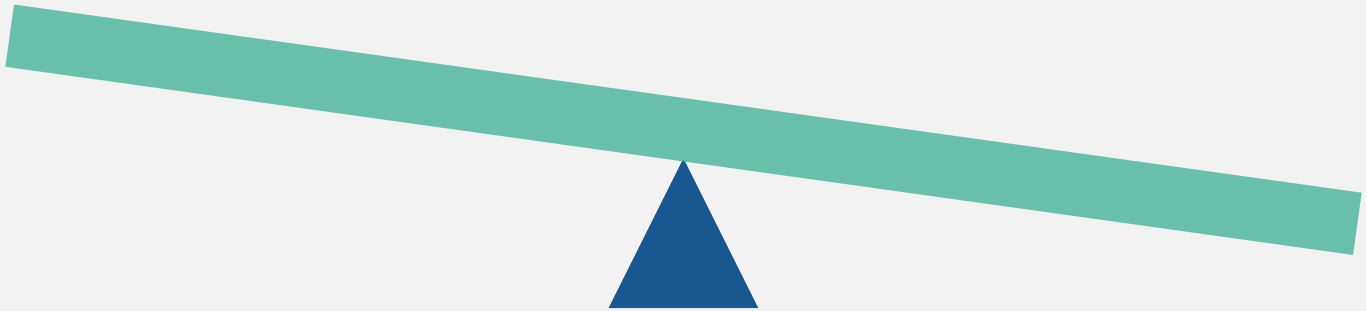
Board reflections on impact of COVID-19 on service provision

Opportunities

- Most boards reported that COVID-19 enabled the use of remote access for services, facilitating and creating access for those from more remote and/or rural locations.
- Some boards reported that STEPPs was particularly successful when delivered remotely.
- Remote working increased ‘joined up’ working and increased access to staff.
- Group sessions worked well when delivered remotely.
- Adaptation to new working procedures meant there was more positive risk taking and avoidance of hospitalisation.

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 .
- COVID-19 delayed areas of planned improvement work within services.
- Wait times for services were significantly impacted, creating a backlog that some boards are still working through.
- Increased pressure on staff due to additional needs throughout services .
- Loss of links with the third sector .
- Careful consideration in use of remote facilitation to ensure that patients do not feel negatively impacted . Also consider access to technology, private spaces, and knowledge of how to use technology .

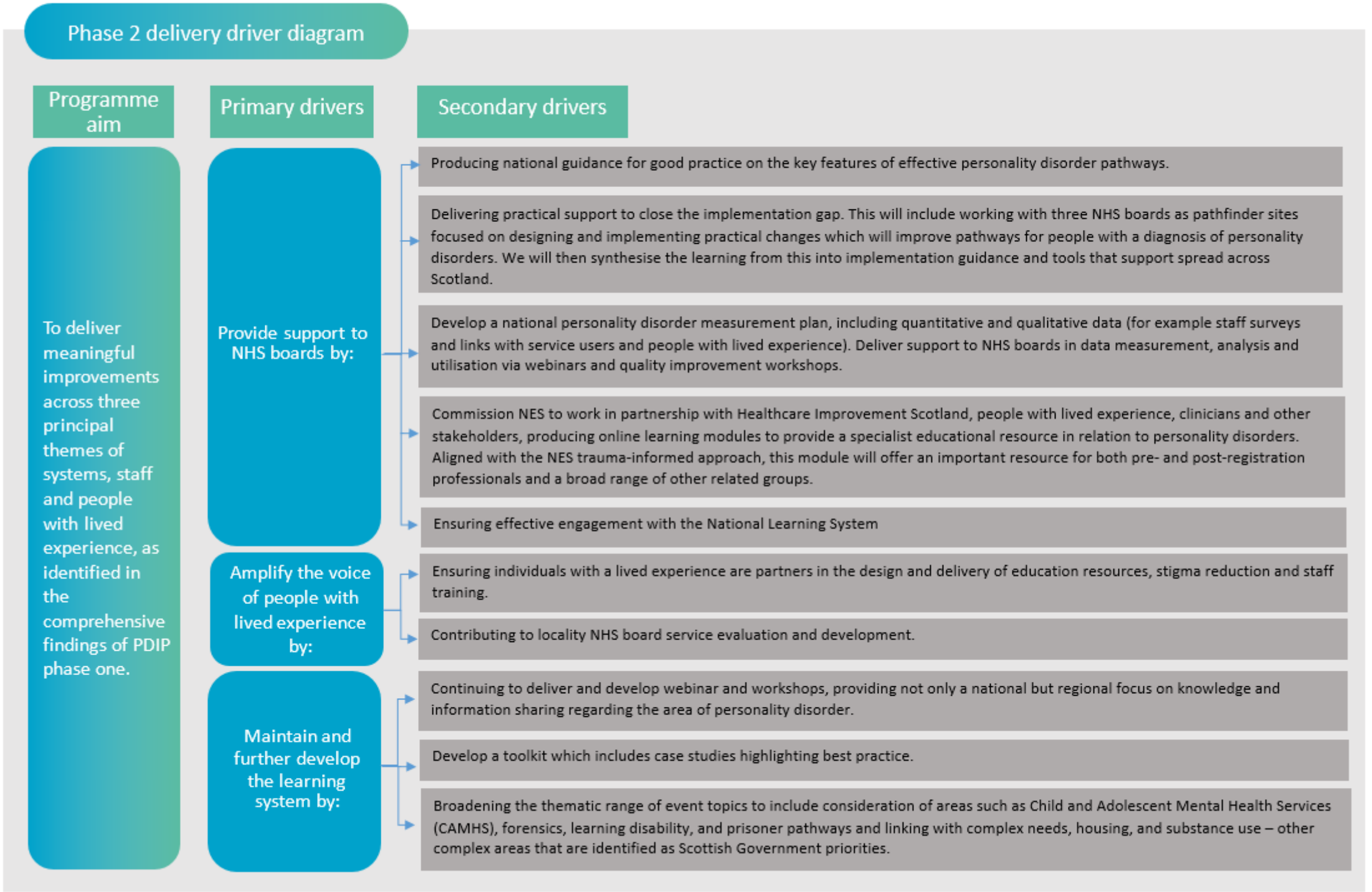


Recommendations for future work

Phase one of PDIP has drawn on the combined knowledge and experience gained through the programme's work to produce recommendations that deliver improvement activity in phase two. Across all sectors there is a clear consensus that improvements are essential and that this group of people deserve better.

A copy of the proposed driver diagram for phase 2 can be found on the next page.

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). • 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
Primary drivers
Secondary drivers
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.
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.

Next steps

Healthcare Improvement Scotland are currently engaging with our colleagues in the Scottish Government, discussing the scope and presenting the case for funding of PDIP 'Phase Two'. We are proposing a programme of work to run over **two and a half years** that will deliver the range of activity outlined in our recommendations and driver diagram. We hope to be able to begin phase two of PDIP in Autumn 2023.

Acknowledgements

Healthcare Improvement Scotland and the Personality Disorder Improvement Programme would like to acknowledge and thank those who have supported and contributed to this work.

We are especially thankful to those with lived experience who gave their time freely and shared their personal experiences and reflections through our third sector partners the Scottish Recovery Network and Voices of Experience; and in their involvement with the Expert Reference Group.

We would like to thank all the members of our Expert Reference Group and the Scottish Personality Disorder Network who have supported the programme throughout. We thank all those who also generously contributed to our learning system events.

We also extend our appreciation to all the staff who have contributed to this work and to all 14 NHS boards and associated health and social care partnerships for taking the time to meet with the team, particularly given the service constraints and pressures experienced currently.

"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..."

Shared by a range of participants at PDIP workshop events, 2022.

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Bibliography

- Scottish Government. A stronger and more resilient Scotland: the programme for government 2022 to 2023. [Internet] 2022. Performance, Delivery and Resilience Directorate. [no date]. Available from: The Programme for Government 2022-23 - A stronger and more resilient Scotland: the Programme for Government 2022 to 2023 - gov.scot (www.gov.scot)
- Scottish Government. Mental Health Strategy 2017-2027. [Internet] 2017. Population Health Directorate [no date]. Available from Mental Health Strategy 2017-2027 - gov.scot (www.gov.scot)
- Royal College of Psychiatrists. Services for people diagnosable with personality disorder. Position statement. 2020.
- Mental Welfare Commission for Scotland. Capacity, consent and compulsion for young people with borderline personality disorder: good practice guide. 2019.
- World Health Organisation (2022) *International statistical classification of diseases and related health problems (11th ed.)* https://icd.who.int/browse11/l-m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f37291724
- Brickman LJ, Ammerman BA, Look AE, Berman ME, McCloskey MS. The relationship between non-suicidal self-injury and borderline personality disorder symptoms in a college sample. Borderline personality disorder and emotion dysregulation. 2014 Dec;1(1):1-8.
- Rethinking personality disorder. Lancet. 2015 Feb 21;385(9969):664. doi: 10.1016/S0140-6736(15)60272-0. Epub 2015 Feb 20. PMID: 25706202.
- Castle DJ. The complexities of the borderline patient: how much more complex when considering physical health?. Australasian Psychiatry. 2019 Dec;27(6):552-5.

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