Personality Disorder Improvement Programme

Companion report

April 2023

www.healthcareimprovementscotland.org

Companion report guidance

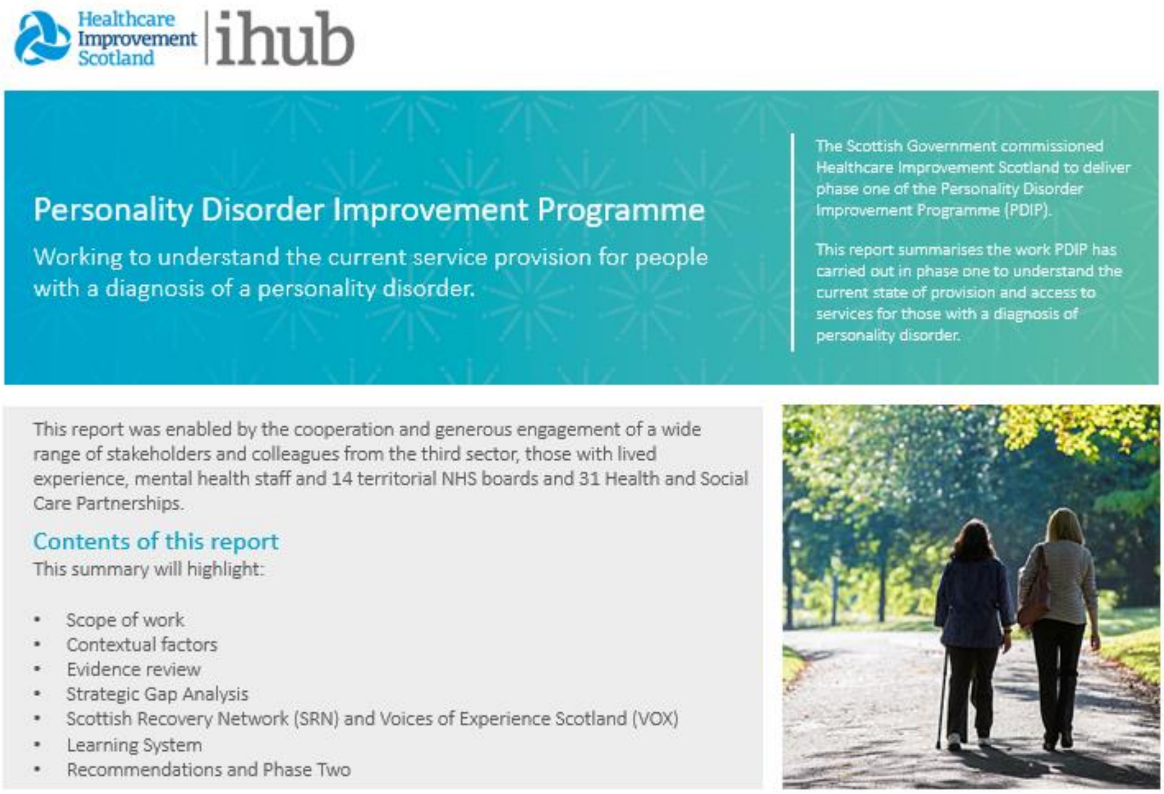
The purpose of this report is to enhance the reading of the final report by providing further context and scope to the improvement work undertaken by the Personality Disorder Improvement Programme throughout 2022 and into early 2023.

Where necessary, in the following sections each element of the final report is presented with an additional information section and a supporting documentation section. The additional information provides rationale and explores in a more detail, the contextual factors surrounding current provision of care for those with a diagnosis of personality disorder. The supporting documentation section provides links to external documentation and articles that have been used to guide and inform the programme. Links with appropriate internal documentation (contained with the appendices) are also included.

The appendices section contains each output report in its entirety.

The information contained within this report is for use by Scottish Government, Healthcare Improvement Scotland and the Personality Disorder Improvement Programme Expert Reference Group and is not intended for publication or distribution.

Report page 1: Introduction



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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

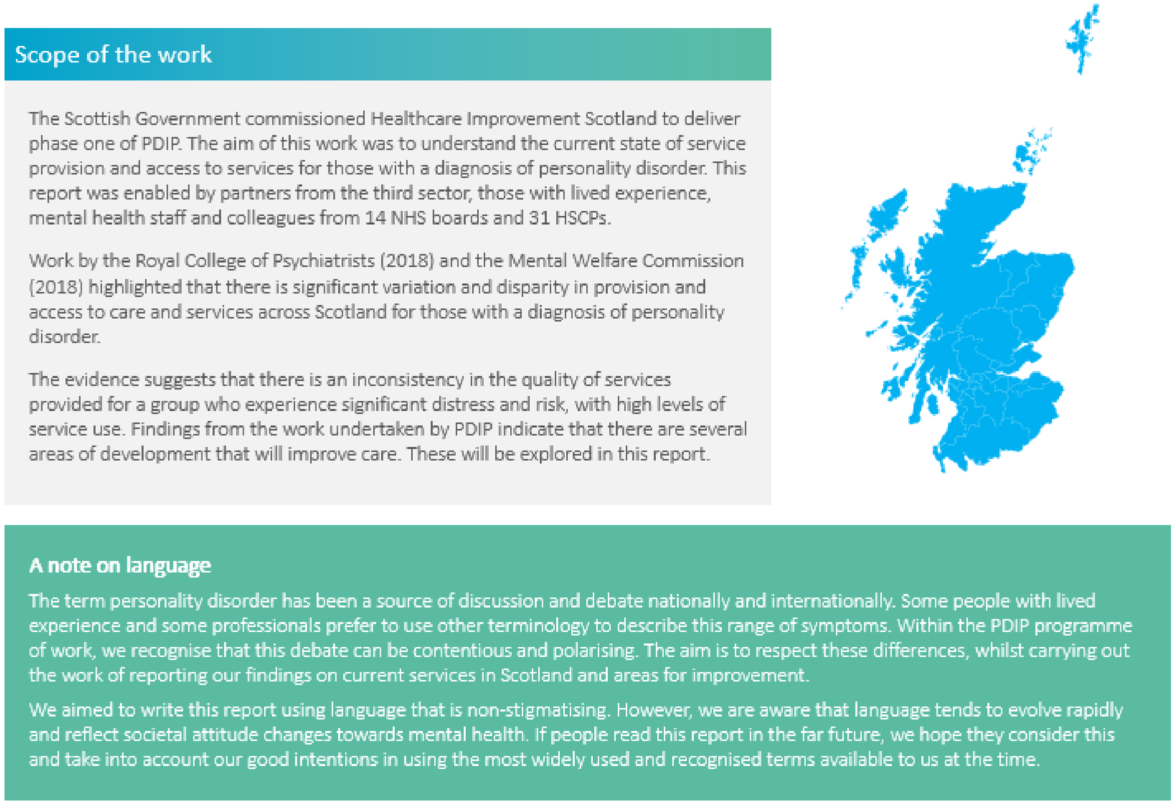
1. Introduction - additional information

This work sits within the context of improving access, services and outcomes for those with a diagnosis of personality disorder.

Links to related documents

- Mental health strategy
- Programme for Government 2022-23
- Mental health transition and recovery plan 2020
- Royal College of Psychiatrists position statement on services for people with a diagnosable personality disorder
- Mental Welfare Commission for Scotland report: Living with Borderline Personality Disorder

Report page 2: Scope of the work



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.

2. Scope of the work - additional information

2.1. Background

Publications by The Royal College of Psychiatrists[1] and The Mental Welfare Commission[2] have highlighted that there is significant variation in the provision of care for those with a diagnosis of personality disorder. This can lead to inconsistent and inequitable outcomes for those seeking help and support.

Our work within PDIP was limited to understanding provision of services across adult mental health services. In effort to achieve this, we engaged with multiple stakeholders including all 14 boards and associated HSCPs, professionals working in mental health services and the third sector. Improvement cannot occur in isolation and strategic links and joined up thinking is needed across services that offer care and support to those with a diagnosis. This will serve to limit variation in how care is experienced by the individual seeking support.

Within our work it has been clear from our discussions with services such as CAMHS (Child and Adolescent Mental Health Services), forensic services etc., that there is a view that further scrutiny and improvement across a broader range services is warranted. Other key stakeholder that could contribute to PDIP going forward include:

- CAMHS
  Personality disorder can be diagnosed in those under the age of 18, if the young person meets the diagnostic criteria[3]. However, within youth services, it is more likely that diagnosis will be delayed as the young person is still developing. In these

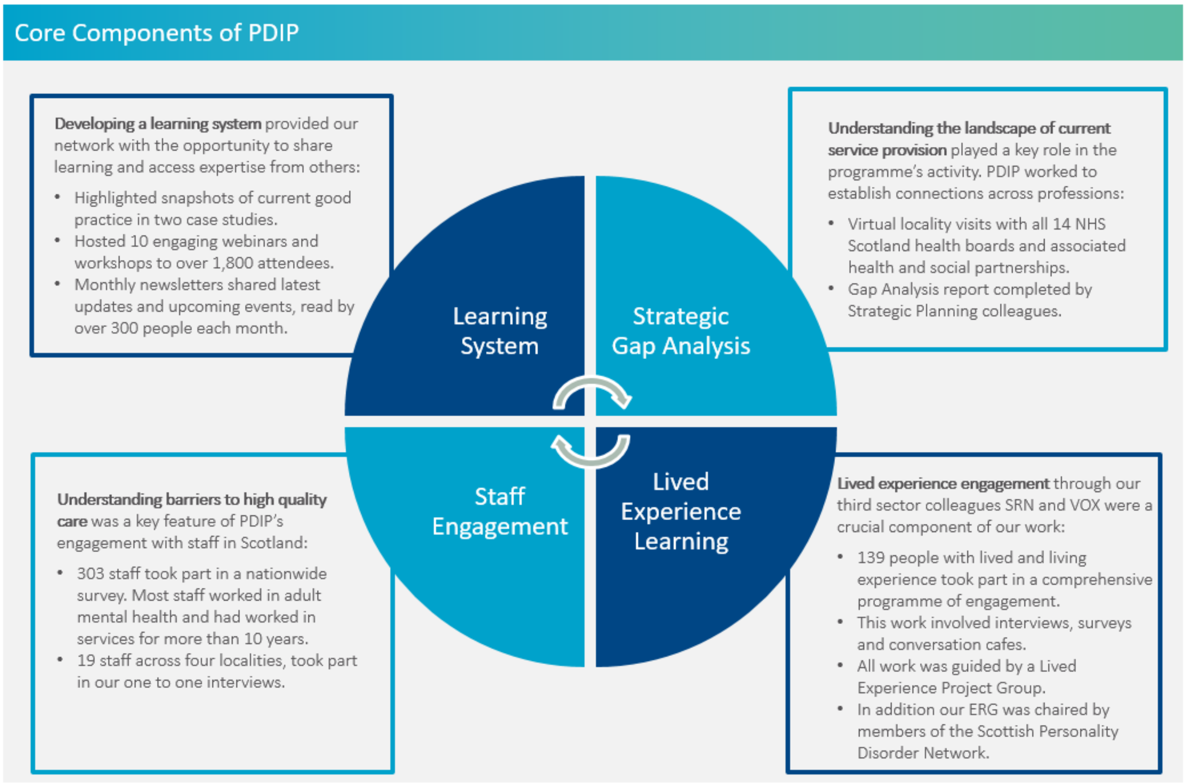
instances, it is more likely that presentations will be described as ‘emerging’[4]. It is of significant importance that presentations consistent with diagnosis seen in youth and adolescence are attended to. Evidence[5] indicates that symptoms of BPD detected at the age of 12 are associated with poorer psychological and social outcomes.

- Forensic
  There are varying estimates of personality disorder in forensic settings. A recent publication from the National Offender Management Service and NHS England suggested that in excess of 50% of this population could have a diagnosis[6]. A recent position paper from the Forensic Network[7] has highlighted that a diagnosis of personality disorder is linked with higher rates of reoffending.

Links to related documents

- Royal College of Psychiatrists. Services for people diagnosable with personality disorder. Position statement. 2020.
- Mental Welfare Commission for Scotland. Living with Borderline Personality Disorder: The experience of people with the diagnosis, families and services in Scotland. 2018.
- Larrivee MP. Bordeline personality disorder in adolescents: the He-who-must-not-be-named of psychiatry. Dialogues in neuroscience. 2022 April 1.
- CAMHS Dorset. Borderline personality disorder (BPD). [Internet]. 2022 [cited 2023, March 6]. Available from https://camhsdorset.org/about-camhs/what-can-we-help-with/borderline-personality-disorder
- Wertz J, Caspi A, Ambler A, Arseneault L, Belsky DW, Danese A, Fisher HL, Matthews T, Richmond-Rakerd LS, Moffitt TE. Borderline symptoms at age 12 signal risk for poor outcomes during the transition to adulthood: findings from a genetically sensitive longitudinal cohort study. Journal of the American Academy of Child and Adolescent Psychiatry. 2020 Oct 1:59(10):1165-77
- Craissati J, Joseph N, Skett S. Working with offenders with personality disorder: A practitioners guide. London: Ministry of Justice, National Offender Management Service. 2015.
- Russell K. [internet]. Position Paper: Psychological Approaches to Personality Disorder in Forensic Mental Health Settings. Scottish Group of Forensic Psychologists [cited 2023, March 6]. Available from https://forensicnetwork.scot.nhs.uk/wp-content/uploads/2022/03/Position-Paper-Psychological-Approaches-to-Personality-Disorder-in-Forensic-Mental-Health-Settings.pdf

Report page 3: Core components of PDIP



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.

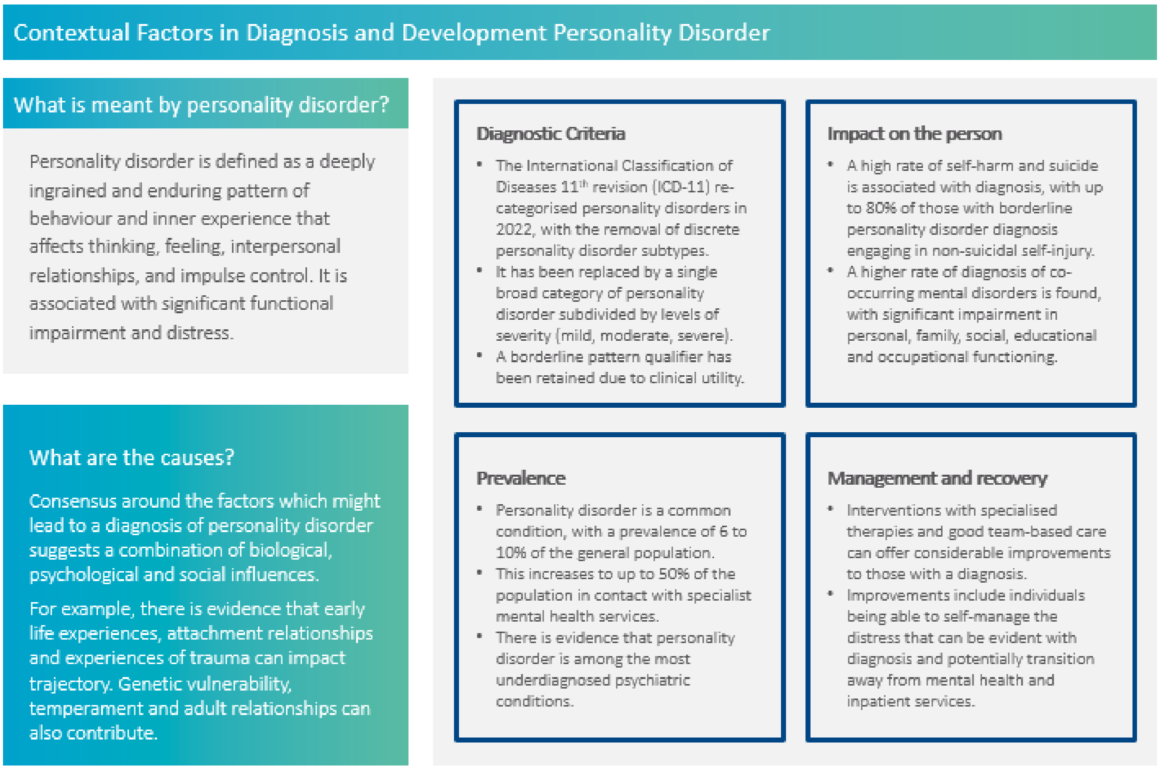
3. Core components of PDIP - additional information

No additional information

Links to related documents

No additional information

Report page 4: Contextual factors in Diagnosis and Development of Personality Disorder



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.

4. Contextual factors - additional information

2.1 Background

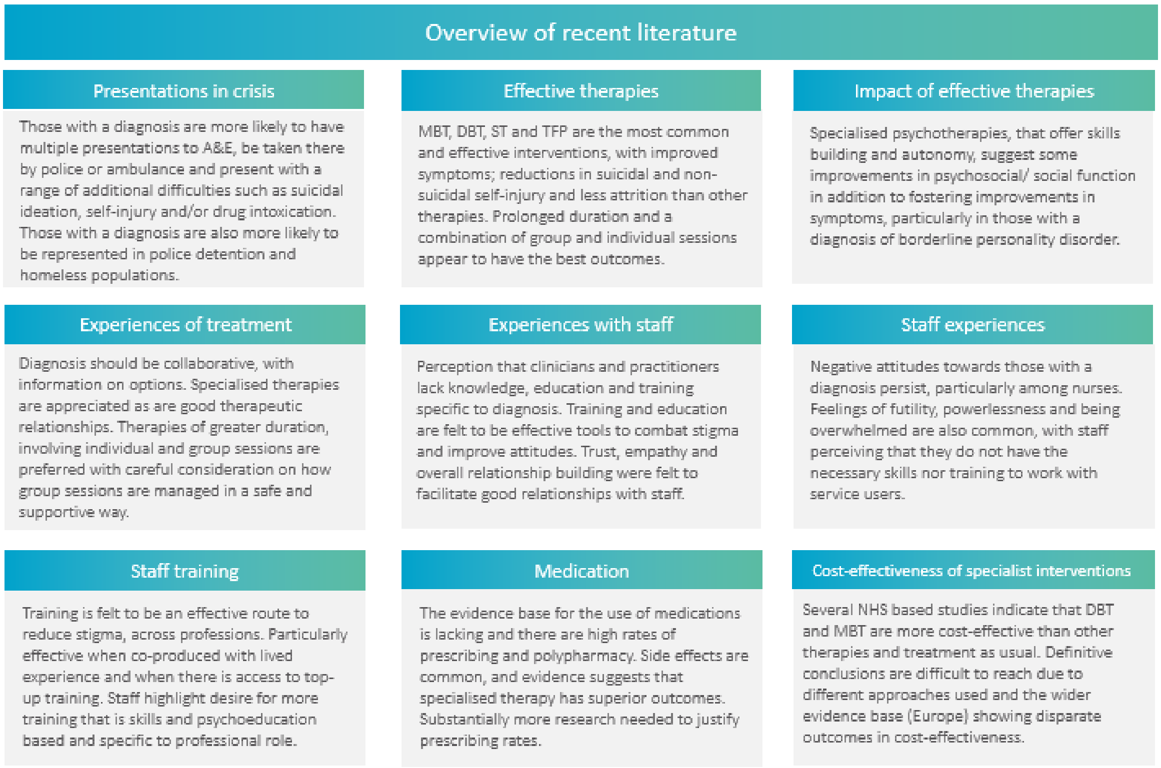
The main report and summary report details the contextual factors that are associated with the diagnosis of personality disorder. Prevalence of the condition is estimated to be up to 50% of the population in contact with mental health services.

Links to related documents

- Bozzatello P, Rocca P, Baldassarri L, Bosia M, Bellino S. The role of trauma in early onset borderline personality disorder: a biopsychosocial perspective. Frontiers in Psychiatry. 2021 Sep 23:1512
- Widom CS, Czaja SJ, Paris J. A prospective investigation of borderline personality disorder in abused and neglected children followed up into adulthood. Journal of personality disorders. 2009 Oct;23(5):433-46.
- 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
- Royal College of Psychiatrists. Services for people diagnosable with personality disorder. Position statement. 2020.

- Rethinking personality disorder. Lancet. 2015 Feb 21;385(9969):664. doi: 10.1016/S0140-6736(15)60272-0. Epub 2015 Feb 20. PMID: 25706202.
- Brickman LJ, Ammerman BA, Look AE, Berman ME, McCloskey MS. The relationship between non-suicidal self injurt and borderline personality disorder symptoms in a college sample. Borderline personality disorder and emotion dysregulation. 2014 Dec;,1(1):1-8
- Paris J. Suicidality in borderline personality disorder. Medicina. 2019 May 28;55(6):223.
- Castle DJ. The complexities of the borderline patient: how much more complex when considering health? Australasian Psychiatry. 2019 Dec;27(6):552-5.
- Ng FY, Townsend ML, Miller CE, Jewell M, Grenyer BF. The lived experience of recovery in borderline personality disorder: a qualiatative study. Borderline personality disorder and emotional dysregulation. 2019 Dec;6(1):1-9
- NICE guidelines
- ICD 11

Report page 5: Evidence and literature reviews



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.

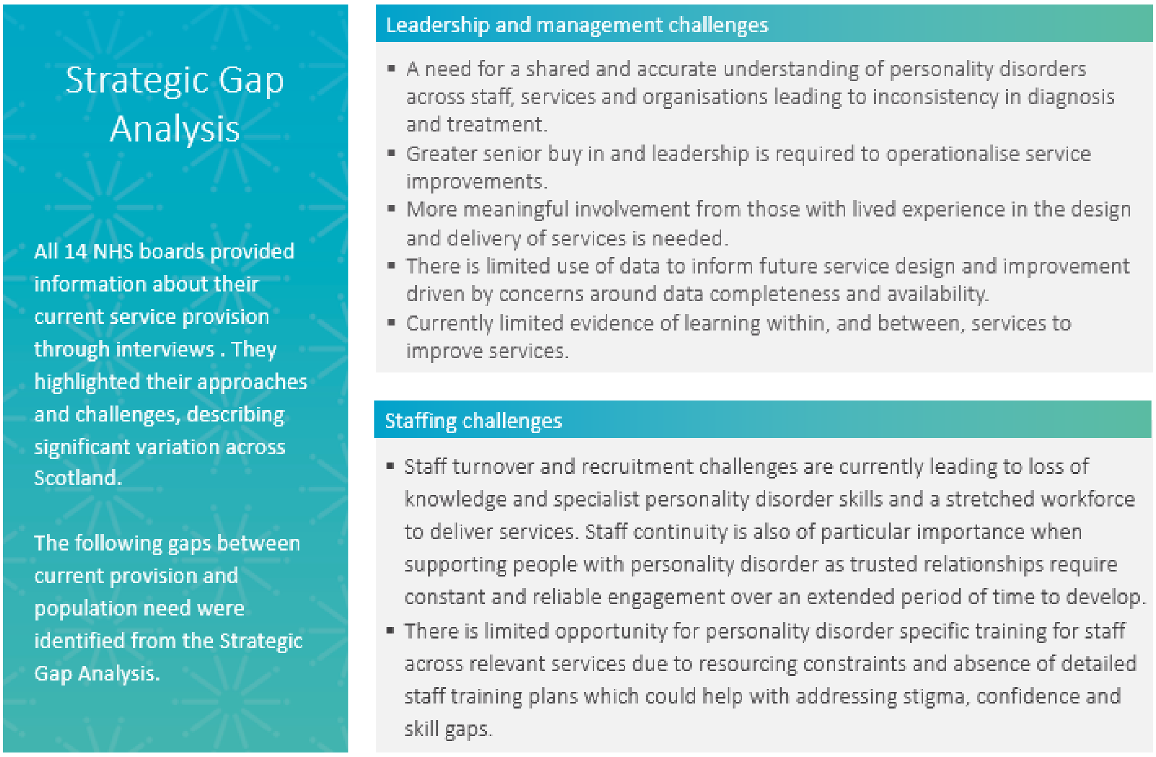
5. Overview of the current literature on contextual factors in treatment and cost effectiveness of treatment - additional information

No additional information

Links to related documents

- Appendix A – Personality disorder- A Rapid Literature and Evidence Review
- Appendix B – Personality Disorder- A Rapid Literature and Evidence Review Concerning Presentations in emergency care, police detention and homelessness
- Appendix C – Personality Disorder- A rapid literature review of cost effectiveness of specialised interventions

Report page 6: Strategic Gap Analysis



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.

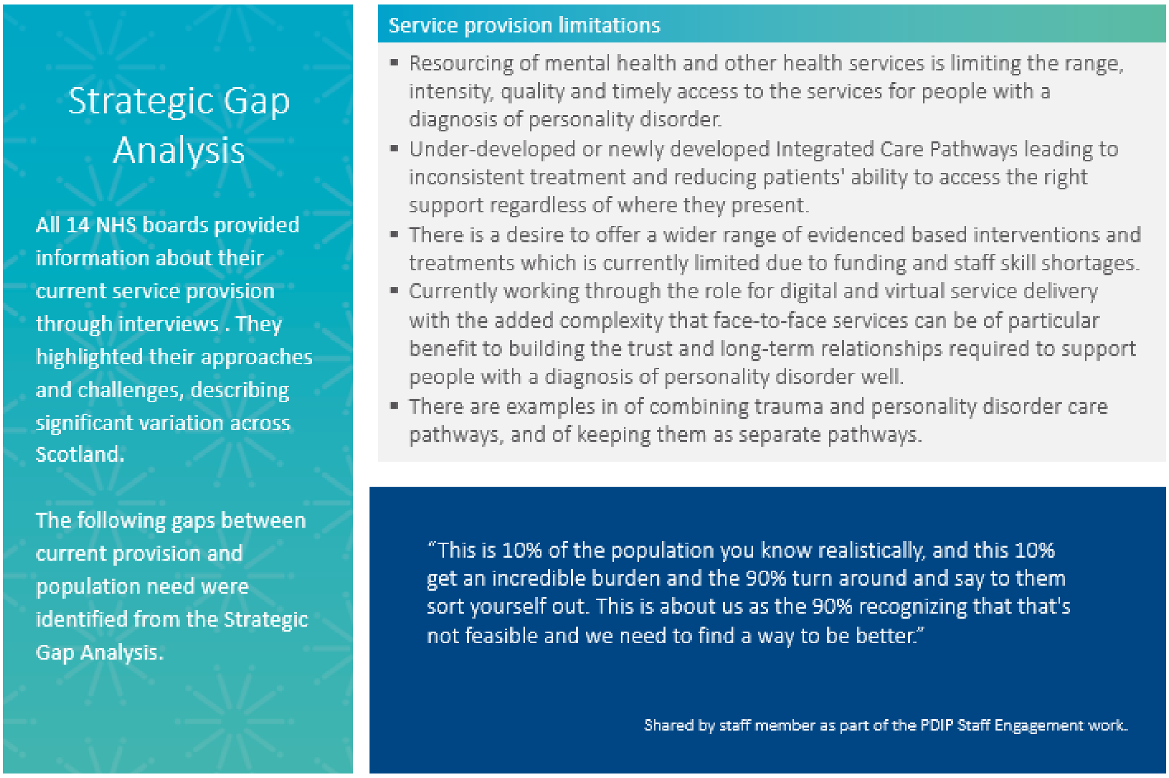
6. Strategic Gap Analysis - additional information

No additional information

Links to related documents

- Appendix D – Strategic Gap Analysis Report

Report page 7: Strategic Gap Analysis



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.

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.

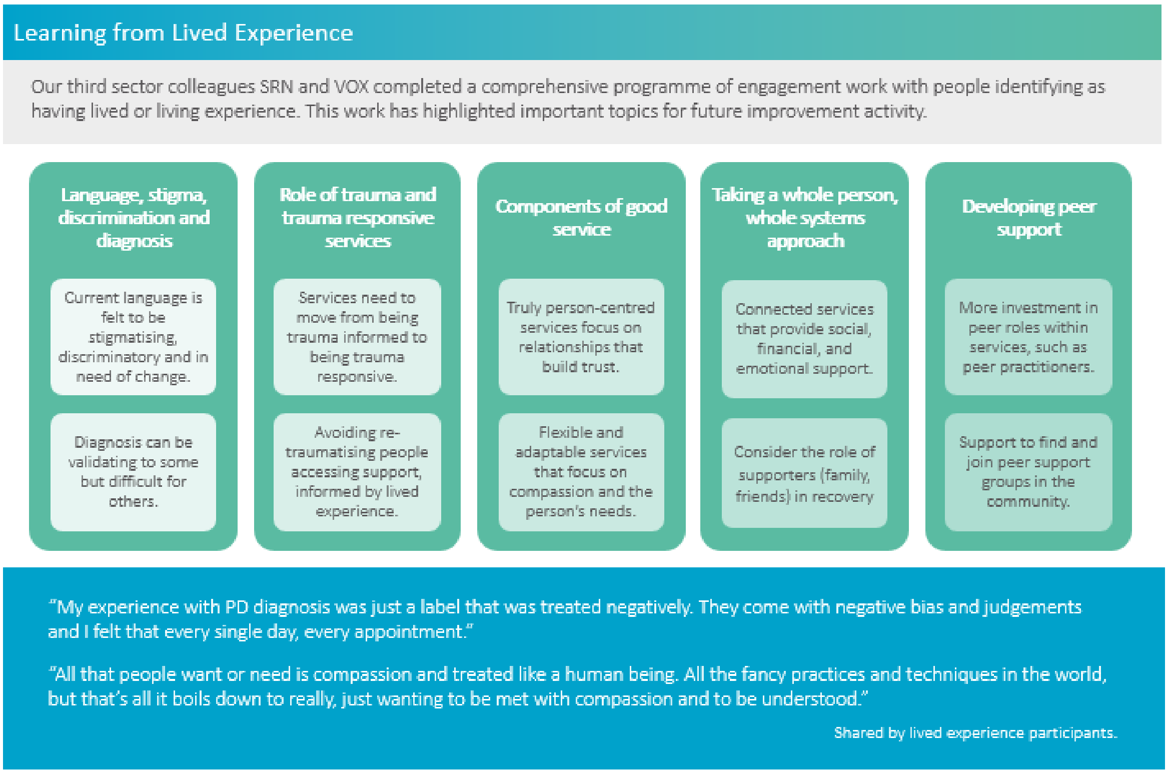
7 Strategic Gap Analysis - additional information

No additional information

Links to related documents

- Appendix D – Strategic Gap Analysis Report

Report page 8: Lived Experience Engagement



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.

8. Lived experience engagement - additional information

No additional information

Links to related documents

- Appendix D – Strategic Gap Analysis Report

Report page 9: Staff Engagement

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

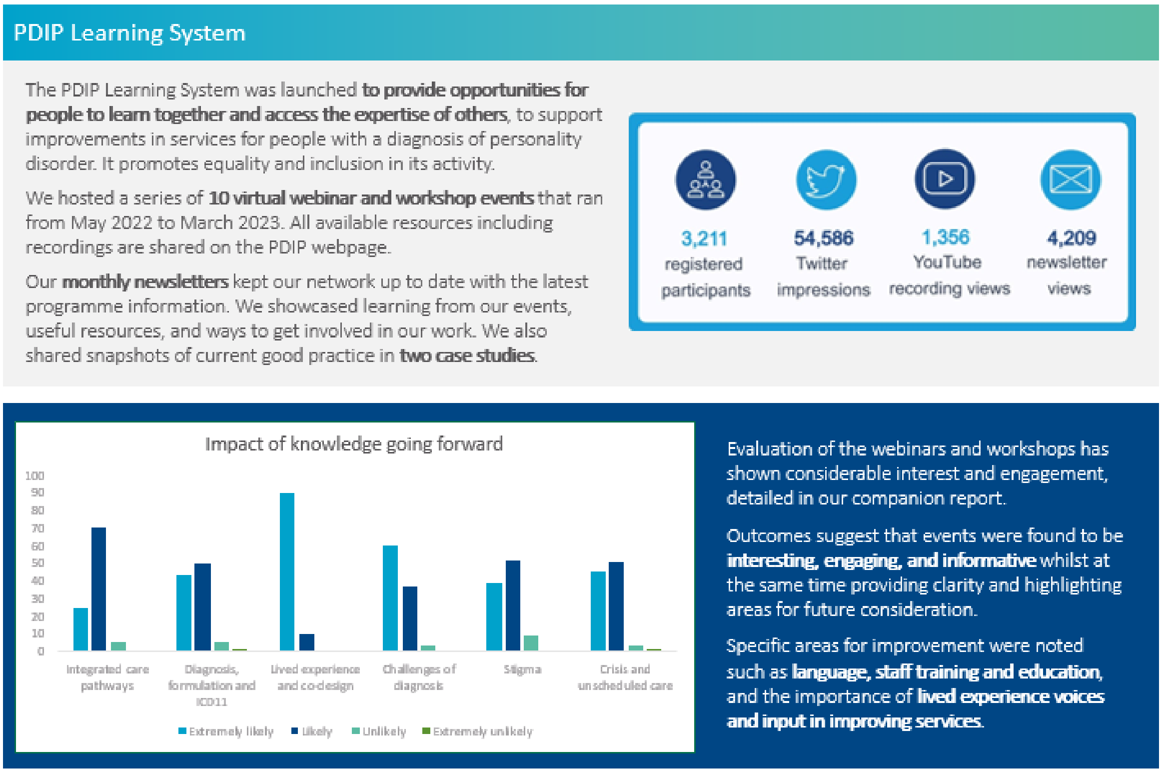
9. Staff engagement - additional information

No additional information

Links to related documents

- Appendix F – Staff engagement report

Report page 10: PDIP Learning system



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**.

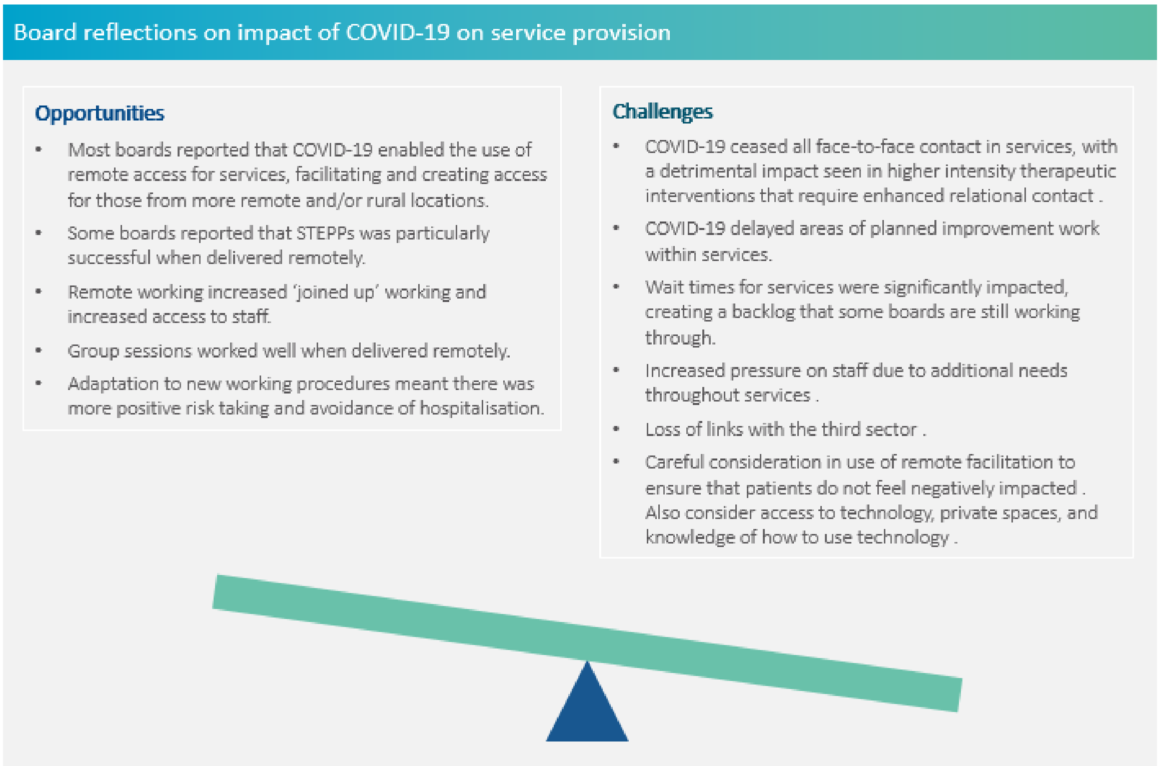
10. Learning system - additional information

No additional information

Links to related documents

- Appendix G

Report page 11: Board Reflections on COVID-19



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 .

11. Board reflections on COVID-19- additional information

10.1 Background

COVID-19 placed unprecedented challenges on health services and posed significant barriers for those being supported by services. This was highlighted in our conversations with boards. The pandemics legacy may have inflicted enduring challenges for services. The evidence for the short term impact would suggest that:

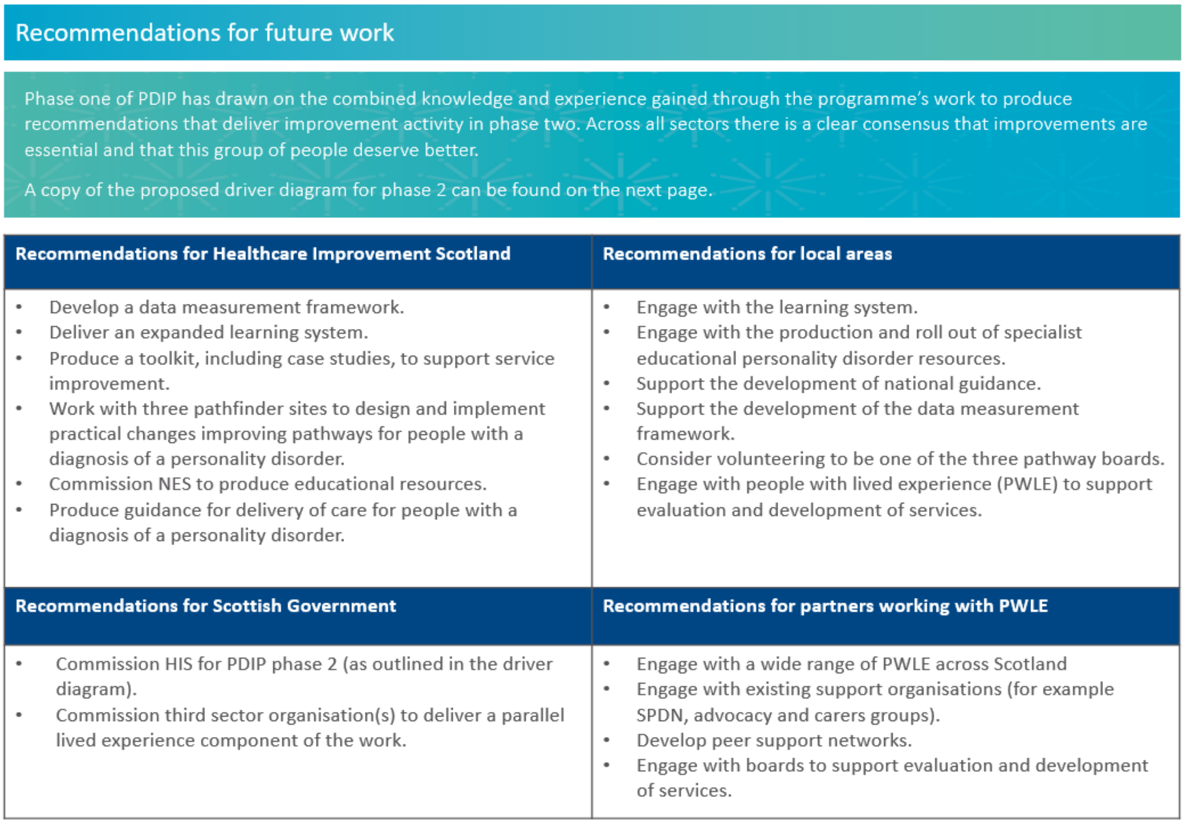
- COVID19 and associated restrictions had a negative impact on services and on mental health[1 2].
- Those with a diagnosis were particularly impacted by the pandemic and associated restrictions[3]
- A UK based study on acute care services evidenced that rates of diagnosis for EUPD fell from 16% in 2019 to 6% in 2020 and for other personality disorders, diagnosis fell from 5% to 0%[4].

Links to related documents

- Johnson S, Dalton-Locke C, Vera San Juan N, Foye U, Oram S, Papamichail A, Landau S, Rowan Olive R, Jeynes T, Shah P, Sheridan Rains L. Impact on mental health care and on mental health service users of the COVID19 pandemic: a mixed methods survey of UK mental health care staff. Social psychiatry and psychiatric epidemiology. 2021 Jan;56:25-37.

- Byrne A, Barber R, Lim CH. Impact of the COVID-19 pandemic-a mental health service perspective. Progress in Neurology and Psychiatry. 2021 Apr;25(2):27-33b
- Preti E, Di Pierro R, Fanti E, Madeddu F, Calati R. Personality disorders in time of pandemic. Current psychiatry reports. 2020 Dec;22:1-9
- Abbas MJ, Kronenberg G, McBride M, Chari D, Alam F, Mukaetova-Ladinska E, Al-Uzri M, Brugha T. The early impact of the COVID19 pandemic on acute care mental health services. Psychiatric Services. 2021 Mar 1;72(3):242-6.

Report page 12: Recommendations for future work



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.

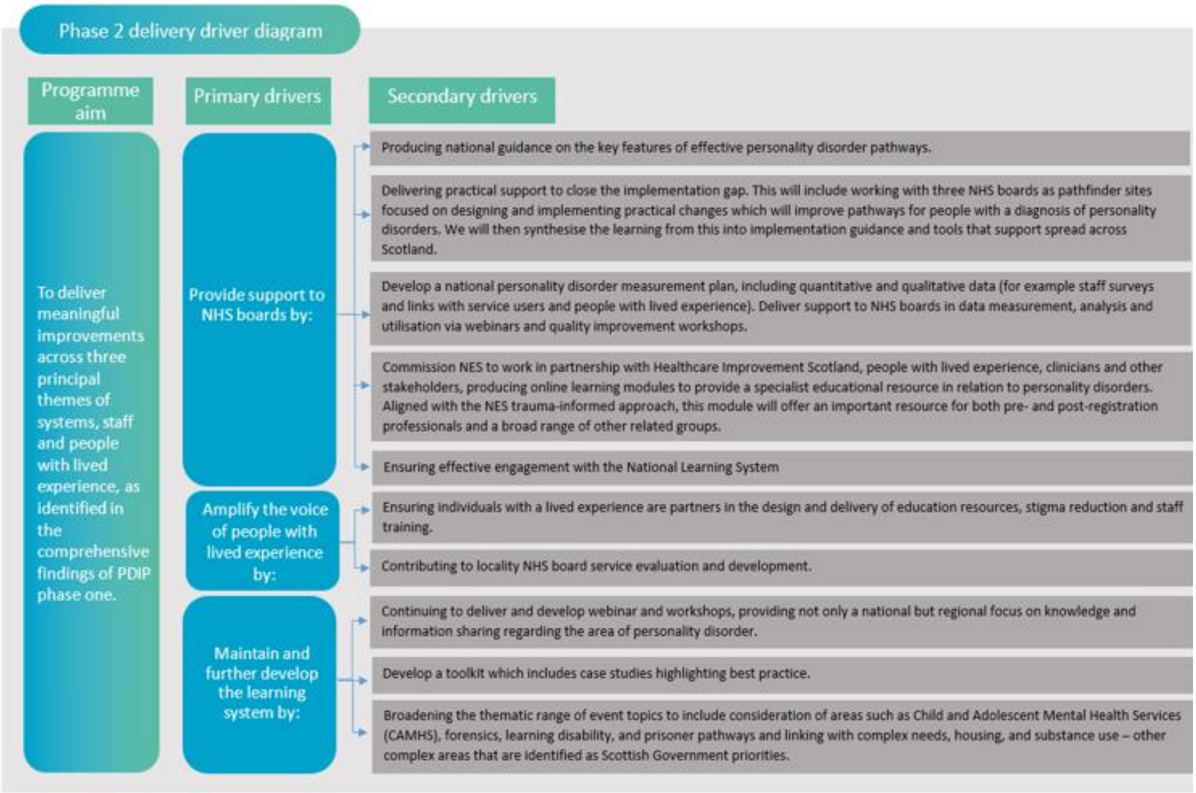
12. Recommendations for future work - additional information

No additional information

Links to related documents

No additional information

Report page 13: PDIP Phase Two Driver Diagram



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 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.

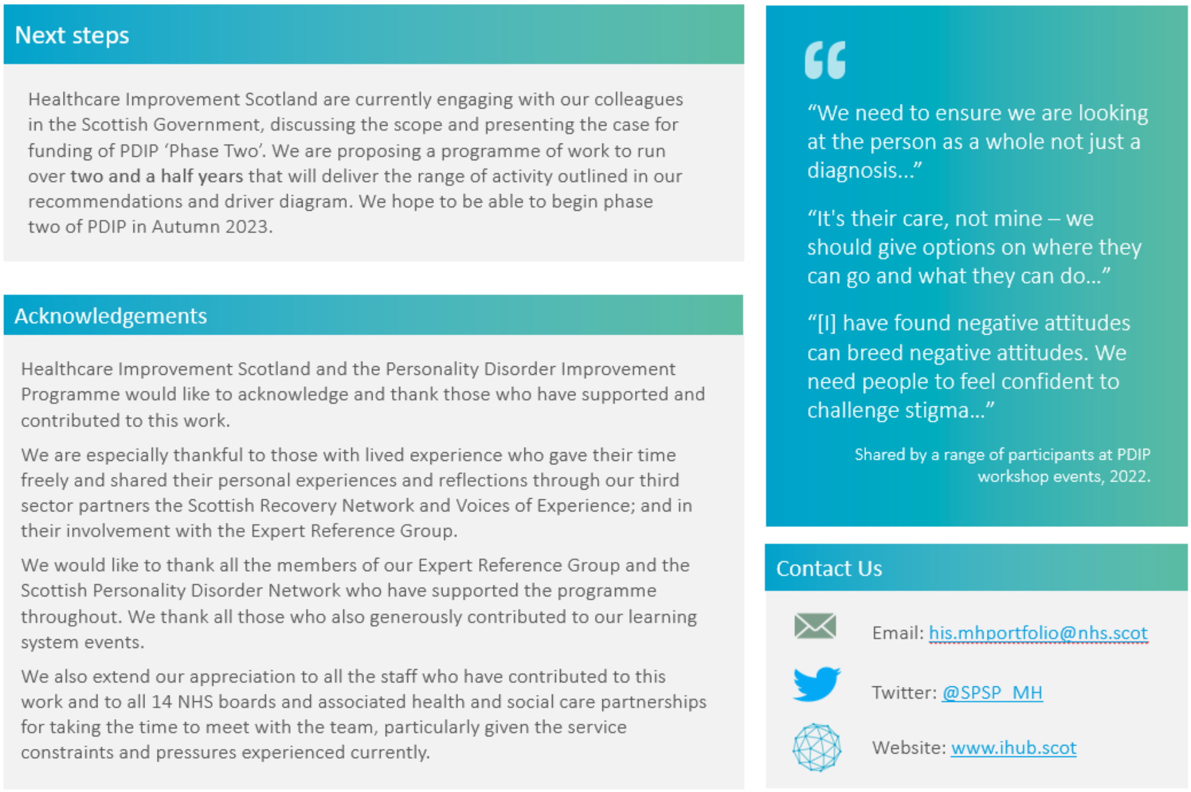
13. Recommendations for future work - additional information

No additional information

Links to related documents

No additional information

Report page 14: Next Steps



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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14. Recommendations for future work - additional information

No additional information

Links to related documents

No additional information

Appendices

Appendix A- Personality Disorder- A Rapid Literature and Evidence Review

Appendix B- Personality Disorder- A Rapid Literature and Evidence Review Concerning Presentations in emergency care, police detention and homelessness

Appendix C- Personality Disorder- A rapid literature review of cost effectiveness of specialised interventions

Appendix D- Strategic Gap Analysis

Appendix E - Scottish Recovery Network and Voices of Experience Lived Engagement Report

Appendix F -Staff Engagement Report

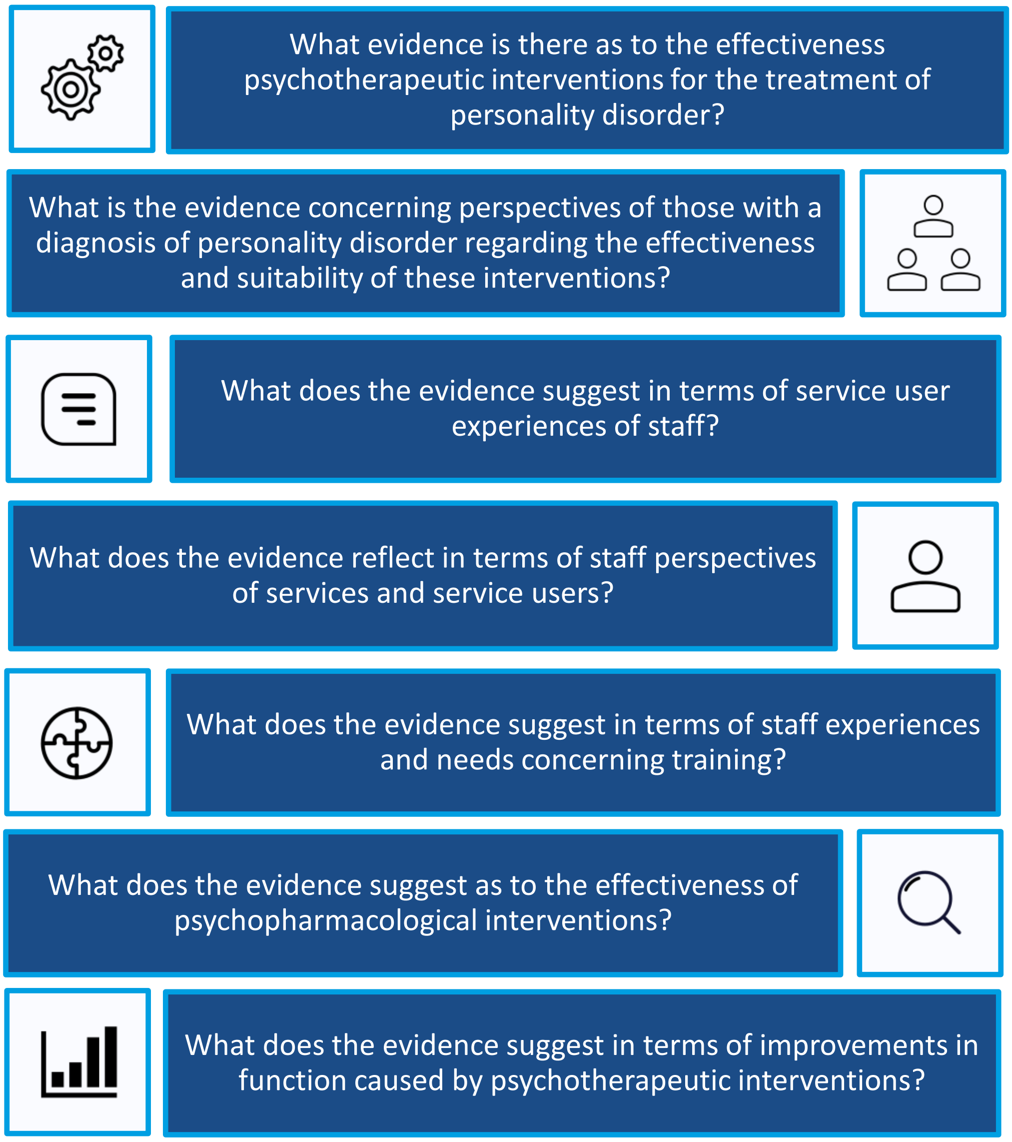
Appendix G- Evaluation of webinars and workshops from the PDIP learning system

Appendix H- References

Appendix A- Rapid Literature and Evidence Review

Summary

This is a rapid review of the recent evidence relating to the effectiveness of psychotherapeutic and psychopharmacological treatment options for those with a diagnosis of personality disorder. The review also examined service user perceptions of psychotherapeutic treatment and staff as well as improvements in function that may be attributable to psychotherapeutic treatment. Staff perspectives of training and service users was also examined. The report has several sections based around the following questions:



What evidence is there as to the effectiveness psychotherapeutic interventions 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 these interventions?

What does the evidence suggest in terms of service user experiences of staff?

What does the evidence reflect in terms of staff perspectives of services and service users?

What does the evidence suggest in terms of staff experiences and needs concerning training?

What does the evidence suggest as to the effectiveness of psychopharmacological interventions?

What does the evidence suggest in terms of improvements in function caused by psychotherapeutic interventions?

Figure 1. Research questions addressed in this report.

Main findings

Effectiveness of psychotherapeutic interventions

The majority of the reviews focused on specialised interventions for personality disorder (such as MBT or DBT). Key summarised outcomes are contained below.

Synthesis of key outcomes

- The majority of reviews assessed BPD and were delivered in outpatients settings.
- DBT, MBT, ST and TFP are among the most commonly assessed and utilised specialised psychotherapies, with DBT being the most common.
- Specialised psychotherapies for the treatment of personality disorder (mainly BPD) have evidenced considerable effectiveness in relation to improvements in symptoms and psychosocial functioning in addition to reduction in risk.
- MBT appears to be the most effective treatment in terms of reductions in suicidal and self-injurious behaviours.
- Specialised psychotherapies tend to have lower levels of attrition than other psychotherapeutic interventions.
- Therapies tend to be most effective when small groups are used in combination with individualised therapy.
- Brief specialised psychotherapies can be effective, but interventions of a prolonged duration evidence greater efficacy.
- Efficacy appears to reduce with advancing age.
- One review reported that specialised psychotherapies were associated with symptom reduction in BPD and in medication usage. Given the considerable side-effects associated with psychopharmacological interventions, this could be a considerable positive of specialised psychotherapies.
- Low to moderate quality evidence were applicable to the majority of reviews assessed and significant under-representation of males was evident.

A systematic review and meta-analysis[1] examined 27 RCTs assessing the effectiveness of short term specialised interventions for BPD. Meta-analysis outcomes revealed that symptom reduction was greatest in interventions that involved additional support (for example TAU). The majority of studies had high levels of bias, particularly in attrition and reporting bias, and high levels of heterogeneity were evident. Meta-analytic outcomes suggest that planned generic treatment outcomes may be as effective as specialised in terms of symptom reduction and social functioning. Sample participants comprised those with a diagnosis of personality disorder or with characteristics indicative of same (N=2,219) and were majority female.

An additional review[2] assessed the evidence from 14 studies concerning the efficacy and effectiveness of mentalisation-based therapy (MBT) for those with a diagnosis of personality disorder (N=1,438). A mix of study designs were included, with the majority being RCTs. Overall, it was concluded that MBT was superior to other therapeutic modalities (traditional psychodynamic treatment, structured clinical management, or other forms of psychotherapeutic treatment) and TAU regarding improvements in symptomology and personality functioning in those presenting with difficulties and comorbidities. Effects were sustained in the long term. No risk of bias or quality assessment indicators were cited within the study. No meta-analysis was conducted and of the 14 included articles, the majority had samples comprised of mainly adult females (N=11), however adolescents were also included (N=3).

A systematic review and meta-analysis[3] from the Netherlands synthesised 20 RCTs (N=1,375) assessing the effectiveness of DBT, MBT, ST or TFT. Most studies were UK based (N=10), focused on outpatients (N=18) and comprised adult females with a diagnosis of BPD. Specialised psychotherapies were generally compared with TAU, CTBE, and client centered therapy. Meta-analysis revealed that specialised therapies were associated with improvements in symptom severity and reductions in self-injury. Evidence tentatively suggests that specialised psychotherapies are more effective than TAU and CTBE. Post-hoc analysis comparing specialised therapies with TAU or CTBE showed medium effect sizes. Specialised psychotherapies had lower levels of attrition and were well tolerated. The review could not conclude which therapy works better for whom. Quality of evidence was downgraded in light of imprecise effect size estimates within studies and evidence was rated as moderate quality.

One systematic review and meta-analysis[4] was a follow up to previously published reviews (2012 and 2020) and was comprised of 31 studies (N=1870) with majority female samples. Stated aims were to evaluate standalone and adjunct psychotherapies for the treatment of BPD or emotionally unstable personality disorder (EUPD). 6 studies were UK based and 20 of the 31 trials investigated standalone treatments: DBT (N= 10), MBT (N= 4), interpersonal therapy adapted for BPD (IPT-BPD; N= 2), cognitive–behavioural therapy (CBT; N= 2) and dynamic deconstructive psychotherapy (DDP; N= 2). Twelve more studies focused on psychotherapeutic adjunct interventions intended to compliment ongoing individual psychotherapies. Interventions evidenced statistically significant moderate to large effects in reductions in symptomology, self-injury, depression and improvements psychosocial functioning (DBT, MBT and DDP). MBT was found to be most effective in terms of reductions in self-injury. For CBT, a statistically significant effect on BPD severity was found by one study.

Risk was detected in more than half of the included studies and evidence quality was rated as being very low.

An additional systematic review and meta-analysis[5] assessed effectiveness of psychological treatments for BPD using all study designs. The review identified 87 studies (N=5,881) with adults (majority female) who had a diagnosis of BPD. 35 studies were RCTs and the majority assessed DBT (N=33). DBT, MBT and ST were all associated with improvement, however MBT was associated with greater improvements in suicidality (improvements in this context meaning reductions in these behaviours). CBT was evidenced to have less efficacy than specialised interventions. TUA and CTBE were associated with smaller improvements. Overall, findings indicate that specialised treatments appear to yield the largest improvements and effect sizes. Authors highlight that interventions of a longer duration tended to be more effective. Furthermore, it should be emphasised that the average effect size for treatment effectiveness was moderate to large. Of note, effectiveness decreased as age increased, highlighting the need for tailored interventions and additional research in respects to older adults.

A meta-analysis[6] assessed the effectiveness of group psychotherapy as opposed to TAU. The review assessed 24 RCTs (N=1,595) of interventions among adults (majority female) with a diagnosis of BPD. Concurrent treatments, such as individual therapy, case management, and psychotropic medications were allowed, however, group therapy had to be the primary treatment assessed. Treatment settings included inpatient (1), outpatient (18), and day hospital (1). All studies included other support activities in addition to group treatment, such as pharmacotherapy, individual therapy, or case management. For 17 of the 24 studies, participants in the group treatment and comparison conditions received pharmacotherapy. Larger groups were associated with reduced effectiveness, however group therapy as an adjunct to individual therapy was associated with the largest effect sizes. No significant differences were found between DBT and other specialised therapies. Heterogeneity was high among all studies and the majority of the studies had low to unclear risk of bias, with greatest risk being seen in incomplete data (attrition bias).

The final systematic review[7] comprised 14 studies (N=885) with samples that were by majority female adults with either a diagnosis of BPD or characteristics indicative of BPD. Samples also included adolescents and children. 2 studies were UK based. Overall outcomes evidenced that MBT was associated with multiple measures of symptom improvement (suicidality, self-harm, anxiety, depression, etc.), with moderate to large effect sizes (e.g. with improvements imply reductions in symptoms). Reductions were also evident in the use of medication and improvements in wellbeing and social adjustment. MBT achieved better outcomes than comparison treatments (supportive group therapy, standard psychiatric care, etc.). However, one study within the review compared MBT to ST and reported similar effect sizes. Evidence was rated as being low to moderate quality, despite large effect sizes. No meta-analysis was conducted.

Service user perspectives of therapeutic interventions

7 studies were identified which examined service user perspectives on psychotherapeutic interventions for personality disorder and these included a range of designs. Key synthesised outcomes are contained below.

Synthesis of key outcomes

- Diagnosis can be problematic and traumatising if not approached in a way that provides information sharing concerning the condition and its development.
- Information should be provided on therapeutic processes and options, enabling clients to have autonomy over their care.
- Specialised therapies appear to be well tolerated and appreciated by service users, with recognised symptom reduction evident.
- Specialised therapy can assist with improving service users' self-understanding and their understanding of the condition.
- Establishment of trust between client and therapist is integral in successful outcomes.
- Empathic, non-judgmental attitudes and appropriate boundaries are important from a therapeutic stance.
- Group sessions can be problematic with difficulties arising from sharing traumatic personal experiences, specific voices dominating the group, group conflict and lack of safety felt.
- Group sessions require structure and processes that promote safety, security and enable all those who wish to be heard a space to do so.
- Individual therapy in combination to group sessions can enable deeper exploration of areas of concern, distress and problem solving for difficult group dynamics.
- Duration of group and individual therapy is often felt to be insufficient.

A qualitative[8] study from England assessed outpatients (N=8) experiences of undergoing MBT, among an entirely female sample. The study identified three superordinate themes (*being borderline, being in the group and being on a journey*). Positive and negative experiences of diagnosis, as well negative self-perceptions were described ("unfixable", "lost cause"). The importance of the therapeutic relationship between clients and practitioners were highlighted, with **trust**, **empathy** and **consistency** being most significant, although group sessions were preferred. These were also seen in respects to its positive and negative aspects with sessions being **physically and mentally draining**, **however having a voice** and **feeling safe** and **peer support** were found to considerable positives, albeit sessions had limited time for in-depth exploration. Hopes for the future were expressed although some doubt was evident in terms of participant expectations on recovery. Recommendations included supportive strategies to be adapted into group sessions to support service users as well as monitoring of service users in terms of management of difficulties and fears. More research in terms of service user experiences of therapy was also recommended.

Figure 2. Summary of findings on what has worked well for service users in therapeutic relationships between clients and practitioners, and in group sessions.

An additional English review[9] of 38 studies aimed to synthesise evidence concerning service users and family experiences of mental health care for BPD. 4 main themes were identified (*assessment and diagnosis, approach of professionals, therapeutic interventions and service provision*). Information sharing and exploration of professional roles, assessment, diagnosis and therapeutic options was felt to be lacking. Feeling unsupported, pessimistic and stigmatised following diagnosis was common, with diagnosis felt to be both helpful and unhelpful. Therapy and adult mental health services were viewed favorably and were seen to work best when the focus was on **skills building**, the person was **seen as an individual**, **listened to**, **treated with empathy** and **respect**, in combination with professionals being **knowledgeable** on personality disorder and treatments. Inpatient staff were felt to be the most stigmatising. Service users also felt that there was a lack of understanding and empathy from professionals concerning their fears and behaviours, which was attributed to lack of knowledge and skills concerning personality disorder. Group sessions were felt to be too short and factors influencing success were **supportive therapists**, **regular sessions** and **managed termination** to therapy. Medication was felt to be unnecessary by some, however other felt benefit when they were involved in decision making, given appropriate information concerning their medication and its management. Approximately half the reviews included were published within 5 years of the publication date of the review (2021), highlighting increased interest in service user experiences of therapy. Identified areas of improvement were considered to be access to services and staff empathy and compassion as well as using co-production in future studies.

Another English review[10] synthesised studies (N=7) concerned with experiences of DBT among those with BPD (N=95). Four main themes were identified (*life before DBT, the relationships that support change, developing self-efficacy and a shift in perspectives*). Lack of self-understanding and hope were evident prior to diagnosis. Feeling **valued**, **heard**, **respected** and **not judged** were key within the therapeutic relationship, although not everyone was given choice in their treatment. Imbalances in power impacted change, however **therapist knowledge** and **common experiences** within the group were facilitative of change. Nature of discussions meant that group work could be **overwhelming**. **Skills building** to manage emotions and increased confidence in emotional management were also facilitative of change. Technical nature of language used in DBT could be off-putting, however having autonomy and agency within the process of therapy also facilitated positive change. DBT enabled an understanding of problem development as well as acceptance of individual difficulties but framed within the context of increased **skills** in condition management. Shifting perspectives also brought a shift towards hope as opposed to hopelessness, although fear of relapse was evident. Recommendations considered within the review pertain to the use of accessible language in DBT and support for interpersonal relationships external to therapy.

A recent mixed methods study[11] examining perceptions of the therapeutic experience in those with a diagnosis of personality disorder undergoing MBT or DBT reported statistically significant outcomes for the effectiveness of group therapy, techniques for reducing distress and difficulties with other group members (p<.01). Qualitative outcomes were categorised as positive or negative experiences and encapsulated 10 themes (*support and insight from one to one session's, feeling understood and gaining alternative perspectives from other group members, becoming more self-aware, not reacting impulsively, questioning thoughts and assumptions, behavioural techniques for reducing distress, communicating more effectively, difficulties in the therapeutic relationship, difficulties interacting with other group members and painful introspection*). In terms of positives, being able to **trust**, be **open** and **not feeling judged** were important in success of therapeutic relationship (same for DBT and MBT). **Peer support** was also key in fostering feelings of **shared experience** (more so MBT) and increased quality of communication and relationships outside of therapy, but working with peers was difficult when there was a perceived lack of **safety** and opportunity to **share experience** and difficulties with other group members. Therapy increased **self-awareness** and **skills** in terms of emotion management during times of stress (DBT), increased questioning of maladaptive thoughts (DBT and MBT). Negative experiences were described in terms of negative feelings towards therapists (DBT and MBT), with some reports of therapists being hostile (DBT).

Participants expressed the difficulty of thinking about and discussing difficult experiences, with therapy felt to be **draining**. However, this was also associated with reductions in self-injurious behaviours. Recommended that future research could investigate whether training group members to use emotional validation strategies with each other could help patients feel more understood.

A qualitative study based on an earlier RCT of ST[12] and concerning experiences of therapy among those with personality disorder identified five main themes (*benefits gains and difficulties faced in ST, perceptions of ST as compared to previous therapies, group experience and dynamics among group, structure and format of therapy, therapeutic relationship*). ST was preferred over other types of therapy, and was thought to be more effective despite being emotionally **draining**. ST assisted in developing self-understanding, emotional connectedness and reduced self-injurious and self-harming behaviours. Group experiences could elicit discomfort and conflict with some feeling **unsafe** to **share experiences**. Overall, group session were seen positively particularly in regard to **peer support** and **shared experience**. Having mixed gender groups was beneficial, but there was reluctance and discomfort for both discussing past experiences around the opposite sex. Most felt duration was insufficient, with longer timescales needed (>18mnths+). Value in having group and individual therapy. Valued was found in psychoeducation but some found the terminology off-putting and overly technical. Access to therapist contact outside of office hours increased feelings of **safety** and **security**, with good therapeutic relationships seen as integral to outcomes, with participants using positive adjectives to describe their therapist (amazing, brilliant, and supportive). Minority felt misunderstood leading to frustration and dissatisfaction. Recommendations include that group and individual sessions are adapted into the design of ST and the duration of treatment is reconsidered in light of service user preferences. Attention payed to group process to mediate and mitigate group conflict.

A further qualitative study[13] examined service user and therapist perspectives on ST, among 15 participants diagnosed with personality disorder. As with a previous study[11] results were categorised as either positive or negative in light of service user experience. *Therapeutic relationship:* was viewed as helpful and unhelpful. When helpful, the therapeutic relationship was viewed as positive, intensive and different to other forms of psychotherapy. Therapist contact was seen as an important part of building and maintaining the therapeutic relationship and improving outcomes. When viewed as unhelpful, it was cited as the reason that service users disengaged from therapy. In terms of being helpful, ST was felt to provide a framework by which service users could understand their problems. Techniques specific to ST were also found to be helpful and facilitated different ways of thinking about and understanding problems. *Time pressures* and *lack of information* were viewed as unhelpful aspects, with not enough time being given to enact meaningful change and a lack of clear information regarding the boundaries for the client-therapist relationship. *Lack of practical application:* service users felt that there was a lack of clear targets and a lack of clarity on how imagery could contribute to the problem. *No shared focus between patient and therapist* was a further point, with some service users not feeling ready to engage with certain aspects of therapy.

The final study[14] included in the review was a qualitative study with seven majority female participants exploring service user perspectives of MBT. 4 major themes were identified (*experiencing group MBT as unpredictable and challenging*, *building trust, putting the pieces together: making sense of the overall MBT structure, seeing the world differently due to MBT: a positive shift in experience*). Challenges were felt when engaging with the group, with time needed to build feelings of **safety** and **security**; however some did not find the group to provide a **safe space** or **opportunity to share experience. Trust** was an integral feature for individual therapy and group sessions, albeit it was felt to be more readily achievable in group sessions. Being informed of therapeutic format through introductory sessions was beneficial, as was individual therapy which allowed **safety** and expression. Therapy enabled a different view of the world to form, with individual and group sessions allowing additional perspectives and the development of a positive self-view. Recommendations include considerations of how to improve the group experience, via highlighted to participants particular areas of difficulty. Having introductory sessions and full intervention sessions closer together. Enhanced contact between the MBT team and service users.

Service user perspectives on staff

Only three studies were available that examined service user perspectives on their relationships with staff.

Synthesis of key outcomes

- ➢ Service users felt that clinicians and staff lacked knowledge, education and training in working with those who have a diagnosis of personality disorder.
- ➢ Education, knowledge and training were felt by service users to reduce stigma, marginalization and improve staff attitudes towards them.
- ➢ As with discussions in previous sub-sections, trust, empathy and active listening were felt to build rapport and positive relationships between service users and staff.

A recent qualitative study[15] which aimed to identify actions of mental health nurses that contributed to recovery among service users with BPD identified three themes (*learning about BPD, building trust and being empowered*) that influenced the relationship and by extension, treatment and outcomes. Positive relationships with staff facilitated improvements in symptoms, with group psychotherapy allowing a **safe space** to talk and benefit from **shared experience**. **Trust** was integral to successful outcomes, as was being **heard** and **empathy**. Feeling **valued** as a person, **respected** and **recognised** emotionally was also of importance in conjunction with **shared decision making**. Recommendations cited further research to describe a set of aspects supporting the therapeutic relationship. The study further suggests a series of actions by community mental health nurses (such as displays of **empathy** and genuine interest in the individual) that may be helpful to supporting and treating those with BPD.

A recent systematic review and meta-synthesis[16] examined service users' (and other stakeholders') experiences of crisis care within the qualitative literature. 4 meta-themes (*acceptance and rejection when presenting to care, interpersonal process and dynamics in crisis care, managing recovery from a crisis and equipping and supporting healthcare staff to provide quality care*) were identified. Feeling **listened to**, being able to **trust** and receiving **empathy** were integral in recovery from crisis, however service users felt there were limited options for crisis care. Therapeutic relationships that were **non-judgmental**, **open**, seen the **individual**, had good **boundaries**, open communication and were welcoming ensured service user engagement with crisis care. Crisis care was felt to be inflexible and not person-centered, and many experienced poor communication, which felt service users feeling marginalised, stigmatised, defined by their diagnosis and discriminated against as opposed to other service users within crisis care. Having a crisis plan in place, with knowledge of support and resources assisted recovery as did collaborative approaches and autonomy. However, many felt that links with non-crisis support and the suddenness of discharge without explained and detailed plans and support from staff increased vulnerability to additional crisis. Service users felt clinicians and practitioners within crisis care needed education and training specific to personality disorder, which could assist in altering perceptions and negative attitudes towards this service user group.

A final integrative review[17] explored the relationship between those with a diagnosis of personality disorder and student mental health nurses, utilising 37 studies, 15 of which were UK based. 3 themes were identified (*psychosocial skills, relationships and environment)* with an overarching theme of *Impact of Time.* **Trust** was key in successful outcomes and in building a successful therapeutic relationship and facilitating successful outcomes. Being seen as a '**whole'** person and only in light of diagnosis was also vital. Service users found support through their interactions with **peers** (inpatient) rather than nursing staff, with the feeling that their needs were unmet and the environment was harmful to them. Service users felt that pressures on staffing meant that there was little time for relational support and interaction. Recommendations for further research could aid the protection of vulnerable novice practitioners and improve the experience and outcomes for service users.

Effectiveness of pharmacological interventions

No pharmacological interventions are recommended in the treatment of personality disorder, however, many of those with a diagnosed will be treated with a range of medications. Indeed, at upper bound estimates, antipsychotics are used in approximately 80% of inpatients and

60% of outpatients[18]. As a result of this, the review sought to access the evidence (N=4) in relation to the treatment of personality disorder via pharmacotherapy.

Synthesis of key outcomes

- Despite the evidence base lacking in the area of psychopharmacology for the treatment of personality disorder, there are high instance rates of prescribing and polypharmacy.
- The evidence would support that lamotrigine is neither clinically nor cost effective in the treatment of BPD.
- Side effects are common among most antipsychotics and antieleptics utilised in treatment.
- Within the selected studies only one mentioned psychopharmacology vs specialised therapy, in which the specialised therapy was superior.
- Deficiencies and methodological inconsistencies mean that it is difficult to draw firm conclusions on the efficacy of psychopharmacological interventions.
- Substantially more research is needed.

A systematic review and meta-analysis[18] assessed the effectiveness and tolerability of lamotrigine (an antiepileptic medication with mood stabilising effects, used in the treatment of epilepsy and bi-polar disorder) in those with a diagnosis of BPD. The review assessed 5 studies (N=378), including 3 RCTs. Meta-analysis results revealed that despite lamotrigine being generally well tolerated, it was not superior to placebo. Only one RCT and one retrospective study showed lamotrigine may have an effect on aggression in BPD. The review did report that there were low levels of adherence to medication protocols within the studies and that the evidence base for the use of this drug is inconsistent. Recommendations cited examination of lamotrigine efficacy on specific symptom reduction in BPD.

A further systematic review[19] assessed the effectiveness of antipsychotics in the treatments of schizotypy or schizotypal personality disorder across 16 studies (N=857). Some improvements in social functioning were reported, with mild to moderate improvements noted across most studies in condition specific symptomology. Among the antipsychotics used, haloperidol was the most common either in isolation or combination and was generally superior to placebo. 2 studies showed no differences between antipsychotics and placebo. Study evidence was graded using criteria from the Centre for Evidence Based Medicine, with ratings from A (being placebo-controlled double-blind trials with a diagnostically well-defined sample) to level D (case studies and case series) and E (studies with low evidence and considerable methodological problems). Only four studies were considered to have a level A rating but only one had a level E. Insufficiencies in the evidence base, and the varying quality and methodologies utilised meant that conclusions could not be accurately drawn.

A systematic review[20] assessed 66 studies in relation to effectiveness of psychotropic interventions (antipsychotics, antidepressants, antieleptics and others) in those with a BPD diagnosis (N=4,769), reported that **antipsychotics** were effective in treating some BPD symptoms. Some medications resulted in considerable side effects and general intolerability (clozapine and paliperidone). In terms of **antidepressants** several SSRIs and SNRIs (duloxetine, fluoxetine, flupentixol, fluvoxamine and venlafaxine) have been shown to be effective in ameliorating affective symptoms and have shown efficacy in treating other BPD specific symptoms such as impulsivity and aggression. **Antieleptics** have been evidenced to result in reductions in symptomology, however with lamotrigine the research evidence is inconsistent and inconclusive. Other medications (topiramate, gabapentin and carbamazepine), appear to be effective in some symptoms, with **other drugs** (memantine, naloxone/naltrexone, clonidine and oxytocin) also showing some effectiveness in specific symptoms, but with scant evidence for their usage is and some being proven to be dangerous (baclofen). Omega 3 fatty acids and specific traditional medicines (Yi Gan San) have been shown to boost the effectiveness of other medications when used in combination. However, conclusions drawn regarding different classes of medications should be tentative as the review argues that more longitudinal research is warranted as most effectiveness assessments have been related to short term usage.

The final review[21] concerned published, unpublished and ongoing studies and was an update to an earlier review that fell outside of the stipulated date range. The review encapsulated 7 studies (N=548) concerning pharmacotherapy for adults with BPD. **Antidepressants**: outcomes from two recent trials for fluoxetine evidenced no difference from placebo and when compared to DBT, evidenced higher risk of suicidality. No new evidence was available as to the effectiveness of antidepressants, despite increased prescribing among those with BPD. Whilst comorbid depression is common in BPD, rates of prescribing in those with and without comorbidity is not substantively different. **Antipsychotics**: outcomes from three new studies and two unpublished placebo controlled trails evidenced no significant differences in effectiveness, with one study reporting that quetiapine showed effectiveness, but with considerable side-effects. Authors conclude that substantially greater research is needed. The authors also highlight the high prescription rates for quetiapine despite the lack of justifiable evidentiary support, and the lack of robust evidence to support the use of second generation antipsychotics in the treatment of BPD. In relation to **mood stabilisers** two studies compared the effectiveness of lamotrigine to placebo and reported no significant differences. **Other drugs** (memantine used in the treatment of dementia and mifepristone used as a progesterone receptor modulator) have been considered as potential treatments but lack efficacy against placebo in RCTs. N-Acetylcysteine (an anti-oxidant) has been assessed in conjunction with DBT, however despite some effectiveness the study was abandoned in light of considerable attrition and compliance issues. Authors overall conclusions state that the evidence base for psychopharmacological interventions in BPD is lacking despite the widespread use.

Evidence for improvements in functioning

Only three studies were available concerning individual functioning following interventions for personality disorder, one of which was a review and meta-analysis[22], one was a qualitative study[23] on brief admission and the other[1] was mentioned in a previous subsection relating to effectiveness of interventions. There is a paucity of evidence within the last 5 years concerning how interventions can improve function for service users, however tentative evidence would suggest that specialised psychotherapies and greater autonomy over care can improve daily functioning.

Synthesis of key outcomes

- Psychotherapeutic interventions, in addition to brief admission in facilities where these interventions can also be applied, appear to be effective in improving psychosocial functioning among those with a diagnosis of BPD.
- Specialised psychotherapies appear to be effective in improving psychosocial outcomes in those with BPD primarily.
- Skills based interventions and those that offer some level of autonomy and control may also be effective, however given available evidence conclusions drawn are tentative.

A systematic review and meta-analysis[22] assessed 10 RCTs examining the impact of specifically designed psychotherapies (DBT, MBT, CBT and TFP) on psychosocial functioning. Participant (N=880) within included studies were comprised of adults with a diagnosis of BPD. The review and meta-analysis reported improvements for individuals within each respective intervention group opposed to controls or TAU, with functioning being assessed via standardised measures such as the Global Assessment of Functioning Scale (GAF), the Social Adjustment Scale Self-Report (SAS-SR) and the Inventory of Interpersonal Problems (IIP). The majority of studies included within the review reported moderate to unclear risk of bias.
A qualitative study[23] explored the impact of brief admission on daily functioning among those with a diagnosis of BPD and self-harming behaviour. Overall outcomes indicated that brief admission enabled a sense of **security** within daily life and allowed for collaboration and self-determination over individual care plans in times of crisis. Brief admission also assisted service users in maintaining structure to their daily lives during periods of admission, facilitating speedier return to routine activities following admission resulting from less time away from family/friends and from employment.

A systematic review and meta-analysis[1] discussed previously highlighted that planned generic treatment may be as effective as specialised in terms of outcomes in social functioning. Within the review it was reported that both group and individual sessions were effective, with group sessions having larger effect sizes both following the intervention and at follow-up. Again, as stated previous there was significant risk of bias and heterogeneity within these studies, weakening the strength of this evidence.

Staff perspectives of training

Staff training is has been mentioned significantly in terms of service users opinions, particularly on how this can be a vehicle to improve attitudes and reduce stigma. Within this context the literature was examined to assess the effectiveness of training in terms of improved attitudes but also in terms of what staff perspectives were on training more broadly.

Synthesis of key outcomes

- Training is effective in reducing negative staff attitudes towards those with a diagnosis of personality disorder.
- Training that is co-produced appears to be the most effective in reducing negative staff attitudes.
- Staff have a desire for training that increases skills in addition to knowledge.
- Training increases skills, confidence, empathy and understanding.
- Staff highlight the desire for more time for training and more training opportunities.
- Training appears to be effective across diverse range of mental health professions.
- Training appears to be effective in the medium term but more assessment needed in term of long term effects.
- Staff highlight that training needs to be specific to the working environment.
- Training should incorporate clinical skills (such as DBT) as well as psychoeducation.
- Despite training having a positive impact on staff attitudes, not all negative attitudes are ameliorated, highlighting the need for regular training and supervision.
- Training should be ongoing to ensure that reductions in negative attitudes are sustained in the longer term.

A recent English systematic review[24], assessing the effectiveness of training in terms of improving staff attitudes towards those with a diagnosis, examined 19 studies (N=2,582). Training was delivered either face to face, remote or blended, with sessions ranging from 60 minutes to 6 days. All studies reported **improvements** in attitudes towards service users following training, with small to moderate effect sizes. Studies that utilised a period of follow up also report that improvements tended to be maintained in the medium term, albeit only five studies used follow up. Training that was underpinned by a psychological model (such as the biopsychosocial) and actively incorporated **lived experience** into the design had the greatest effects. Inclusion of **clinical skills** (such as DBT) was also associated with effectiveness. Gender and profession of practitioners had no impact, however those with less experience tended to respond more positively to training. Authors noted that the majority of studies within the review were of low quality. Recommendations included additional research via use of RCTs with longitudinal designs, to assess training that is co-produced using lived experience.

An additional qualitative study[25] assessed effectiveness of MBT training among English trainee psychiatrists (N=49). Training consisted of 2 3 hour lectures on theoretical and developmental aspects of personality disorder, in conjunction with **practical MBT skills** role plays. Significant improvements in attitudes were noted with modest effect sizes. Paper recommended that MDT (in addition to DBT, ST, etc.) can be incorporated into routine training for staff, as they are effective in improving attitudes and do not place additional strain on resources.

An integrative review[26] from Australia, aimed to identify, synthesise and summarise the current evidence base concerning effectiveness and impact of BPD related educational interventions on staff attitudes. Overall findings highlight the **positive** impact that educational training can have upon attitudes, with effects being maintained within the medium term. Quantitative outcomes evidenced that educational interventions engendered **confidence** in being able to make a positive difference with clients, clients being more open and non-avoidance in attending to the care needs of this group. **Lived experience** was found to make a significant contribution, particularly in terms of stigma reduction. One study highlighted that there was no change in attitude post training but there were changes in outcomes (clinical practice/patient outcomes), with the author contending that it may be that training and practitioner experience with the client group is necessary to enact attitude change. 4 themes were also identified from the synthesis of qualitative outcomes: *Brief pragmatic education interventions:* training that followed this principle was found to be the most effective in stigma reduction and relationship improvement, with reflections that training needed to suit the practitioner and their environment. *Generalised vs specialised models of care:* many practitioners felt that the **skills** needed were external to their role or to their capabilities. Reluctance in terms of delivering training was evident but the review findings are supportive of the impact that brief interventions can impart. *Building a compassionate workforce:* review supported the need for ongoing training for staff, as training has been shown to increase **compassion** and reduce negative perceptions. *Adapting a system level approach to addressing BPD stigma in health care:* enhanced investment in systems level approaches to improve response and service provision to those with a diagnosis. Recommendations include that multi-level, multi-strategy system-wide approaches are needed to upskill health practitioners in the effective treatment of BPD, and embed these interventions into health service provision. High quality studies are needed to confirm this. Also noteworthy that training did not impact upon this service user group being seen as ‘time consuming’.

Figure 3. Overarching themes on the benefits of staff training.

A qualitative study[27] to explore student nurses (N=16) experience of training focused on personality disorder and its influence on attitudes. 3 over-arching themes were identified: *therapeutic priorities:* **trust** was as a key component, in addition to recognition of strengths, goals and practical support with the additional recognition of client past **experience**. **Consistency**, stability and team working were also highlighted as key factors. *Knowledge and Understanding Framework (KUF) as an alternative view:* training increased **confidence**, willingness to challenge negative views and increased **empathy**. Barriers to these factors were identified as interpersonal challenges and professional power, which junior nurses felt they lacked. Training allowed staff to refocus from **skills** required to manage difficult behaviours to the **skills** needed to understand this service users. Training enabled staff to **self-reflect** and modify behaviour. Recommendations for longitudinal approaches to evaluate training and its impact as well as wider roll out of training that emphasises psychological perspectives. It is also important to note that the sample used within this study was small, however negative attitudes still persisted to some degree after training.

A US based quantitative study[28] assessed the effect of alliance focused training among therapists treating those with a diagnosis of personality disorder. Training assisted increasing therapist's affirmations and expressiveness towards their clients and reduced inclinations towards control and blame. However, this did not relate to session impact or treatment outcomes.

A Scottish based mixed methods study[29] with mental health nurses (N=28) from NHS Grampian evaluated an education intervention in its effectiveness at changing nurses attitudes to people diagnosed with BPD. Training for the educational intervention was co-produced with an individual with **lived experience**. Nurses attitudes were measures pre, post and at 4 month follow up and with focus groups to explore nurse's experiences of the intervention. Intervention involved two components (*Positive about Borderline* and *'wot are you like'* led by someone with **lived experience**). Quantitative outcomes revealed positive changes in cognitive and emotional attitudes, with large effect sizes noted. Attitude change sustained at 4 month follow up, however negative attitudes did pervade despite training. 3 themes were also identified. *Evaluating content new learning vs old group:* Some participants found benefit to the training but others found it to be patronising and repetitive. Aspects delivered by the individual with **lived experience** attracted the most positive feedback, with participants feeling that this was informative, interesting, offered hope and suggestions for practice. *Care setting: inpatient vs day hospital:* training needed to be relevant to workplace setting, and there were reflections that there were too many demands on wards, leading to an inability to deliver the care needed to this group as these patients were felt to take up too much time. *Longer term reflections: change vs stasis:* Training allowed staff to gather together and gain **peer support**, share ideas and increase self-awareness. Some felt that training was futile as it was non-reflective of the realities of practice. Recommended that regular sessions for nurses to get together and explore experiences and learning should be facilitated as this may improve attitudes and practice. Clinical supervision may also offer this. Additionally, future learning needs to bring education and training together, facilitate more team networking, **consistency** across care, individual practical tools rather than introductions to therapeutic methods; and more service user input.

A US based quantitative study[30] with pre, post, and 6 month follow up measures aimed to assess effectiveness of one day training in good psychiatric management on clinical outcomes for clients with BPD. Some positive attitudes were evident pre-training such as in judgements on clinical abilities, and negative attitudes such as dislike of this client group. At post-training negative attitudes remained. This persisted to 6 month follow up but with some change with previously held negative attitudes changing to positive (for example the belief that BPD causes distress to patients). Over the course of the three time points, positive changes were seen in 11 of 13 items assessed, with change in direction (negative>positive) being seen in seven items. Clinicians expressed increased belief that some psychotherapies can be helpful for BPD. Notably, however, observed changes were not sustained during follow up. When viewed on the whole, outcomes are suggestive that (and in accordance with clinicians views) for ongoing or continued training. Recommendations that future work examines attitudes within specific disciplines and across care provision. Additionally, future work that examines how and whether attitude changes translate to behavioural changes.

The further quantitative based study[31] examined data obtained from the Insider's Guide to Graduate Programs in Clinical and Counselling Psychology, which collates data on 336 American Psychological Association accredited PhD and PsyD programmes. This study aimed to assess to what extent accredited programmes offered training in personality disorders. Only 16.4% (55/336) programmes had a faculty member interested in personality disorder. Despite the low ratio, this represented a 129% increase over 12 years. 14.9% (50/336) offered availability of personality disorder related specialty clinical or practitioner training. This paucity of training and education means that graduates of these programmes are embarking onto professional practice with considerable deficits in knowledge and skills in relation to a demographic that has considerable engagement with services.

A quantitative study[32] assessing the impact of co-produced personality disorder training on staff burnout, knowledge and attitudes among mental health staff (N=253). Training was co-produced by a clinician and an individual with **lived experience** and based on the Knowledge and Understanding Framework (KUF). Training was delivered over 3 days with six mandatory online modules to be completed between training days, which were spaced 2 weeks apart. Outcomes relating to burnout showed that emotional exhaustion has significantly decreased, while personal accomplishment increased. Training also significantly increased practitioner **understanding** and **empathy** towards clients, with significant endorsement of the training. Recommendations include research to investigate the sustainability of reductions in burnout for mental health professionals attending training. Additionally, authors note that improvements going forward are contingent on supervision and opportunities for learning.

A mixed methods study[33] concerning impact of training on staff (N=47) attitudes. The study concerned one hour standalone training with pre and post outcomes, as well as qualitative analysis undertaken via content analysis of participant written feedback. Significant improvements were seen in staff **understanding**, **compassion** and attitudes towards those with a diagnosis, with small to medium effect sizes being evident. Content analysis highlighted that training was helpful and improved understanding of personality disorder as a diagnosis. It also assisted in reducing negative attitudes towards this group. Participants also stated a desire for more staff time to be dedicated to training and more opportunities for training to be available. Recommendations highlight need for support for staff and regular training. Additional recommendations posit that service users' and carers' views are incorporated into the design of future training will be important.

The final study[34] also involved a mixed methods pre-post design among staff from predominately inpatient teams, with the most common participants being from psychiatry, psychology and nursing. The study aimed to improve staff training over a 3 day clinician delivered training course. Participants of the training were also encouraged to leave post it notes concerning their work with this group, which was included in the analysis. Quantitative outcomes revealed that 38% reported work related stress. Significant differences were found between the two assessed time points in terms of **confidence** in working with those who have a diagnosis of personality disorder, however non-significant differences were found in wellbeing and attitudes towards those with a diagnosis. Analysis of the post it notes revealed that pre-training the majority of the group had negative views (49%), with 26% having positive views. Post training negative views reduced to 22%, with 40% being positive. 6 themes were generated from qualitative data (*available resources, client demand, medical model, emotional components, human qualities and positive rewards).* Staff felt that there was a lack of resources and time to adequately work with this group, who were perceived to place a demand on staff time with staff using negative descriptors ("manipulative", "selfish"). Difficulties and stigma concerning diagnosis were discussed as well as comorbidities. The importance of seeing the person behind the diagnosis and hearing client's views was discussed as was the ability to see the positives in working with this group. Overall training was felt to have positive impact despite some negative views remaining. Recommendations to broaden training to a wider staff group, follow up assessment and involvement of lived experience recommended in training.

Staff perspectives of service users

Staff perspectives in terms of working with service users who may have a diagnosis of personality disorder is well described within the literature in terms of stigma etc. However, what is less well understood is additional factors that may play a role within staff perspectives of this service user group, such as issues concerning appropriate treatment, therapeutic relationship, staff wellbeing etc.

Synthesis of key outcomes

- Negative attitudes are pervasive among staff who interact with service users, particularly nursing staff.
- Feelings of futility among staff are common, whether this is with the service, their skill level or with perceived ability to enact change in service users.
- Feelings of powerlessness and being overwhelmed are common in staff who offer treatment to those with a diagnosis.
- Staff feel there is a lack of training available.

A qualitative study[35] from Ireland examining staff perspectives on working with inpatients with a diagnosis of BPD, identified six key themes (*problematic experiences, problematic patients, problematic treatment, problematic environment, problematic responsibility and problematic solutions).* Lack of job satisfaction, feelings of powerlessness and high emotional stakes were highlighted by nurses, as was the need for **training** and **supervision**. Negative views of service users were evident ("manipulative", "treatment resistant"). Need for **consistency** and communication between staff was evident, with a lack of this adding to feelings of futility. Inpatient environment was felt to be non-conducive to recovery, with nurses feeling that they had little impact over admission or length of stay and that other countries were managing treatment more effectively. Recommendations included provision of educational programmes to invest in the development of therapeutic **skills** for nurses and increased education around BPD so nursing staff can transfer these **skills** to clients. Managers advised to consider how **supervision** may play a role in skills development but also in how to manage the strong emotions evoked when working with this service user group.

A quantitative study[36] from Italy among 17 psychotherapists caring for outpatients (N=43) with personality disorder assessed clinical symptom severity among those with a diagnosis and the self-reported attitudes of therapists in light of these. Outcome measures for the study revealed there was no significant relationship between psychotherapist's attitudes towards their patients and their client's symptom severity. The authors contended that this may be caused by therapist specialised knowledge with this service user group.

A qualitative study[37] based in England among 15 GPs assessed their views and experiences managing those with a diagnosis and were engaged with the Increasing Access to Psychological Therapies (IAPTs) programme. The study was designed in collaboration with **lived experience** in terms of design, aims, etc. Analysis identified 11 themes (*GP experiences of managing patients with PD, Challenging consultation behaviour, Challenge of treating in primary care, Referrals being knocked back and patients falling in the gaps between services, Referrals being knocked back and patients falling in the gaps between services, GPs views on IAPT for patients with PD, Personality disorder patients need a service that can 'hold' and manage ling term risk, IAPT does not engage patients with personality disorder due to pressures on the service, The need for skilled therapists and GPs want better treatment for patients with personality disorder).* Overall, outcomes from the analysis showed that there were significant negative perceptions of those with a diagnosis ("manipulative", "unpredictable", and "challenging") who were difficult to condition manage and monitor in regard to perceptions that they were likely to be non-attenders. GPs felt that they were unable to adequately meet the needs of this group, caused by lack of condition specific knowledge and what treatments in secondary care were available. Difficulties with referrals and appropriateness of the IAPTs service were also raised, with CBT being felt to be inadequate and that group therapy was used by default and that the service did not offer enough sessions. Need for skilled therapists and the opportunity to upskill clients was also raised. Recommended that specially designed and targeted treatments are needed by this group and that GPs are in need to greater guidance and information.

An Australian qualitative study[38] also examined GP (N=12) perspectives concerning provision of care for those with a diagnosis of BPD. As with the previous study, this study also incorporated input from those with **lived experience** and from clinicians and academics. Four major themes were highlighted (*challenges surrounding diagnosis of borderline personality disorder, comorbidities and clinical complexity, difficulties with patient behaviour and the GP-patient relationship and finding and navigating systems for support*). The clinical complexity of this condition was highlighted, with this being seen as a barrier to effective diagnosis and treatment. Collaboration between services and practitioners was appreciated when it did happen, as it allowed for reassurance and support. Lack of personality disorder specific knowledge, **skills** and treatment guidelines were cited as an explanatory factor impeding care and in delaying diagnosis, however there was also a reluctance to diagnosis this condition. High rates of comorbidity with other mental and physical health issues also added to complexity of managing patients. Management of patients, in light of clinician time, **skills**, funding, referral pathways and patient needs was described as stressful and **overwhelming**, as well as often being inadequate, with GPs feeling powerless to affect change. GPs described patients as being troubled and being likely to non-attended, impacting the GP-patient relationship. Recommendations included additional education, training and support for GPs.

A further qualitative study[39] examining experiences of futility among nurses (N=12) providing care to those with BPD in Greece reported an overarching theme of *futility,* which reflected that care to those with a diagnosis lacked purpose and meaning as there was little they could do to enact change. Three major themes were identified (*uncertainty, frustration and unsupportiveness*). There was reported lack of understanding concerning the underlying causes and developmental influences of BPD and in how nurses should interact with this service user group. The use of different psychotherapeutic and medical interventions evoked feelings of uncertainty resulting in increased stress. Negative perceptions were common, with patients felt to be 'untreatable' and a 'burden' resulting from high levels of use and disengagement with services. Lack of change in patients led to feelings of disappoint which led to further withdrawal and negative emotions towards service users. Nurses did feel remorse for feeling this way about patients but there was an overall lack of compassion evidenced towards those with BPD. System was felt to lack support, such as in training, wellbeing and supervision. Lack of specialised training in Greek mental health settings for nurses.

A quantitative study[40] among psychiatry trainees (N=82) in Australia concerning confidence in meeting the needs of clients with BPD as opposed to those with schizophrenia reported that trainees had significantly less confidence when it came to working with those how may have a diagnosis of BPD. Trainees within their first year did not have any BPD specific training, with second and third year trainees highlighting that any training had to be independently sought. Those who had some level of training had higher confidence levels but not to a level that was statistically significant. Participants felt that supervision, training, assessment and management for BPD was inadequate as opposed to what was offered for schizophrenia. Authors did not cited any recommendations.

An additional quantitative study[41] among various mental health professionals (N=860) concerning attitudes towards those with BPD in Italy reported that nurses and social workers had the most negative and stigmatising attitudes towards those with a diagnosis as opposed to all other professions (psychiatrists, psychologists, social health educators). The least stigmatising attitudes were seen in those who had the highest number of BPD patients and who had attended the greatest amount of BPD specific training. As with the previous paper, no recommendations were cited.

Finally, an earlier cited paper[17] concerning crisis care among those with a diagnosis also included some staff perspectives. Within the paper, accident and emergency staff as well as GPs felt that they were unable to appropriately service this client group for various reasons, such as inadequate resources, staffing numbers, training and confidence and skills. Difficulties with boundaries, empathy were also cited, as were negative attitudes ("attention seeking", "manipulative") well as frustrations with being repeat presenters who were thought to be consuming. Additionally, practitioners and clinicians all reported a lack of confidence in regard to working with this client group, particularly in terms of knowledge and skills for supporting those in emotional crisis. Furthermore, staff reported difficulty regulating emotions when working with those in crisis with burnout and stress reported. Increased communication, peer support and clinical supervision were cited as means to improve staff confidence, patient care and reduce burnout.

Guidelines

NICE, the Royal College of Psychiatrists and the Mental Welfare Commission for Scotland have guidelines and best practice recommendations for the treatment of those with a diagnosis of personality disorder. The ICD-11 have recently published revised guidance pertaining to the re-codifying of personality disorder using a dimensional rather than categorical approach.

- NICE – Borderline personality disorder: recognition and management
- NICE – Anti-social personality disorder: prevention and management
- Royal College of Psychiatrists - Personality disorder in Scotland: raising awareness, raising expectations, raising hope.
- Mental Welfare Commission for Scotland - Living with Borderline Personality Disorder: The experience of people with the diagnosis, families and services in Scotland.
- ICD-11 – Personality disorder and related traits.

Overall summary and conclusions

Personality disorder is common throughout clinical samples and within the general population, however it is clear that those with this diagnosis do not experience the same level of care, and are subject to stigma in comparison to those with other mental health diagnoses. Specialised psychotherapies (DBT, MBT, ST and TFT), of both brief and intensive durations, have shown efficacy in symptom and risk reduction, as well as improvements in psychosocial functioning and appear to be well tolerated with less attrition that other therapies. No specialised therapy would appear to be superior to another given the available evidence, however advancing age and group work involving large numbers appears to reduce efficacy. Despite extensive and widespread usage, psychopharmacology has shown less effectiveness, with poor justification within the literature as to its use.

Endorsement of specialised psychotherapies has also come from service users, complimenting clinical outcomes in reduced symptoms and risk, as well as improved psychosocial functioning and increased self-awareness. Skills based interventions and personal autonomy also impact psychosocial outcomes. Establishment of trust, boundaries, empathetic open communication and non-judgmental attitudes also appear to facilitate improvements.

Information sharing between practitioners and clients in terms of roles and treatment.

The over-use of psychopharmacological interventions despite lack of consensus in the evidence base.

Problems with group work, group size and duration of therapy.

Incorporation of lived experience into the design of training interventions for staff.

Implementation of ongoing training for staff to reduce stigma and enhance skills.

Figure 4. Summary of identified gaps in existing evidence.

Problematic areas remain, such as information sharing regarding professional roles, therapeutic options, the dynamics and safety of sharing within group work, perceived insufficiencies around psychotherapy duration and staff knowledge and training. However, the evidence supports that training that is co-produced with lived experience tends to be the most effective across a range of professions in the medium term, however there is a noticeable drop off following post-training. Overall, training has been evidenced to reduce stigma, increase confidence, empathy, skills and understanding among practitioners. It is clear from the evidence provided, which is by no means exhaustive, that staff desire training, particularly training. However, negative attitudes are not entirely ameliorated by training, and are particularly pervasive among nurses, further strengthening the argument for training to be ongoing. Access to ongoing and appropriate training may reduce reported feeling of futility, powerlessness in working with this service user group and also reduce stigmatisation service users.

Appendix B- Rapid Literature and Evidence Review Concerning Presentations in emergency care, police detention and homelessness

Summary

This is a rapid review of the recent evidence relating to the effectiveness of psychotherapeutic and psychopharmacological treatment options for those with a diagnosis of personality disorder. The review also examined service user perceptions of psychotherapeutic treatment and staff as well as improvements in function that may be attributable to psychotherapeutic treatment. Staff perspectives of training and service users was also examined. The report has several sections based around what the literature suggests on the following questions:

- What is suggested on the prevalence of presentations to 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 Introduction

Main findings

Presentation prevalence

Key summarised are shown below (please see appendix 1 for summary table).

Synthesis of key outcomes

- Those with a diagnosis of personality disorder are more likely to present at A&E as opposed to those with common or serious mental health conditions
- Those with a diagnosis of personality disorder are more likely to have multiple presentations to A&E as opposed to those with common or serious mental health conditions
- Those with a diagnosis of personality disorder are more likely to present in extreme crisis, with suicidal ideation, self-injury and/or drug intoxication
- Based off the studies available for the review, despite the fact that those with a diagnosis are more likely to present at A&E and are more likely to be repeat visitors, they represent a small percentage of emergency care patients (<3%)
- Limited evidence would suggest that those with a diagnosis are at increased risk of premature mortality compared with population average.
- Concerning presentation at A&E, a diagnosis of personality disorder is more likely to present comorbid with another mental health condition
- In the study concerning police custody, one fifth of detainees screened as positive for a personality disorder.
- Lived experience perceptions of emergency care in A&E highlighted that there are limitations serving this cohort, with those who have a diagnosis perceiving stigma among staff and staff also feeling unsupported in serving this patient group.
- One study examined homelessness and highlighted that a BPD was represented in more than one third of homeless women. Additional, the study that examined police detainees also revealed that access to accommodation was a particular unmet need for those with a diagnosis.

9 papers assessed presentation of those with a diagnosis at A&E. The majority of papers were primary research articles with one being a systematic review 42. Several papers were complimentary in their outcomes from the included articles in that those with a diagnosis of personality disorder were more likely to present at A&E as opposed to those with other MH diagnoses (REFS study 43-47). It was also highlighted that those with a diagnosis were more likely to be repeat presenters at A&E (43,44,48,50). Additionally, those with a diagnosis were more likely to be brought to A&E by police and/or ambulance (44,48); furthermore those with a diagnosis were also more likely to be suicidal and/or self-injured (43,44,42,50) or be under the influence of drugs whilst presenting at A&E (42). 3 papers also revealed that those with a diagnosis were more likely to experience longer stays at hospital and be more likely to be admitted than those without a diagnosis (42, 43, 48). One paper provided a cost benefit (49) analysis which highlighted that MH costs within A&E were ¾ of total health care costs.
One paper included in the review (45) highlighted that those with a diagnoses of personality disorder experienced elevated levels of premature mortality as opposed to the population, with males with a diagnosis having their life expectancy reduced by up to 13 years as opposed to their counterparts and women experiencing a 9 year reduction. Comorbidity was also

highlighted in three studies (42,43,51), with one study reveling that psychiatrists were reluctant to give a diagnosis of personality disorder due to high levels of stigma associated with diagnosis (48).

Two studies assessed police involvement as pertains to personality disorder. One study assessed prevalence of developmental disorders among police detainees (50). Outcomes of this study revealed that approximately one third of participants has a MH diagnosis, however more than one fifth of these individuals were applicable for a diagnosis of personality disorder (as assessed using psychometric tools within said study). There were also elevated levels of suicidality reported within the sample, with one fifth of participants being at risk of suicide. The second study (52), which is the only Scotland study; assessed place of safety referrals over a 12 month period. Outcomes of the study revealed that 34% of those given referrals had a diagnosis of personality disorder and that those with a diagnosis were more likely to experience admission following referral. Authors of the paper highlighted that admission to hospital occurred despite Highland having an integrated care pathway which states that hospital admission for those with a diagnosis is “at best neutral and at worst harmful”. Authors highlight that a combination of factors such as difficult deescalating crisis and high risk of harm may underlie the rates of admission for those with a diagnosis.

An additional study concerned rates of personality disorder among homeless women (51). More than one third (36.6%) of the women involved in the study had characteristics and scores on measure of personality disorder that would be indicative of diagnosis. Of interest among this sample was the estimation that personality disorder was 26 times more prevalent among homeless women that among the general population.

Two papers assessed lived experience in terms of A&E care (53, 54). Both studies highlighted that emergency care as experienced by those with a diagnosis had significant limitations, such as individuals feeling stigmatised, poor after care support and referrals when discharged to the community and a lack of interaction and integration between emergency care services such as A&E and community services.

Overall summary and conclusions

Personality disorder is common throughout clinical samples and within the general population, however it is clear that those with this diagnosis do not experience the same level of care, and are subject to significant stigma as opposed to those with other mental health conditions. Emergency care such as A&E is a common place for those with a diagnosis to seek care in times of crisis. Indeed the studies included within this review would highlight that as opposed to other MH conditions, those with personality disorder are more likely to present at A&E. Furthermore, those with a diagnosis are more likely to be repeat presenters at these locations. Included studies also highlight that those with a diagnosis are also more likely to have interactions with the police and have a high level of representation among homeless women.

Strengths and limitations

A strength of the review is that it has collated and synthesised recent, relevant evidence from the empirical literature. It has aimed to broadly assess the evidence in terms of prevalence rates for presentations at key services among those with a diagnosis of personality disorder. It has also, albeit briefly examined service user perspectives as to care revived at accident and emergency. Several gaps have been identified, such as:

- Information sharing between services that are involved in the care of those with a diagnosis, particularly between emergency care and community care.
- The role of service user experience within the care experienced, and how these experience can be improved.

However, the above must be seen and interpreted with caution due to several limitations concerned with this review, two major limitations being that article screening and selection was conducted by one reviewer and the limited time frame that was in place for the turnaround of this review. This means that there is the possibility that some relevant studies were omitted from the review. The time frame associated with synthesis also means that a deeper level of analysis was not feasible.

Appendix C Personality Disorder- A rapid literature review of cost effectiveness of specialised interventions

This rapid evidence review focused explored what information there was on the cost-effectiveness of interventions for people with a diagnosis of personality disorder. The evidence review identified that there is some information available on the cost effectiveness of particular specialist therapies. This evidence is summarised below. The rapid evidence review (and the Strategic Gap Analysis completed as part of the programme) highlights the need for further information on the cost effectiveness of better coordinating care and supporting people beyond specific therapies. This wider focus on economic considerations is intended to be explored during Phase 2 of the programme.

Summary of summaries on the cost-effectiveness of specialist therapies:

- There is evidence from one NHS study that DBT is more cost-effective than CCT (client centred therapy)
- The evidence that DBT is more cost-effective than treatment as usual is considerably more uncertain, across four NHS-based studies. However, wider international evidence was slightly more promising although it remains difficult, given differences in methods used to summarise the economic benefits of DBT in these studies, to conclude definitively that DBT is an efficient strategy compared to treatment as usual.
- There was some further NHS-based evidence 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.
- 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 PD 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. Two of these[55,56] were interventions specifically for patients with BPD, whilst the study population of interest in the paper by Priebe[57] and colleagues was participants with a personality disorder and at least five days of self-harm within the previous year . This study[57] had explored the effectiveness of DBT, which was also assessed within the economic evaluation by Brazier and colleagues[55], whereas the study by

Day and colleagues had assessed the cost-effectiveness of the Helping Families intervention for parents with BPD and their children[57].

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 and colleagues; DBT versus client-centred therapy; CCT) for two specific outcomes; the cost per parasuicide event avoided and the cost per QALY gained.

DBT

For parasuicide events avoided, in the DBT studies DBT dominated (i.e. was both less costly and more effective) than CCT as a comparator, and for one of the studies where treatment as usual (TAU) was the comparator. For a further two studies against TAU as a comparator, the incremental cost per parasuicide event avoided was between £40 and £43,124. This range suggests considerable uncertainty.

When the outcome of interest was QALYs gained, again DBT was shown to be both cheaper and more effective than CCT. Only one of the three studies where the comparator was TAU had included QALYs as an outcome. This study by Koons and colleagues, which was cited in the Brazier study[55], found the additional cost of DBT per QALY gained to be £273,801. This is considerably in excess of what is typically viewed as the maximum society is willing-to-pay for a QALY gain and so would not be considered cost-effective.

One further NHS-based DBT study by Priebe and colleagues[57] containing economic evidence has since been published (2012). This RCT compared DBT and TAU among participants with a personality disorder and at least 5 days of self-harm in the previous year and found that for every 2 months spent receiving DBT the risk of self-harm decreased in 9% relative to how the risk of self-harm changed in the TAU group. Costs were not statistically significantly different between groups (95% CI -£603 to £4,599); although mean costs were higher in the DBT group (£5,685 versus £4,754) costs are typically skewed data. An additional perspective included the costs of lost employment but again there was no significant difference between groups. No significant differences were found in any of the secondary outcomes, which did include Quality of Life (Manchester Short Assessment of Quality of Life instrument) but not from an instrument that would readily allow health state utilities (and therefore QALYs) to be derived, although mapping algorithms may allow this. The cost-effectiveness of DBT per 1 percentage point reduction in the incidence of self-harm was estimated to be £36 on average, which is promising, and the study noted that results were substantially greater for those who completed the intervention than those who did not, which suggests adherence is a key factor.

MBT

For the intervention of MBT, as reported in the by Brazier and colleagues, there was one study by Bateman and colleagues was included in the analysis and this had compared MBT with treatment as usual. The additional cost per parasuicide event avoided was £38, and the additional cost per QALY gained was £7,242 indicating MBT was cost-effective.

MACT

For MACT, within the work by Brazier[57] and colleagues, one study by Tyrer and colleagues, compared this intervention against treatment as usual and found that it was more costly and prevented fewer parasuicide events. However, the intervention did suggest QALY gains associated with MACT and the additional cost per QALY gained was £84,032. This is unlikely to be viewed as cost-effective.

The results are subject to considerable uncertainty. For example, none of the studies showed significant QALY gains (all 95% confidence intervals include zero), although with the exception of the study by Tyrer and colleagues (MACT vs TAU), most studies were able to show an increase in the number of parasuicide events avoided. It is not clear whether clinical practice in the NHS (especially at present as the Brazier study was published in 2006) is more closely reflected by the Koons et al (for DBT) and Tyrer et al (for MACT) studies where there was more uncertainty about the cost-effectiveness, or rather by the Turner et al (for DBT) and Bateman et al (for MBT) studies that showed considerably greater promise for these interventions compared to CCT (in the case of Turner et al) and TAU (in the case of Bateman et al).

Family intervention for parents with PD

A feasibility study for an RCT, as reported earlier[56], explored the cost-effectiveness of a family intervention for parents (aged 18-65) with personality difficulties (including personality disorders) whose children have mental health problems. The intervention sought to a) develop psychoeducational tools, b) to assess these tools in the form of the “Helping Families Programme - Modified” in terms of acceptability and viability for future evaluation and c) conduct a randomised feasibility trial compared with usual care (which included the economic analysis component). The evaluation suffered from difficulties in recruitment and retention and as a result, there were considerable missing data in the economic analysis, particularly for the usual care group.

Costs were not collected at baseline but at two follow ups (Time 2 and Time 3). EQ-5D data were collected from both parents and children at all three time points. Two cost-effectiveness analyses were conducted to try and ensure as much of the collected data as possible could be used in the analysis. This is potentially problematic given that baseline cost data are not available, and the conclusions completely change depending on which set of data are used. For both analyses, all 95% confidence intervals for incremental costs included £0, meaning no conclusion can be drawn on whether or not the intervention is more or less costly than usual care. All the 95% confidence intervals for incremental QALYs included zero, meaning no conclusion can be drawn about whether or not the intervention is likely to confer quality-adjusted life year gains to parents or children involved. No conclusions can be drawn about the cost-effectiveness of the “Helping Families Programme – Modified” intervention for parents with personality difficulties including personality disorder.

Context: wider international evidence on cost-effectiveness

International evidence must be treated with caution as differences across healthcare systems, in addition to differences in currency and price year (depending on when the study was conducted) may make the results less generalizable to an NHS context. We have limited descriptions of the international evidence for individual studies to the European studies listed below, however we also describe a systematic review of economic evaluations in BPD by Meuldijk and colleagues58 which describes a wider range of international evidence as well as some overlap to the studies highlighted here[55,57] - and its associated studies – and a costing study by Amner and colleagues[59] (summarised below) as it included 29 studies, the majority of which were DBT studies versus treatment as usual.

DBT

A study conducted in the Republic of Ireland by Murphy and colleagues[60], looked at the effects of DBT over time. Patients’ baseline data served as their own controls, owing to insufficient treatment as usual data being available from a separate cohort. The base case found that DBT improved QALYs gained (0.2) over 18 months but was more expensive (€393) leading to a nominal ICER of €1,965 per QALY gained which the authors conclude <u>can be considered cost-effective in the short-term</u>.

DBT among other therapies

Wetzelaer and colleagues[61] compared specialised outpatient psychotherapy with treatment as usual for patients with borderline personality disorder over 1 year in the Netherlands, based on a simulation model using data derived from the literature, for the outcomes of BDI and EQ-5D. The literature review identified several studies already cited in this review and other e.g. pre-post studies of interest to the authors. Some of the studies looked at more than one intervention, but briefly 8 of the studies looked at DBT, 3 used transference focused psychotherapy (TFP), 2 used schema therapy and one used MBT. The weighted average number of QALYs gained was 0.08 (95% C.I: 0.03 –0.16), indicating that specialised outpatient psychotherapy confers health benefits, and given the additional cost of providing the interventions was €2,367 (95% C.I. €1717 – €3272) the incremental cost-effectiveness ratio (ICER) for specialized outpatient psychotherapy was found to be €29,588 (95% C.I. €13,455 – €75,940) per additional QALY gained. <u>This suggests, specialised outpatient psychotherapy, particularly DBT could be cost-effective, based on Netherlands population values</u>.

The systematic review by Meuldijk[58] calculated cost offsets associated with psychotherapeutic intervention (most commonly DBT) and additional cost savings per patient per year for patients with BPD. Costs were reported in US dollars.

- Comparing the pre-and post-intervention periods, studies reported a cost saving in the range of $4 to $56,024 per person/per year; the weighted cost-saving expected was quantified as $5,840.92 (SD:$10,816.56) per patient per year. One CBT study reported an increase in costs per patient per year post intervention.
- Excluding all non-controlled studies (i.e. studies that had only pre-post data), the saving associated with psychotherapeutic intervention was reduced to £2,987.82 (SD: $4390.31) per patient per year.
- Compared to treatment as usual, the additional weighted mean cost-saving of implementing evidence-based psychotherapy was £1,551.37 (SD: $6,574.17) per patient per year (range was from $83 to $29,392 per patient per year) across fifteen evaluations. Five reported an increase in costs.
- Specifically for DBT the weighted mean cost offset was $78,43 (SE: $184.01) across 344 patients pooled from six studies compared to treatment as usual.
- <u>However, comparison of the cost savings of DBT versus other forms of psychotherapies did not lead to a significant difference in the cost reduction; therefore the authors conclude that this strengthens the rational for using any form of well evaluated psychological therapy as the main treatment of BPD.</u>
- The non DBT studies included in the review were conversational model (CM) (2 evaluations), mentalization-based therapy (MBT) (2 evaluations), schema-focused therapy (SFT) (2 evaluations) and one each for CBT, CBT-PD crisis intervention (CI), crisis plan and treatment as usual (CP), long-term psychoanalytic psychotherapy (LT-P), manual-assisted CBT (MACT), outpatient individual psychotherapy (OPC), stable psychotherapy in community (SCP), individual and group therapy (SDC) and transference-focused therapy (TFP).

App-based DBT compared with paper-based DBT

A study by Laursen[62] compared a mobile diary app with paper-based diary cards within a DBT programme for 78 patients with BPD in a psychiatric outpatient facility in Denmark. The cost-consequence analysis included various outcomes including QALYs. Mobile app patients recorded more days of treatment and more skills per week than participants in the paper group. Both groups experienced QALY gains and a decrease in depression severity, borderline severity and suicidal behaviour (indicating health benefits of DBT generally are seen). The paper based group showed significantly higher QALYs than the app group. No significant differences were found in use of resources but implementation of the mobile diary app will lead to higher costs than paper-based diary cards. <u>The conclusions indicate positive as well as negative consequences</u> for mobile app use compared with paper-based cards. In addition, <u>patients may value the estimated 1 minute per day that clinicians estimated the app saves these participants in terms of time to complete diaries</u> and so there may be patient preferences of relevance for further research. However, from a cost-utility point of view the mobile app is unlikely to be cost-effective based on these results.

MBT

A study by Blankers and colleagues[63] in the Netherlands found that treatment as usual dominated (was less costly and more effective) than MBT in terms of QALYs gained and the cost associated with one additional remission with MBT was approximately €29,000 from a societal perspective (although this reduces to €22,106 when a healthcare sector only perspective is considered). MBT is unlikely to be considered cost-effective given these results.

Schema therapy

A study by Bamelis[64] which had conducted a cost-utility analysis in the Netherlands on schema therapy, clarification-oriented psychotherapy and treatment as usual for patients with avoidant, dependent, obsessive-compulsive, paranoid, histrionic and/or narcissistic personality disorder, had used the UK value set for the EQ-5D-3L instrument to measure quality of life.

There was no difference in QALYs gained between treatment groups. However, schema therapy was considered dominant (less costly and more effective) than both clarification-oriented psychotherapy and treatment as usual in terms of clinical effectiveness which measured the proportion of recovered patients after 3 years (81.4% compared with 51.2% in clarification-oriented psychotherapy and 51.8% with treatment as usual. Treatment as usual was cheaper to provide than clarification-oriented psychotherapy and so more cost-effective on that basis, given the difference in effects.

NHS-based cost only studies

Three additional studies reported NHS based costs associated with interventions for treating personality disorder but in one of these studies65 looking at management of adults with mental health problems in the community rather than as inpatients, it was not possible to separate costs from patients with personality disorder with those who had other mental health disorders of interest (mild-moderate depression, eating disorder, certain schizophrenia patients) and so no further conclusions could be drawn. The remaining two studies of relevance are summarised below.

DBT

The study by Amner and colleagues[59] estimated the costs of one year's treatment of DBT within a rural Welsh NHS Board (Hywel Dda Health Board) for patients with evidence of BPD symptoms and characteristics (formal diagnosis was not a pre-requisite). Costs were retrospectively compared for the year prior to DBT, the year of active DBT and the first post-treatment year. Data were available for 21 patients. Savings were determined by the post-treatment year compared with the pre-treatment year. Costs in the year of DBT were not significantly different from the pre-treatment year overall (average £174,122 in the pre-treatment year compared with £173,229 in the year of receiving DBT), but the latter total includes the cost of DBT itself at £98,487, so comparative service use costs alone were reduced £74,742. Service use costs in the post-treatment year rose to £137,571 without DBT. This shows that most savings in terms of service use are likely to be made within the first year. It is not clear that savings in the post-treatment year were discounted, but as this was a cost analysis it is not possible to know whether or not it was intended for budget impact assessment use rather than as a cost-avoidance study. The mean saving per participant was £1,741 (reduced to £1,577 upon sensitivity analysis removing outliers) comparing the post-treatment year with the pre-treatment year, but this was not statistically significant.

Managed Clinical Network for Personality Disorders

The study by Kane[66] used a difference-in-difference design to evaluate comparative changes in health costs for service users of the Leeds Personality Disorder Managed Clinical Network (MCN) compared against a control trajectory whose results are based on usual findings from the literature whereby standard treatment for personality disorder identified a case distribution between hospital and community based treatment of 87%:13% and applying this ratio to other studies that have defined “treatment as usual” for hospital treatment. The assumptions of the difference-in-difference analysis are that literature participants are not connected to those seen in the MCN, but that MCN clients would have responded in a similar way to those from the previous studies. The results suggest a reduction in cost of 17.25% compared with pre-MCN estimates of £14,860, i.e. £12,300 per person (2013/14 price year). Wider public sector costs avoided for child services and/or criminal justice system costs were also estimated, based on additional assumptions and so given the method used to value the MCN and the number of assumptions made to generate the savings estimates, the degree of uncertainty about the value of the MCN is expected to be considerable.

Appendix D Strategic Gap Analysis

This is a Strategic Gap Analysis conducted by the Strategic Planning for Redesign Portfolio within the ihub Transformational Redesign Unit.

Healthcare Improvement Scotland engaged with all the regional NHS Boards and HSCPs across Scotland during 2022 to understand the current services and support available for people with a diagnosis of personality disorder. This note is the Strategic Gap Analysis which compares the status quo with best practice and identifies the gaps in current service provision.

This note is structured as follows:

1. A summary of existing service delivery across the NHS Boards in Scotland
2. Outlining the key features of what good practice looks like
3. A gap analysis to identify the areas for future development
4. 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 analysis and recommendations within this Strategic Gap Analysis are based on 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 VOX Scotland and the Scottish Recovery Network – 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 the regional 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 GGC and NHS Grampian have steering groups for Borderline Personality Disorder (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 and Arran have a Care Pathways Steering Group that contributes towards clinical leaderships 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 GGC, NHS Highland, 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 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 characteristics that would indicate a diagnosis, of BPD or EUPD.
- 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 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 (e.g. 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 GGC 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 with 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 for 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 GGC 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 and Galloway have a virtual team for people with Emotionally Unstable Personality Disorder (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 Integrated Care Pathways 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 don’t currently have an integrated care pathway or are in the stages of developing one for example Argyll and Bute (within NHS Highland), NHS Tayside, NHS Ayrshire and Arran, NHS Lothian (excluding West Lothian and Midlothian who are developing and 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.
- Some boards such as NHS Lanarkshire, NHS Western Isles (pathway relates to BPD only), NHS Grampian, and NHS Borders report that they do have an Integrated Care Pathway 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 that 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 GGC has a pathway developed and largely operational for BPD, but other forms of personality disorder care is carried out on a case. They 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 that have been identified by boards is that 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 organsied approach when treating complex cases and working with multiple services. Within NHS GGC they are using an approach they refer to as Coordinated Clinical Care.

Pharmacological management

Most boards that 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 its use. 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 personality disorders. 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, STEPPS, DBT, MBT, psychotherapy, CBT, 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, Ayrshire and 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 18-64.

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, but it was also noted that for a large proportion of people with 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 answered the questions 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 does 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 personality disorder. DBT has service materials that guide families with the management of the difficulties of supporting someone with a 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 patients give consent.

Involving those with lived experience

- 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 people with lived experienced were actively involved including
- NHS Highland have recruited a lived experience volunteer to sit within their specialist personality disorder service.
- NHS Tayside report including lived experience individuals in design workshops for their EUPD clinical pathway.
- NHS GGC 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 communications materials for those newly diagnosed with personality disorder.
- A number of boards mentioned that they collect patient feedback but noted that they were wanting 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 the Scottish Recovery Network, 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 around 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 personality disorder 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 their 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 and they felt that 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 patients.

- Most boards reported issues with high staff turnover and a challenge to recruit suitable permanent staff when advertising positions. A number of boards, including Tayside and 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 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 psychiatrists and psychological therapies. 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 GGC and NHS Highland – excludes 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 GGC integrated Care Pathway was informed by similar pathways for Learning Disabilities and Older People.

What good looks like

Evidence available 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:

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[1]
- 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 Integrated Care Pathways 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 patients including consistency, trust, respect and compassion and use trauma informed practices
- Adherence to best practice guidelines (i.e. NICE, Psychological Matrix, etc.) such as the use of Care Programme Approach, with consideration given to enhancing equity in provision across society (e.g. 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 have choice by the person as key to the person-centred care *for their own care*
- Ensuring that those with lived experience are able to meaningfully input into service design, delivery and review to *inform wider service delivery*
- Making 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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[1] 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 personality disorder
- Consistent and shared view of evidence based approaches to diagnosis, interventions, treatment, and support for people with a 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 and safety, performance and 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.

Gap analysis

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

- A lack of shared and accurate understanding of personality disorders 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 Integrated Care Pathways leading to inconsistent treatment and reducing patients ability 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 patients 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 CAMHS and learning disability services to adult mental health and from adult mental health to older adults. 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 patients

- 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

Recommended next steps

Given the findings of the Strategic Gap analysis, we propose a strategic planning approach is taken to design, plan, and deliver an improved set of services for people with a diagnosis of personality disorder. This section outlines the various suggested activities to enable the use of the Good Practice Framework for strategic planning to guide the service improvement process.

The Good Practice Framework for Strategic Planning is made up of five key themes that guide service redesign processes from start to end.

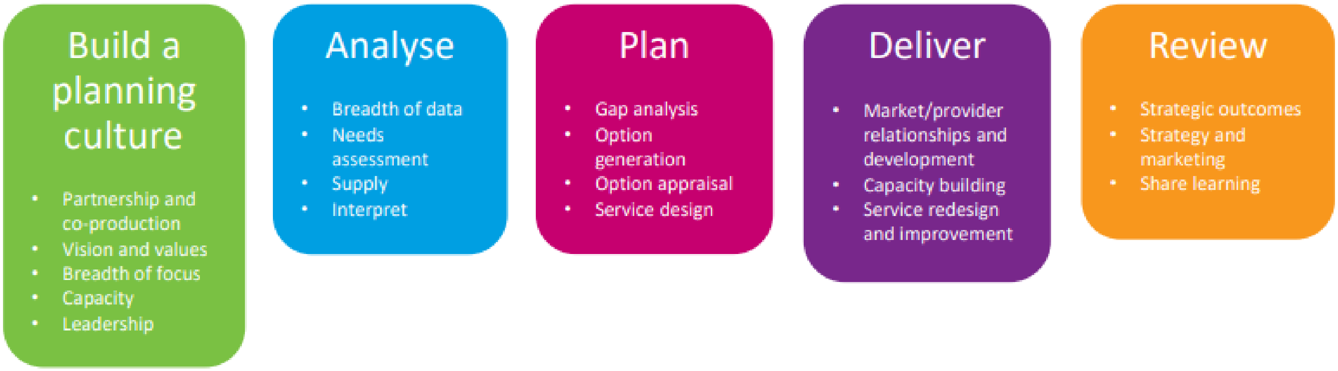

Figure 1 Good Practice Framework for Strategic Planning. (2019). ihub, Healthcare Improvement Scotland. https://ihub.scot/media/6879/good-practice-framework-for-strategic-planning.pdf

Identified gap/challenge	Proposed activities for Phase 2	
Build a planning culture		
Shared understanding of personality disorders	Combination of leadership and learning and sharing activity	
Senior buy-in and leadership	Facilitation of engagement across senior leaders in Scotland to build understanding and buy in	Strategic Planning Team can contribute

Analyse	Plan	
Service development – e.g. Integrated Care Pathways and Interventions for patients	Support boards and HSCPs to further develop their Integrated Care Pathways (or alternative as appropriate) using the Good Practice Framework for Strategic Planning to conduct a needs assessment, option generation, options appraisal, and service design.	Strategic Planning Team can lead
	Conduct a forecast quantified impact analysis (e.g. cost benefit analysis) to understand the benefit of better services for people with personality disorders on the reduction in demand for acute, unplanned and other services. (conduct analysis applicable across Scotland with board buy-in and input)	Strategic Planning Team can lead
Resourcing of services	Develop cost projections for implementing Integrated Care Pathways (or alternative as appropriate)	
	Develop business case for resourcing these changes	Strategic Planning Team can contribute
Involving lived experience	Developing and implementing an approach for those with lived experience to feed into phase 2 of this work ensuring those with lived experience contribute to the design and implementation of this activity	Strategic Planning Team can contribute
	Developing a framework, guidance and support for boards and NHS to enable ongoing involvement from lived experience within their service delivery ensuring those with lived experience contribute to the design and implementation of this activity (conduct analysis applicable across Scotland with board buy-in and input)	
Role for digital and virtual service delivery	Conduct options generation and options appraisal for the way that digital and virtual services play a role in delivery (conduct analysis applicable across Scotland with board buy-in and input)	Strategic Planning Team can contribute
Capacity building		
Staff turnover and recruitment	Identify contribution that the ihub can make to these areas of concern	
Staff training	Identify the training needs and put together a case for investing in training required (conduct analysis applicable across Scotland with board buy-in and input)	
Review		
Data collection and use	Develop an outcomes framework to measure progress (conduct analysis applicable across Scotland with board buy-in and input)	Strategic Planning Team can lead

	Conduct a management and performance data audit and assessment (possibly in two – three case study board areas) to develop recommendations for future data collection (conduct analysis applicable across Scotland with board buy-in and input)	Strategic Planning Team can contribute
Learning and sharing	Establish and facilitate a network for learning and sharing between boards and HSCPs across Scotland including a focus on: • Understanding how personality disorder services operate across the country • Engage with different approaches to leadership • Understand where the Good Practice Framework for Strategic Planning can support them.	Strategic Planning Team can contribute

Appendix E Scottish Recovery Network and Voices of Experience Lived Engagement Report

1. Introduction

Scottish Recovery Network promotes and supports mental health recovery. Our vision is:

Together we can make Scotland a place where people expect mental health recovery and are supported at all stages of their recovery journey.

Our mission is to bring people, services and organisations across sectors together to create a mental health system powered by lived experience which supports everyone's recovery journey. Collaboration and lived experience are central to our work.

VOX Scotland is a national membership organisation, open to all people in Scotland with lived experience of mental health difficulties. VOX Scotland works to ensure that people with lived experience can shape Scotland's laws, influence service design and delivery, promote a better understanding of mental illness in wider society and advance the general interests of people living with mental health issues.

Aim of the project

Scottish Recovery Network and VOX Scotland were commissioned by Healthcare Improvement Scotland to support the work of the Personality Disorder Improvement Programme by engaging with people with lived experience to inform the final programme recommendations. The programme of engagement provided an opportunity for people living with trauma and/or who have been given a diagnosis of personality disorder to share their experiences and what supports their recovery and wellbeing. In particular there was a focus on their experiences of services and their ideas for improving services

This report shares the findings of this engagement and outlines:

- The key stages and activities of the engagement programme
- A picture of current services
- The key components of great, well designed services

- Proposals for improvement and change

2. What we did

Scottish Recovery Network and VOX Scotland believe in the importance of taking an equalities, human rights based approach to engagement with people with lived experience. We used the PANEL principles to inform the design and delivery of the engagement programme. To us this means that any engagement must be focused on what is important to the person, be inclusive and any outcomes be co-produced. Our programme of engagement enabled us to:

- Engage with key groups, organisations and people and work with them to reach as many of those as possible that we needed to involve

- Be open in how we framed the engagement and to listen for issues and themes to build on

- Offer a range of options to that people could choose how they wanted to share their views on what matters to them and how services could support their recovery

- Worked with lived experience throughout the process to ensure the engagement programme and its outputs are co-produced

- Take a whole systems approach, centred on the needs and aspirations of with or may attract a diagnosis of personality disorder to look at what is happening and what is needed in all parts of our mental health system

139 people participated in a comprehensive programme of engagement comprised of four key phases as outlined in the table below.

Phase 1 Reach out June-August 2022	Identifying and reaching out to a wide range of groups, organisations and people to seek their input to the design of the engagement activities and explore how they could help us reach more people. This included two information events attended by 46 participants.
Phase 2 Engagement September-November 2022	Design and delivery of a range of engagement activities including: • 5 conversation cafes which attracted 20 participants • 6 one-to-one structured conversations • an online survey completed by 28 participants • Feedback from one organisations group of 6 participants We also supported lived experience story sharing through the Lived Experience Project Group. To enable groups and organisations to feed into the project we produced a resource pack for groups and organisations to use to host conversations with members and/or people they support and feed back in.
Phase 3 Co-design November 2022	Building on key themes identified during the engagement we held three co-design events where 33 people with lived experience came together with each other and some frontline practitioners to develop proposals for improving services.
Phase 4 Reporting December 2022	Drawing together the findings from the engagement and the proposals developed during the co-design sessions to share with HIS PDIP, those who took part and others.

Ensuring lived experience was at the heart of this project, we also established and hosted a Lived Experience Project Group. The members of this group were initially identified during the reach out phase of the process and a programme of group workshops and meetings has been devised with them to ensure that they inform the engagement and it’s outputs. The group members have been involved in planning and delivering engagement and co-design sessions, collating feedback and identifying key themes and interpreting the findings.

Throughout the project we used the terminology 'people whose lives have been affected by trauma or who may attract a diagnosis of personality disorder. We adopted this in recognition of evolving community discussions around the use of the somewhat contentious term 'personality disorder' and ensuring the engagement reached the full breadth of groups we hoped to, without explicitly labelling. Our approach and the language used also acknowledges that everyone experiences trauma and distress differently and that there is not an extensive list of what classifies trauma as it is unique to each person.

We also recognise that not everyone with a possible personality disorder diagnosis has a history of trauma. However, there was a strong consensus among the people with lived experience who engaged in the project that trauma was important but not always recognised. Many also talked of the interaction between diagnosis of personality disorder and experience of other conditions, particularly neurodiversity.

3. A picture of current services

Many shared their concerns about current services. Whilst people have experienced a lack of empathy and compassion and feel that their diagnosis adversely affects the way people treat them, they were aware this was not solely about the staff themselves. Issues such as gaps in the way the system currently operates, a workforce which cannot currently match the needs required, a general sense of stigma around personality disorder, and a lack of understanding of trauma and how it impacts on people's behaviour, were felt to be causing the lack of empathy and compassion.

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

3.1 Stigma and discrimination

'Personality disorders' are considered to be amongst the most stigmatised mental health conditions, with greater stigmatisation leading to people with a diagnosis experiencing 'exclusion of limited attention' from mental health services[67].

We heard numerous accounts of the stigma and discrimination experienced by people, which led to devastating effects on both their mental health and relationship with services. Attitudes towards people with a personality disorder diagnosis must change, as the current discriminatory attitudes mean people have no trust in services. People feel assumptions are made about them based on the diagnosis. Therefore, they feel treated as a diagnosis, not a person.

“The system can make you feel inadequate. Isolated, different and you have to see past what stigma says a personality disorder is. There is nothing wrong with your personality it just hasn't reached its full potential as something has held you back. There is a way to grow and get past it.”

“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. From being in crisis in A&E to being in hospital, just every single day. I then had my own self-stigma, I started believing what they were saying.”

“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.”

A contributing factor to the stigmatising attitudes is the language around ‘personality disorder’. Indeed, the term has previously been described as ‘appearing to be an enduring pejorative judgement rather than a clinical diagnosis’ [68] and alternative terminology such as ‘complex emotional needs’ is becoming more widely used. [69] [70]

Many feel the wording of the diagnosis and descriptions of symptoms should be changed, as it often causes misunderstanding and contributes to negative attitudes. The current language 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”

“I shy away from disclosing my diagnosis because when I do share it people respond with ‘does that mean you have a bad personality?’… It’s hard to even explain the diagnosis to your loved ones. It’s so misunderstood.”

“Even the name of Borderline Personality Disorder, it’s like there’s something that’s wrong with you, there something not right that needs fixed. When in fact you are a person and have all these great things about you as well. But all they seem to see is this person who has a problem.”

A personality disorder diagnosis can also lead to discrimination when interacting with health professionals about healthcare needs[71]. Many people we engaged with shared that their care for both physical and mental health was affected due to their personality disorder diagnosis.

One person described a change in attitude from mental health staff when the diagnosis was changed from bipolar to personality disorder. They were suddenly refused admission to hospital when this had been an option in the past for the same kind of symptoms. Another person shared their physical health symptoms were not taken seriously once they had a diagnosis of personality disorder, leading to long delays in accessing treatment they needed.

“Having a PD diagnosis has had a huge negative impact on me. A lot of services don’t want to deal with me and they made it clear they don’t want me there. They did the bare minimum.”

“Having a PD diagnosis changed the way professionals interacted with me, and that’s a common experience from my peers. Once you have that label there’s a certain stigma and attitude from not all, but a sad majority of professionals that everything you do is attention seeking and manipulative.”

In order to have services and support that meets the needs of people living with trauma, stigma and discrimination must be acknowledged and addressed.

3.2 Negative impact of seeking support

Many shared that trying to access support has contributed to their complex trauma. The experience of using NHS services has been re-traumatising to some, whilst many others have been negatively impacted when seeking support.

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

Due to the stigma surrounding personality disorder, people are often dismissed with legitimate concerns around their mental and physical health. Being dismissed and not listened to is another trauma for people. Services should validate people’s concerns and offer the appropriate support.

“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 and I was treated like a pest, they all kept saying I had EUPD.”

Although many services claim to be trauma-informed, this knowledge is not reflected in their practice. People are asked to explain their history and experiences repeatedly, with little support being offered in the aftermath. Services should move towards being trauma-responsive, instead of merely trauma-informed.

"If I had known they weren't going to do anything, I wouldn't have retraumatised myself by opening up and disclosing all my trauma. I left the appointment feeling worse afterwards than what I did going in, and that's supposed to be helping me?"

In summary, many services are not supportive for people who are living with trauma and/or have a diagnosis of personality disorder. Instead, they are contributing to the complex trauma experience by many.

3.3 Receiving a diagnosis

Receiving a diagnosis has been a positive experience for some as it meant they were able to access appropriate support in specialist services where they felt they were treated with understanding and respect. It can be validating getting a diagnosis, as it helps to understand and process emotions and behaviours.

"For me it was a bit of validation, and I was like aw that makes sense why I feel those things and do those things…The diagnosis was helpful for me because it meant I was able to get the treatment and support I needed."

However, it is the stigma surrounding personality disorder that often means receiving a diagnosis leads to negative outcomes.

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

"When we know the impact of a PD diagnosis, we shouldn't be handing them out like sweeties…. Diagnosis is important but it has to be the right one."

Too often people shared experiences of being given a personality disorder diagnosis by one clinician, only to have others disagree with the appropriateness of this diagnosis. Time and consideration should be taken to ensure the person is being given the right diagnosis, and compassion should be shown as this can be a difficult experience.

"It feels like a guessing game when giving you a diagnosis, and it can de-rail your life being given the wrong treatment. I had a friend who was completely over-medicated when it turned out she didn't have personality disorder, she had autism."

Many people who have received a personality disorder diagnosis feel misdiagnosis is common. This indicates issues around poor experiences of receiving a diagnosis. Neurodiversity and Complex Post Traumatic Stress Disorder should also be considered.

Deciding on a diagnosis should be a thorough and comprehensive process. People should be informed they can ask for a second opinion if they don't agree with the diagnosis.

"They told me I was extremely neurodivergent. I have ADHD, autism, borderline personality disorder as well as a background of trauma. They are lifelong conditions and for 10 years nobody heard it, or asked me about it, or wanted to help."

Ultimately, the experience of receiving a diagnosis must be improved. Clinicians should take time to consider if personality disorder is the most appropriate diagnosis.

4. What great services would look like

Taking a strengths-based approach, we encouraged people to think about what great services that fully supported them to live well would look like. There is a large gap between what the experiences of those seeking access to services and what the services can actually provide. An openness and ability to see this gap and seek ways to create change is of key importance.

People shared that terms like 'person-centred' and trauma-informed' feel like buzzwords as they are much used by services and practitioners without any recognition that they do not describe people's experiences of services. They feel strongly that we should move away from using terms indicating how things should be and instead be clearer about what this means in practice and the actions required to achieve these ideals. With this in mind, we must think about why the current way of doing things isn't working and be willing to try new approaches.

"There is a huge disconnect between power and people – people need help."

Analysis of international evidence on service users' experiences of mental health services highlights several areas for which there is a strong consensus on what kind of care is required, including providing holistic support (i.e. support that addresses service users' psychological, social, and physical needs), delivered by skilled and compassionate staff who understand the need for a long-term perspective on intervention[72].

4.1 A relational focus

When exploring what works best people with lived experience consistently talked about the importance of building and maintaining good relationships with practitioners. 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. It can be re-traumatising for people to frequently share their experiences. It is also difficult to build trust and maintain a relationship when people are meeting with different practitioners at each appointment. Therefore, a person-centred service would invest in building connection and relationships with the people they are supporting.

"Taking the time to create that relationship builds trust, and when you have trust in a person it can continue. That makes it easier the next time you are in crisis, if it's someone that's already familiar to you it can ease the crisis so much quicker, as you have immediate trust rather than having to spend all that time building the trust with other people."

During our engagement activity people with lived experience expressed a high level of scepticism about the well-used term 'person-centred'. They felt that the use of this term was not one which they would use to describe their experience of services and that it's continued use negated their experiences. People were clear that while the approach of individual service providers differed, many were striving to be person centred. However they operate in a system which is not person centred so even when individual practitioners were person centred the overall experience was still not one that they could describe in this way.

The 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.

4.2 Compassion

Central to a relational focus in services is compassion. People want support to understand and process their emotions and behaviours, instead of being turned away due to these behaviours. Compassion from clinicians will help people feel safer when accessing support and particularly when receiving a diagnosis.

"All that people want or need is just to be met with 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."

Approaching people with compassion is the foundation to building the trust needed before they can engage effectively with trauma-related therapy. Services delivered with compassion recognise how hard it is for people to build trust and engage, so will invest in relationship and trust building.

"It's easier for them to meet people with those attitudes, than to meet them with compassion and really engage as to how have you got to that place, how has this become your coping strategy…when we do dig beneath that, 99% of the time it's because of experiences when we were younger, and so the way that people are makes perfect sense. But it takes time to

navigate that with people, it's easier just to put people in a box and 'other' them, rather than deal with that"

People told us that it is extremely important to them that services acknowledge their life experiences and how this has affected them. Validation and empathy are important aspects of a compassionate approach. For services to better support people living with trauma and/or who have a diagnosis of personality disorder, they need to invest more in providing the time and structured space for people to process their experiences and find their own ways of living.

"Compassion is key! Whatever the service, people need to be met as people – with their own unique experiences, strengths and difficulties – and treated with kindness and non-judgment throughout! People who experience these kind of difficulties already give themselves a hard enough time - they don't need professionals to do it too."

The recently launched Suicide Prevention Strategy for Scotland includes a commitment to embedding the Time Space Compassion principles in support for people experiencing suicidal crisis. Time Space Compassion is not a service model but a set of principles which guide our human reaction whether as fellow citizens or service providers. It sets out what is needed to support someone experiencing distress:

Time – for people to discuss their feelings and be listened to

Space –which is designed to take account of people's emotional and psychological needs and be responsive to trauma and which feels safe
Compassion – be given the attention, validation and empathy needed and offered assistance on your terms

The Time Space Compassion principles chime very much with what people tell us makes a great service. It may be helpful to consider how they can be embedded into the design and delivery of services for people living with trauma, experiencing complex mental health problems and who may have a diagnosis of personality disorder.

4.3 A flexible approach

People told us that they wanted the support they accessed to be more of a journey and feel less like sitting on waiting list to get treatment or support but with little or no choice as to what they receive. Access to support would 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 is not person-centred care.

This would require support to be offered on an ongoing basis. This would reduce the cycle of referrals, waiting lists and people feeling that they are being passed pillar to post. Many people told us that support while they were waiting for specific therapies would have been very helpful in preparing them to make the best of the therapy once they accessed it. They also emphasised the need for support to assist people to make sense of therapies and courses and to embed the insight, learning and skills into their day-to-day life. To achieve this there will need to be much better collaboration between NHS and third sector services and for both to be recognised as complementary but of equal value.

“There would be access to longer-term psychological therapy – not 8 weeks and out. There would be a range of therapeutic modalities, not one size fits all. Within this, people would be free to voice when a therapeutic relationship isn’t working for them and to seek an alternative, without this being pathologized. Not everyone ‘clicks’ with everyone – that’s a fact of life and doesn’t need to be stigmatised.”

Support would be flexible and suited to what the person needs at that moment of time. Not 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.

“Not a one size fits all type of therapy, it would be seeing me as being me, an individual. Not just dealing with my trauma but holistically…. Actively listening to what I have to say, rather than feeling that I am on a conveyor belt at psychology.”
“Listening to me. Seeing me not the diagnosis. Understanding what BPD is and taking away the stigma. Finding ways to cope for the individual instead of a one box fits all.”

This flexible approach means people would feel in control of their care, and able to collaborate on decisions about their support. Moving away from things being done to people, and instead being done with people. Services would build capacity for people to feel empowered and able to make informed decisions about their treatment.

“Person-centred means taking the lead from the person and allowing them to be in control and decide what they want to do. It’s not everyone around them speaking about what’s best for them whilst the person is kept in the dark with no say.”

If services make a commitment to ongoing and consistent support, this will lead to people having a better relationship with services, rather than being seen as problematic and excluded from the care and support they need. A flexible approach with on-going and consistent care means people will recover with the help of truly person-centred care.

5. What needs to happen to make this a reality

We encouraged people to think practically about what would need to change in order to make great services a reality across Scotland. Using a co-design approach, we used the following key themes to develop our ideas for improvement.

5.1 Trauma-responsive approach

We want to see a shift from simply having an awareness of trauma and related behaviours (trauma-informed) to effectively supporting people living with trauma and/or a diagnosis of personality disorder (trauma-responsive). This will require implementing the six core principles of the trauma-informed approach to care (SAMHSA, 2014[73]); safety, trustworthiness and transparency, peer support, collaboration and mutuality, empowerment, and humility and responsiveness.

The core principle of safety should be carefully considered when planning services and supports. People should feel physically and psychologically safe. We should actively take steps to avoid re-traumatising people when accessing support.

"It would be a specific agency that dealt with all the different issues that complex trauma has. This would stop having to repeat my story over and over again to a number of different professionals, feeling that I am starting again from scratch, or being told different things by different agencies."

Another core principle to be considered is collaboration. Making the shift from "what's wrong with you?" to "What happened to you?" will support people to feel empowered and able to use their own experiences to make informed decisions about their care. People want clinicians who are trauma-responsive, and able to work with them to explore their trauma in a safe way.

"Understanding of the recovery model helped and empowered me – it would be good to see services across Scotland have a trauma AND recovery informed way of working."

"Helping me identify the trauma triggers. Helping me build strategies to be resilient to those triggers and how to deal with them."

Lastly, decisions will be made with transparency, and with the goal of building and maintaining trust. Clinicians should be open and honest in discussions about possible diagnoses, and not hide this from people. Part of this includes challenging the language that is often forced onto people, such as the use of the term 'personality disorder'. Investing time to build relationships and trust with people will lead to better outcomes and engagement with services.

"It doesn't take much time and it doesn't cost a lot but taking the time to explain and discuss the diagnosis can make a big difference. It makes us feel heard and like our feelings matter."

In summary, a trauma-informed approach should be taken at all stages when developing services and supports, ensuring we have trauma-responsive staff who understand and are equipped to deal with trauma and/or personality disorder. To do this, we must focus much more attention on how the NES National Trauma Training Programme is being put into practice.

5.2 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.. Many shared they find the support they receive in the community to have great benefits to their recovery. A whole person approach means that they would be connected to other services who can provide financial, social and emotional support.

"Standing back to assess how my life is more holistically rather than fragmented provision. Joined up communication between services to ensure person centred support which promotes health improvement by understanding that the social issues support could help stabilise mental health conditions and make like worth living."

A whole system approach means that people will have a supported journey and will progress through different types of supports as required. Accessing third sector supports should not mean that they are excluded from clinical supports. They should be seen as complementary.

"Support would be joined-up. Services would work together and would have a clear idea of what other services do and to whom they provide support. People would have less of a "passed from pillar to post" experience and would be able to have multiple needs met alongside each other."

"With 3rd sector charities, I find they offer a lot better support rather than NHS. It feels like 'laziness' on half of the NHS, feels like they can see that other agencies can do it, so they don't have to."

Taking a more holistic approach to support means a range of treatment options will be offered with less reliance on medication. Moving away from 'fixing' people and instead supporting people to live well and be accepted.

"It's like there's something that's wrong with you, there something not right that needs fixed. When in fact you are a person and have all these great things about you as well. But all they seem to see is this person who has a problem."

"For years my doctor told me I had a chemical imbalance in my brain and you need to take this medication and I believed that. Nowadays I don't think it's as black and white as that, it's much more complex…it's very unique for each person. Personality is so diverse, it's a diverse categorisation of people's experiences."

Central to recovery is having supportive relationships. Supporters (families, friends, carers) are an integral part of a whole person whole system approach but are often overlooked. Supporters should be listened to, instead of dismissed. We should acknowledge the impact trauma and/or a diagnosis of personality disorder can have on them also. We must offer support to family, friends, and carers to help them understand behaviours and attitudes that may occur as a result of complex trauma.

"Offer support and education for significant others in my life; too often parents/carers are left behind struggling, putting an added burden on them as well as the person seeking help who is left trying to explain things to them as well."

Services and supports should take a whole person, whole systems approach. They should focus on supporting people holistically, and before they reach crisis point.

5.3 Peer support

Connecting with others with similar experiences is important to people and benefits their recovery. Peer support is validating, people feel they can talk openly with no judgement. Especially with trauma and/or personality disorder, it can be reassuring to be with people who identify with the experiences you have. It is a supportive environment with people who are truly compassionate and empathetic. This will require creating space where people can meet and connect with people they relate to. 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 is the best, it's not someone reading off a script. You are speaking to another person. We don't always have the answers but just being able to speak to others in a group can help."

Many people found peer support to be powerful, as even though people didn't have identical experiences, they had a shared understanding of the emotions which helps. Peer support can help people to understand their experiences and embrace change. Therapies and therapeutic courses on their own are not the solution. Peer support and connecting to others is needed to continue to find a sense of hope, belonging and purpose.

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

“The nature of them is so supportive, just meeting other people with shared experiences was transformative…meeting other people who had similar if not the same experiences was wonderful.”

Finally, peer support is a safe space to explore and develop the self-advocacy needed to be able to challenge the system and take more control. We want to create safe spaces where people feel able to advocate for their own care and treatment. Reflecting with peers can help people gain insight on how they want their care and support to look.

“We really need to think differently about mental health services. The current system is broken where you already need to be in crisis to access support and then you have to wait months and even years sometimes. More investment needs to be put into community-based support and early intervention / prevention. And more access to support when you are in crisis or just really struggling needs to be available out with the NHS.”

For the mental health system to meaningfully support people living with trauma, we must create spaces where people can feel a sense of acceptance and belonging, and recognise the value of peer support. To do this, we need to see both investment in community and wellbeing-based spaces, and in peer support opportunities across Scotland.

6. Proposals for change

6.1 Whole person, whole system care pathways

When looking at how to take a genuinely trauma-informed approach, we need to re-think what our services are there to do and the role of practitioners. While people do value medical-based treatments, deciding treatment of the basis of diagnosis alone is not person-centred. Moving away from the limitations or typically narrow clinical pathways will mean that people can access a wider range of clinical, community-based, social and practical supports and have some choice in the supports that they feel will work for them.

“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.”

Whole person, whole system care pathways 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. This contrasts with treatment which is portrayed as an intervention that will ‘cure’ or ‘fix’. The pathway will look at what support the person feels they need, instead of taking a diagnosis specific approach. It will be co-produced and feature genuine shared decision making. This co-production could operate at two levels: ensuring the individual is fully involved in putting together their own care pathway, and also working with lived experience to ensure that the service is designed in a way that is informed by lived experience as well as what professionals feel is required. The aim for clinicians should be to help the person feel in control of their recovery, supporting them to be empowered. The third sector implement this approach well, they support people without taking their power or agency away from them. Therefore, joined up working between NHS and third sector is essential to this approach.

“There is a lot of good support out there but the trouble for everyone is finding it. A national approach to organising the service landscape to make it easy to navigate would be hugely beneficial. At the moment if anyone moves region they have to go about searching for help/services all over again because every region does it differently. Should be an alternative to GP being the gatekeeper of services and help. Not everyone has a positive experience of NHS or wants the medical model.”

Taking a whole person, whole system approach to care pathways mean they will be more flexible and holistic. A key aspect of this is someone who works with the person to co-ordinate care, such as a peer navigator or co-ordinator. This is not a medical staff member, but they will have role to listen to the person and support them to identify strengths, barriers, and the type of support they need. Then connect the person with the appropriate support in their area. This means people will not be put on a waiting list with no support, instead they will have an assigned person to link them into wider support whilst they wait for specialist clinical treatment.

This proposal is loosely based on Self Directed Support principles and policy. This policy and approach did not become embedded in mental health but still has good intentions, including placing people in the driving seat of their care and increasing the choice of supports. For this to work we need to recognise that people can be in control of their own care and support, they are experts of their own experiences. We also need a commitment to joined up working between statutory and voluntary sectors.

This approach will require a mindset shift and support from NHS to try out a new way of working and view the third sector as equal partners. This is a cultural issue and whilst not easy to solve needs to be addressed if improvements are to be realised. NHS must equally value non-clinical approaches and staff. If they are open to embracing these new roles and working alongside peer navigators/co-ordinators, it will be easier to provide seamless, person-centred care.

Taking a whole person, whole systems approach to care pathways will link people with organisations who can provide people with will safety, stabilisation, and any other support they need. Leading to people being able to fully benefit from intense therapeutic interventions, resulting in less reliance on medication. Over time it should mean that there is less pressure on GPs and CMHTs as people are supported to access a wider range of supports and diverted from the medical system. They won't feel passed pillar to post as they will be linked into the right support at the right time. Support will be truly person-centred and based on what the person needs at that time, rather than based on a diagnosis. The consistency of the navigator/co-ordinator allows for a trusting relationship to be developed, which will lead to better engagement with services and support. People would get better support to help them move forward in their recovery and build the support networks and self-management skills they need to live well.

6.2 Peer led support

Whilst people do value good experiences with psychiatry and psychology, they also recognise that want support from practitioners that use more of their self and own experiences to create a reciprocal relationship. This fits best with peer support. We need to build peer support into the mental health system. People want support from motivating role models who can share their own lived experience. It allows people to connect with others who have similar experience in a safe and supportive environment, which we know is beneficial to recovery. 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.

"It is emotional to get a diagnosis, so if you had further opportunity to meet up and explore the condition, you would feel able to start to open up and build trust with the practitioner. There is a need for follow on / aftercare which is extended, as when you receive a diagnosis of BPD media and society see you as you 'need help and have a serious disorder'. However, when you ask for help it is limited. There needs to be a better framework or pathway e.g., where you are assigned a support worker for 6 months, to put all of this new diagnosis into place."

Within services there should be more investment in peer roles, such as peer practitioners who are part of clinical services. Peer practitioners can be involved in:

- Supporting people to prepare for therapies or therapeutic courses
- Co-facilitating therapeutic courses and offering lived experience support during therapy
- Delivering peer support groups for people finishing therapy and therapeutic courses, as a bridge to community-based peer support groups
- Supporting people as they move on from therapy to embed any learning in their life and implement self-management and self-care strategies.

Having these roles located in services is a way for people to explore peer support groups without having to be discharged. This also will help clinicians encourage people to join the peer-led groups in the community, and build confidence in people that the community-based peer support groups can offer meaningful support. Peer practitioners will work alongside local peer support groups and be able to link people into these as they move on from services.

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

People should be supported to access peer-led support groups in their local communities. These groups often take an informal approach to support, incorporating activities which creates a relaxed environment. It can range from talking groups, to crafting or walking groups – the possibilities are endless however the underlying commonality is the connections that people are able to make. This is what makes peer support powerful. To make this a success, we will see investment in capacity building for local peer support groups, and training for peer group facilitators. People will be supported to find and join peer support groups in their community which will assist their ongoing recovery and minimise future crisis.

In order for peer led support to be a key component of the mental health system, we need to change the culture of services and the way they provide support. The third sector and NHS need to work more collaboratively, in line with a whole person, whole system approach.

Focusing on a peer pathway, we will see investment in community-based support and the personal development of peer practitioners. Learning from community models which invest in local peer activity to provide networking, training, and support for facilitators which ensures the organic approach to peer support in maintained – such as Edinburgh Thrive. More opportunities for peer support can reduce isolation and stigma, whilst also increasing self-management skills and agency. It can also encourage people to embrace changes which we know benefits recovery. Overall, building peer support into the mental health system is a powerful way to support and develop recovery
focused practice.

6.3 A new approach to crisis support

We need to re-think the way current crisis support is offered to people living with trauma and/or a diagnosis of personality disorder., as the current picture is one that often triggers and re-traumatises people. Offering crisis support in high pressure, clinical spaces like A&E may feel unsafe. Similarly, crisis support over the phone can be difficult for people to engage with, as they feel they aren't able to connect and build trust with the practitioner. To address this, we propose crisis support should be accessible and effective. With this in mind, a community-based approach to crisis support would be a suitable alternative as non-medical approaches to distress are effective.

"Seeing me as an individual and not a label. Providing more upstream support, working more with the third sector to ensure less people need crisis and more in-depth support."

Support shouldn't be dependent on a person's history or diagnosis, but instead based on what they need at that moment in time. Especially in crisis, people need effective support for the triggers, rather than a generic diagnosis-based approach. The approach should offer flexibility and consistent support that will promote recovery and wellbeing for people living with trauma and/or a diagnosis of personality disorder. Having crisis support based in the community means a more holistic approach to support can be taken. We would move from simply assessment and self-management to effective crisis support.
There are many community-based approaches to crisis support internationally which we can learn from, such as:

- Peer-led recovery houses (New Zealand)
- Peer specialists in emergency rooms (USA)
- The Trieste Model of Care (Italy)

Within Scotland there are innovative programmes that could also inform this new approach, such as Distress Brief Intervention (DBI) and the Navigators programme within the Scottish

Violence Reduction Unit. One idea that was proposed for effective and accessible crisis support was a community-based crisis hub, however this needs further exploration. Underpinning all the approaches and ideas is strong links between NHS and third sector, who would be working together seamlessly. A willingness to embrace this new approach is key, we will be “thinking outside the box, instead of ticking the box” as one participant said.

Having effective community-based crisis support will reduce pressure on frontline NHS services such a GPs and A&E, as well as first responders. By offering support on an ongoing basis approach, it will reduce the cycle of referrals and stop people feeling passed pillar to post. The holistic approach taken means we will see more joined-up working and collaboration between NHS and third sector.

Further exploration of this approach is required, but initially we need to shift the culture and power dynamic. We must recognise that third sector organisations have the skills required to provide crisis support and lived experience must have a strong presence round the table. Co-production is key.

6.4 Training that is co-designed and co-delivered

We discussed the benefits of a short training course that is co-designed and co-delivered by people with lived experience and NHS staff with a remit in mental health. When people talked of the need for co-designed and co-delivered training, they envisaged working closely with NHS staff to develop and deliver training that brings lived experience and clinical perspectives together. This is more than people with lived experience sharing their story or having a space in a clinician designed course.

The comprehensive training will look to increase staff understanding of trauma and the way people present when they are in crisis. It will look at communication, attitudes, equality and human rights, and the links between trauma, personality disorder, and neurodiversity. The main goal of the training to shift stigmatising attitudes and increase compassion towards people living with trauma and/or a diagnosis of personality disorder. People told us that they understood that pressures on staff and the effects of staff wellbeing can result in a loss of compassion. They recognise that these pressures are systemic but feel that co-designed and co-delivered training which increased understanding of trauma would contribute to the creation of mental health services which work better for people accessing them and people providing them.

“Practitioners are trauma-skilled and they understand behaviours and reactions as reasonable responses to unreasonable life experiences. Environments where support is provided are also

trauma-informed, as well as facilitating accessibility for those with neurodivergence, physical limitations and other additional support needs."

Training will initially be offered to staff working in mental health, with the intention to roll this out to all NHS staff upon reviewing the impact on staff wellbeing and people's experience of the services. Moving beyond this, the training could be delivered to medical and nursing students at university to ensure a unified and consistent approach. The training will be compulsory for all staff and completed on an annual basis as part of staff continual professional development. Staff will be given adequate time to complete the training, but also time to reflect and look after their wellbeing following the training.

We must see real investment in the development opportunities for people with lived experience, as social contact model is key to the success of this training changing stigmatising attitudes. With this in mind, people with lived experience will be involved in the delivery of the training through online or face-to-face sessions. People told us that it is important that lived experience are involved in the delivery of training through online and face-to-face sessions. While the use of pre-recorded videos may be beneficial to some extent people did not see this as an effective substitution for real interaction with lived experience during training. Learning from the 'Co-ordinated Clinical Care' training which was developed with the BPD dialogues group in Glasgow can be utilised.

There was a strong consensus among the people engaged in the project that training of this type would greatly improve understanding among staff in NHS services. This improved understanding would result in a more empathetic and compassionate response which would reduce distress and re-traumatisation when accessing services. People also felt that there could be shorter hospital admissions as people had better experiences in services. Staff would be trauma-responsive with less incidents of discrimination. People will feel supported and have positive experiences when engaging with services. It would also contribute a shift in power dynamics, as we will recognise people as 'Experts by Experience'. As part of the training will focus on staff wellbeing, we envision seeing decreased compassion fatigue amongst NHS staff. Ultimately, this training has the potential to shift stigmatising attitudes towards people living with trauma and/or a diagnosis of personality disorder, and contribute to a trauma-responsive NHS.

7. What next

7.1 Personality Disorder Improvement Programme

This work was carried out as the lived experience engagement element of the Personality Disorder Improvement Programme which is led by Healthcare Improvement Scotland. The overall aim of the project is to better understand the current picture of service provision for people with a diagnosis of personality disorder. This will help to identify the key opportunities for improvement and to then develop proposals to deliver those improvements. We strongly advocate for the voice of lived experience to continue to be involved in the development and delivery of any new recommendations. If any of the proposals mentioned in this report are to be acted upon, we recommended further facilitated discussions with Scottish Government, NHS, third sector organisations, and people with lived experience, to explore how these proposals can be put into practice.

7.2 Resources

Scottish Recovery Network, VOX Scotland, and our Lived Experience Project Group are developing a suite of resources in line with the findings of this report. The resources will aim to address some of the issues around stigma and discrimination, as well as provide support for services to develop best practice. The following resources are planned.

- Practice learning resource for organisations and services
- Storytelling through photography booklet
- An animation

These materials will be ready for publication in Spring 2023.

“Each connection with a person is an opportunity to get things right for them.”

8. Get involved

Ultimately, the voice of lived experience should be valued and involved in all decision making around mental health services and supports. We want to see a commitment to ensuring the mental health system is powered by lived experience.

If you or your organisation are interested in engaging with the voice of lived experience, you can:

Download our **Recovery Conversation Café toolkit** to have conversations about what matters most to people and let us know how you use it

Sign up to the Scottish Recovery Network **newsletter** to hear about upcoming opportunities and new resources. Contact us to find out more!

Keep up to date with VOX Scotland through our Twitter account, and if you have lived experience of mental health issues you can join as a member.

If you have any questions or need this report in a different format please contact us:
Call us on **0300 323 9956** | British Sign Language (BSL) users can contact us directly using **contactScotlandBSL**

Email us:
- **info@scottishrecovery.net**
- **info@voxscotland.org.uk**

Check out our websites
- **www.scottishrecovery.net**
- **www.voxscotland.org.uk**

Appendix F Staff Engagement Report

Executive Summary

The Scottish Government has made mental health a priority as identified in the Programme for Government for 2022-23[1]. Recent reports by the Royal College of Psychiatrists and the Mental Welfare Commission[2,3] highlight that access to services and interventions for those with a diagnosis of personality disorder have considerable variation across Scotland. This is significant as there are considerable risks associated with diagnosis, with evidence indicating that those with a diagnosis are at greater risk of suicide[4,5]. Indeed, up to 10% of those with a diagnosis of borderline personality disorder will die by suicide[6] and estimates suggest that between 25-70% will have at least one suicide attempt in their lifetime[7,8]. Borderline personality disorder is also significantly associated with higher rates of deliberate and repeated self-harm[9,10].

To understand the realities of current service provision, the Personality Disorder Improvement Programme (PDIP) engaged with staff across Scotland, who support and provide treatment for those with a diagnosis. This evaluative report details the findings of this work (i.e. survey and one to one interviews). Key findings from the survey and interviews are:

- Most staff are confident of their knowledge and understanding of personality disorder
- Most staff are confident in their skills working with those with a diagnosis
- Most staff feel empathic towards those with a diagnosis and believe that individuals can manage their symptoms and move on towards recovery, however;
- Staff feel there are significant limitations and challenges within services, such as:
    - Challenges around diagnosis and diagnostic language
    - Challenges with service design
    - Challenges with access to training, supervision and staff wellbeing
    - Challenges with consistent approaches to treatment
    - Challenges with staff/service stigma towards diagnosis
    - Challenges managing therapeutic and professional relationships and
    - Challenges for staff in terms of clinical time and staff numbers.

Recommendations and conclusions based on these outcomes are contained within the final sections of the report.

Introduction

The aim for the staff evaluation work was to engage with staff across a range of professional disciplines throughout Scotland. The survey was available to all staff nationwide and was circulated among various professional groups (nurses, psychologists, psychiatrists, occupational therapist, etc.). The interviews involved a small number of staff self-selecting for participation, from key locations (Greater Glasgow & Clyde, Lanarkshire, Ayrshire and Arran and Fife). These locations were thought to best represent the general demographic makeup of Scotland, including urban and remote and rural.

The objectives for both the survey and interviews was to obtain a deeper level of understanding of staff perceptions on challenges to providing high quality care for those with a diagnosis of personality disorder[*]. Whilst not a primary aim of the engagement work, it was also important to understand areas of perceived good practice and what staff found to be rewarding from their work.

A combination of qualitative and quantitate approaches were used (please see methods section for a detailed commentary on methods and approaches). Due to COVID related restrictions in place at the beginning of the programme, all engagement work was conducted remotely.

It is the intention that outcomes from the staff engagement evaluation will allow for improvement recommendations by identifying areas of challenge and how these may be barriers to high quality care.

Methods

Methodology

All data was collected remotely between July and October of 2022. Survey data was obtained through staff completing an online survey, which was available from July until October of

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[*] The term diagnosis of personality disorder is not intended to be pejorative and the larger issues surrounding the diagnostic term and its use has been extensively discussed with the PDIP Expert Reference Group and The Scottish Personality Disorder Network. Its use throughout this report also includes those without formal diagnosis but who have characteristics that would be indicative of diagnosis

2022. Survey questions were developed by members of the PDIP team and were informed by an evidence review produced by PDIP and clinical knowledge. The survey contained both scale based questions (scored from strongly agree to strongly disagree) and open response questions where staff could leave more detailed answers.

Descriptive outcomes (percentages) from the survey can be seen in the main findings section of the report. Analysis of open response question was informed by thematic analysis[11], which involves a 5 stage process: familiarisation, generation of initial codes, searching for themes, reviewing themes, defining themes.

Interview data was obtained through one to one interviews using MS Teams. An interview procedure was developed prior to the interviews by the PDIP team and was based on clinical experience and the evidence review mentioned above. A 'critical friend' also reviewed the interview procedure prior to interviews beginning in August of 2022. The final staff interview took place in October of 2022.

The Framework method was used to analyse all staff interviews. Framework is a popular method within health and social research, due to its usability and flexibility[12].

Data was analysed in line with stated aims (identification of challenges to high quality care, areas of good practice), using the five stage process of the framework method:

- Familiarisation
- Identification of thematic framework
- Indexing
- Charting
- Mapping and interpretation.

Interviews were transcribed before being coded, following this initial codes were then checked by another experienced researcher outside the programme. Discrepancies were addressed and the resulting codes formed the framework which was applied to the remaining interviews. Codes that were conceptually linked were grouped into categories. Categories and codes were then organsied into a matrix (using Excel) to enable interpretation and the generation of final themes. Survey questions and the interview protocol are available in appendix 1 and 2.

Main findings

In total, 322 staff took part in the evaluation. A broad (but not exhaustive) range of staff who would have contact with those who may have a diagnosis of personality disorder were represented. A total of 303 staff participated in the survey and 19 staff participated with the one to one interviews.

Quantitative outcomes

Data collection for the survey was completed on the 31st of October 2022. Table 1 (page 6) shows participant characteristics for professional role and years of experience working in mental health services. Most staff worked in adult mental health (86.6%) and the most represented professional groups were nursing (48.18%) and psychology (25.08%). Most staff (69.3%) had more than 10 years' experience and most (91.1%) agreed that they had a good understanding of diagnosis and the factors associated with development.

81.9% of staff felt that they had the skills to work well with those who have a diagnosis and most staff reported feeling empathy and compassion towards those with a diagnosis (93.1%). Most staff (96.1%) reported that there were challenges to working within this area of mental health and with this patient group and more than three quarters of staff surveyed (76.3%) felt that there were limitations in service provision for those with a diagnosis.

Most (94.4%) staff felt that those who have a diagnosis could be supported in creating improved quality of life and felt that their service was good (73.3%). Access to supervision was felt to be adequate (83.8%), with 5.3% disagreeing. Most staff (79.9%) felt that they had the opportunity to apply reflective practice to their work. Most staff felt their wellbeing was supported within their service (75.9%), however 15.5% of staff reported neutral responses to this statement.

Outcomes from the survey indicate that most staff felt confident in their skills and knowledge, and feel empathy towards those with a diagnosis, with a belief that individuals can be supported towards distress management and recovery. Outcomes also indicate that staff feel adequately supported with clinical supervision, wellbeing support and opportunities for reflective practice. However, most staff agreed that there were limitations in service provision for those with a diagnosis, with recognition that this area of work has considerable challenges.

Table 1. *Participant characteristics*

Professional Role	
Nursing	48.18%
Psychology	25.08%
Psychiatry	5.94%
Medical	2.64%
Occupation therapy	8.25%
Other:	9.9%
Social work	
Midwife	
Police	
Speech and language therapist	
Peer support worker	
Mental health practitioner	
Counselling	
Housing support	
Years of experience	
>10 years	69.31%
5-10 years	16-17%
1-5 years	11.88%
<1 year	2.64%

Answers from the open response questions were represented by five themes, which related to specific areas of challenge (see figure 1, page 7 for visual representation of identified themes).

Challenges supporting clients: difficulties establishing and maintaining relationships with individuals who have experienced significant levels of trauma and therefore find it difficult to build trust was a key area of challenge. Managing and enforcing boundaries within relationships, in addition to managing the ending of the therapeutic relationship was also mentioned as challenging. Providing wider support (i.e. support outside of therapeutic contact), particularly in the context of additional aggravating factors (e.g. substance abuse, abusive or dysfunctional relationships) were felt to be challenging. Managing risk (e.g. suicidal ideation, self-injury, aggression, etc.) and helping clients take ownership of their recovery were cite as additional challenges.

Consistency in team approaches to treatment: interdisciplinary relationships and collaborative working was cited as challenging, particularly if teams were felt to be '*split'* in terms of views on diagnosis and approaches to best support clients and manage issues such as positive risk taking. Perceived "manipulation" of the team or specific team members by clients was also mentioned. Lack of consistency in approaches and some teams/staff not using trauma informed or evidence based approaches aggravated feelings of challenge. A lack of shared understanding around diagnosis, its relationship to developmental/early life trauma and the implications of this for building positive relationships also featured.

Attitudes towards diagnosis: negative perceptions among staff, wider stigmatisation within services and the broader context of how this leads to further misconceptions of diagnosis featured. Issues such as the stigma of 'labeling' and comorbidity (which potentially masks and/or exacerbates symptoms) was also mentioned. The lack of attention given to perceptions and experiences of diagnosis among those with lived experience was also a cited as a challenge.

Figure 1. Areas of challenge identified from survey responses.

Service based challenges: lack of specialist or dedicated services/pathways across boards, as well as limited access and availability of interventions for those with a diagnosis was considered a challenge. Lack of communication between services (e.g. crisis, inpatient, A&E, police) was mentioned, as was timely access to accurate patient records. Crisis care pathways and perceived lack of suitable inpatient care also featured. Additional challenges concerned referral practices and long waitlists, which were felt to cause delays in care, with potential harmful effects on the person.

Staff wellbeing: the emotional impact of providing care to a those who potentially have heightened risk for self-harm and suicide was a significant feature. Many staff questioned themselves over whether they are “good” enough. Resources to support staff (supervision, wellbeing and organisational support) are not always felt to be available. This was echoed in terms of access to training and professional development to ensure competence. Repeated client presentations to services was mentioned to have an impact on wellbeing. Additionally, expectations of staff from service users and from services themselves were often felt to be unrealistic given available resources. Indeed, staff shortages as well as recruitment/retention was a key feature of discussion, with many describing the pressures of working within mental health services.

In contrast to challenge, 66.7% of staff felt their work was rewarding (see figure 2, page 9 for visual representation of themes identified). Staff were asked to share their perceptions of reward within open response answers. The areas of reward mentioned were covered by three main themes.

Seeing positive outcomes for those with a diagnosis: seeing reductions in risk, improvements in symptoms and seeing those with a diagnosis move on or need less input from services was felt to be rewarding. Seeing recovery, skills building, changed perceptions of services and seeing patient gain greater understanding of their diagnosis was also mentioned. Greater self-understanding and improved relationships (e.g. family/friends etc.) was seen felt to be rewarding.

Seeing services and service access improve: increased use of dedicated services and pathways or improvements/developments underway for these was highlighted. Combating stigma in personal perceptions and within services of those with a diagnosis was mentioned. Effective care planning and having time to dedicate to those with a diagnosis featured, as did access to training.

Building relationships and enjoying the work: enjoyment of working in an area that challenged practitioner skills, enabled professional growth and provided opportunity to help others featured. Engaging and collaborating with individuals in their treatment and recovery was mentioned, as was gratitude from clients. Having the time to build deeper therapeutic relationships due to time spent with individuals was also cited as a reward.

Figure 2. Areas of reward identified from survey responses

Areas of reward

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

Whilst most staff found their work rewarding, 25.7% reported feeling neutral and just under 8% of staff either disagreed or strongly disagreed that their work was rewarding.

Survey outcomes should be viewed in light of several limitations. Firstly, outcomes do not claim to represent all Scottish staff working with individuals who may have a diagnosis. Secondly, survey measures have notable issues in terms of bias and outcomes should be viewed with this in mind. Finally, survey measures do not allow for deeper levels of understanding of personal experience. To address this, the staff interviews will provide a more detailed account and enable a more in depth understanding of staff experience.

Qualitative outcomes

Staff interviews took place between August-October 2022 with staff from adult and older adult services, with representation across inpatient, secondary and crisis care seen among participants. See table 2 (page 10) for interviewee characteristics.

Over 15 hours of interviews were recorded and transcription was done by the PDIP social researcher. Using the framework method[12] to analyse the interviews generated 49 codes. Based on similarity of topic, codes were clustered into 12 categories (see appendix 3). Analysis across codes and categories generated 4 overall themes (*Challenges around diagnosis and diagnostic language, Service design challenges*, *Access to training and job satisfaction* and *Stretch and system pressures on staff*). The potential impact on individuals with a diagnosis was also explored in relation to these themes. Figure 3 (page 13) displays the themes associated with being barriers to high quality care.

Table 2. Interview participant characteristics

ID	Role	Years in service
Participant 1	Forensic psychologist	1 year
Participant 2	Clinical psychologist (CMHT)	8 years
Participant 3	Specialist nurse	11 years
Participant 4	Occupational therapist	6 years
Participant 5	Psychology lead	30 years
Participant 6	Physiotherapist	4 years
Participant 7	Occupational therapist	18 years
Participant 8	Psychiatrist	28 years
Participant 9	Specialist nurse	13 years
Participant 10	Psychotherapist	35 years
Participant 11	Occupational therapist	22 years
Participant 12	Crisis team nurse	25 years
Participant 13	Community psychiatric nurse	26 years
Participant 14	Project nurse	37 years
Participant 15	Inpatient mental health nurse	26 years
Participant 16	Service manager CMHS	32 years
Participant 17	Forensic Psychiatrist	5 years
Participant 18	Clinical lead older adults	9 years
Participant 19	Clinical psychologist older adults	9 years

Challenges around diagnosis and diagnostic language

Current terminology/language was described as problematic and stigmatising and does not adequately capture the often traumatic experiences leading to diagnosis. Overall approaches to diagnosis were felt to be inconsistent, problematic and reinforcing of negative perceptions (within the individual and staff), with the potential to exacerbate distress and did not involve collaboration or information sharing with patients.

> Participant 1 “it can be harmful if it's a diagnosis that is sort of slapped upon someone, it isn't thought about or explained, as in formulated, it isn't used in a sort of shared language type way. I think that can be quite damaging, but I think there is potential for it to be used in quite a useful way if it's explained and considered properly, sort of properly understood by the team and by the person”

Staff expressed that there is often an overly medicalized approach to difficulties considered to be fundamentally emotionally and/or psychologically based. This was also felt to influence service users in the belief that there is a medical resolution to their distress.

> Participant 8 “culturally, if you are ill, then you'd come to the doctor and you'd get medication, and sometimes it feels that they [those with a diagnosis] in order to be recognized as being properly ill, have to have something properly wrong with them, they need to see the doctor and they need to get medication and the focus can often be on medication and I think often with a vain hope that you know, surely if they feel this bad, there must be something, there must be something that you could take that is going to make all this go away”

Whilst the problematic and stigmatising nature of diagnosis was apparent in discussion, diagnosis was also viewed as gateway to treatment. However, further challenges concerning diagnosis were acknowledged, with misattribution of symptoms and distress often leading to misdiagnosis (e.g. bipolar), potentially leading to unsuitable treatments. Discussions further explored changing terminology, such considering how those with a diagnosis chose to self-refer (e.g. complex post-traumatic stress disorder, emotional regulation disorder, etc.). However, it was also felt that changing terminology may not change the stigma associated with diagnosis.

> Participant 10 “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”

Diagnosis is unlikely to be the starting point of service contact for those who present with difficulties consistent with personality disorder. Whilst diagnosis may be a ‘gateway’ for access to services and treatment, how it is approached can lead to further stigmatisation and distress if not done in a collaborative and explanatory way. The medicalization of personality disorder can also be potentially harmful, as absence of psychological interventions increases the likelihood of medical interventions, which cannot address emotional and psychosocial factors. Consideration of diagnostic language (which may or may not affect associated stigma) is also something that should be explored, with an explicit focus on the views and opinions of those with lived experience.

Figure 3. Themes associated as barriers to high quality care

Service design challenges

Staff expressed that those with a diagnosis were the most likely patients to be seen and as such discussions involved dedicated services and pathways. Whilst at present there are only two dedicated services in Scotland, there was disagreement in whether these were necessary or whether their wide-spread implementation is the right approach to achieve high quality care.

> Participant 5 “if you were asking me as a service manager, would I create a personality disorder service? Absolutely not. In no way would I do that, would I create pathways for people with emotional instability? Yes, I would. And that's largely where we're going”

> Participant 11” we need to have dedicated services for this group of people, because we still operate in a system that holds negative attitudes and stigmatizing judgments, and not everybody wants to work with this group of patients”

Others felt there was a lack of clarity on how these services operate, with concerns that moving existing staff to a dedicated service could contribute a skills drain and exacerbate existing service pressures. Some staff also felt that a dedicated service could potentially discriminate by denying those with a diagnosis access to the wider scope of mental health services.

> Participant 12 “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"

> Participant 7 "I don't know if that's the right answer, to be honest, because equally I think there's something about having a skill set across services because that could again become quite specialist and I know there are other areas in Scotland that I've got specialist services, but they are for the, the most disordered group of people, and there's lots of other people who have, who meet the diagnostic criteria that that would be accessing the CMHT"

Other service design based challenges, such as the lack of parity between mental and physical health services, difficulties in service development, the length of time for services to become operational, in addition to lengthy waitlists for psychological therapy were mentioned. Crucially, these challenges were viewed as barriers and inconsistences in providing high quality care. For service users this could result in extended periods on waiting lists or unfortunately being from a locality where pathways/services are either not offered or are not fully operational.

> Participant 18 "I think services are set up in a way where the journey to get to psychologist is not that helpful"

> Participant 7 "we're starting to try, well, I mean I'm saying starting that's been going on for a long time, years, but to try and develop pathways within the service, and we've had pathways in the past but we're like reviewing and looking at pathways again at the minute and looking at you know the evidence base in terms of working with this group of people, it's still ongoing work. The problem is that the pathways not implemented as a whole yet. So we'll get parts of a pathway that we're running, but it's not consistent for somebody"

Participants cited inflexibility in service design, with an over-reliance on targets, an inclination toward speedy discharge and practices of 'disengage/discharge' as further challenges. Given that those with a diagnosis can have difficulties engaging with services (resulting from negative past relationships and/or negative service experiences) these practices could be seen to further isolate and marginalize those with a diagnosis.

> Participant 5 "ultimately this this is a population that don't engage well and we need services that are able to step out-of-the-box. We need open access, we need referral systems that don't involve going to a doctor or you know, a mental health practitioner. You know, it needs to be open access and we need to be flexible in that and that means there will be a lot of waste. So there will be a lot of times that appointments aren't fulfilled, there will be a lot of times that groups are not, you know at capacity. And we need to not be worrying about that, we need to see that as natural attrition"

Appropriateness of inpatient and crisis care, while often seen as well intentioned, was not thought to suit those with a diagnosis. Staff perceived this care to be depersonalized and invalidating, with the danger of increasing risk by escalating symptoms that can be difficult and distressing for the individual and for staff. Additionally, it was expressed that there was a risk for care to become protracted and thereby a barrier to recovery.

> Participant 15 "So probably initially when somebody is admitted and we get them over the initial kind of stress or trauma, which led to their admission, they probably end up staying hospital too long, which sometimes can get you into a vicious cycle and I've seen that over the years, but it's then difficult sometimes because there has been a couple of self-harm attempts or a suicide attempts. It's then difficult to get them back out (of) hospital sometimes, the window of opportunity to get, and sometimes when you know, maybe we are not as good as we can be about taking that positive risk"

> Participant 8 "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 then 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"

Instead, person centered, individualised care that transitions away from a 'one size fits all' mentality was felt to be a better approach. However, within existing service provision this was seen to be a challenge in light of regional and local availability of interventions (Participant 7: "the most evidence based treatment for this client group is DBT and we don't offer it"). This was also felt to be challenging due to staff feeling that there is little time to maintain their own wellbeing alongside dedicating time to patients, to the detriment of patients.

Following diagnosis, accessing appropriate care poses a significant challenge, with staff reflecting that those with a diagnosis can spend prolonged periods on waiting lists for psychological therapies. The extensive time needed to develop dedicated services/pathways, an overall lack of these as well as inconsistent access to treatment across the country also means that individuals can face inequity in provision. This means that use of crisis and inpatient care can become common in periods of heightened distress. However, staff described that this care was not always in the interest of those with a diagnosis. It was also reflected that once an individual has accessed services, the inflexible nature of their design can pose further barriers, with a focus on time bound, target driven practices meaning that the extended relational contact needed for successful outcomes is not always feasible.

Access to training and job satisfaction

There was variation in training and knowledge in early career education across all professions, however this was most acutely reflected for nursing, physiotherapy and occupational therapy. Staff felt that there was little focus applied specifically to personality disorder within early career education and training. Variation in access to ongoing training opportunities (again most acutely reflected for nursing, physiotherapy and occupation therapy) was highlighted, with access being felt (by some) to be inequitable. Prioritisation for specialised and low intensity interventions for personality disorder based on service type (e.g. adult vs older adult) meant that some staff can be excluded from limited training places. This could have considerable consequences for high quality care, with deficits in staff knowledge and competencies between services.

> Participant 18 “our health board has, like say five places that NES will release. 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”

Staff described frustrations surrounding training, such as a lack of ‘one team vision’- where all individuals involved in a person’s care are in agreement in approaches. Training was described as being non-mandatory with no top-up or refresher sessions, which were felt to increase confidence and best practice and potentially assist in stigma reduction and enhance peer support.

> Participant 2 “I know what I found helpful from good training, for instance, from the DBT training, is every few months we have a DBT interest group where we meet with the head of that service for the chance to reflect on our cases and how we're getting on with applying that in practice. So I think that's a helpful thing”

Several staff reported variability and inequity in terms of support, specifically clinical supervision and peer support. Adequate supervision was felt to be crucial in ensuring consistent practice, avoiding burn-out, as well as ensuring client, practitioner and organisational safety. However, outside of psychology and psychiatry, there was often disparity in access and process across staff groups.

> Participant 13 “I don't think we get proper supervision for working specifically with this client group at all because if we get individual supervision from, like the nurse team leader, OK, so you know, there's things that need to get done with governance and everything, but there's never a discussion around about, you know, how did that make you feel, you know? Those kind of things, because that is the most…Like the thing that you can struggle with at times, isn't it? How you felt, you know, especially when something goes wrong”

> Participant 1 “in terms of the wider team and I don't think there's an awful lot of consideration. I mean, nurses, for example, don't even have clinical supervision in place at the moment at all”

The emotional impact of supporting patients was discussed, with individuals often being described as ‘revolving door’ patients who could present repeatedly across services, often with perceived difficult behaviours (suicidal and suicidal self-injury/ideation and/or aggression). Staff also discussed their professional self-management in relation to frustration and disappointment with client setbacks as well as professional self-doubt in providing care. This was felt to be further complicated by staff becoming risk adverse and avoiding positive risk taking.

> Participant 8 “the other thing is about, you know this, this patient group is really risky. In terms of actually completing suicide and staff are obviously concerned about that, nobody wants to feel that the patient that they have been looking after has then ended, ended their life and you know when it happens, as it inevitably it does you know, staff, I think become really quite upset and anxious and concerned and worried about, you know what that means for them and would things have been better if they had known something different”

> Participant 3 “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. So I'm talking about things they are like as soon as somebody you know, makes a move to self-harm even when they tell you there was no intent, no suicidal intent and it's minor, you know people get clapped on constant obs (sic), and then what happens largely is that that behaviour deteriorates, it gets worse”

Once those with a diagnosis access interventions and services, there can be variation in what is experienced. As access to training is felt to be inequitable, this means that depending on where an individual presents, the level of care and interventions available to them can be varied. It was expressed by some staff that low intensity interventions carried out by CPNs, OTs, etc., (such as Decider) could assist in preparing an individual for more intensive therapy (once psychological therapies become available to them), as well as having a more immediate impact on quality of life. It was also felt that ensuring that staff are adequately trained across services, could enable high quality care and consistency across services.

Stretch and system pressures on staff

Staff shortages and concerns with recruitment and retention were felt to cause additional pressure to an already pressurized system. The implications for what kind of services could be offered, and what improvements could be made under such conditions were highlighted by staff.

> Participant 5 “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?”

Staff shortages were felt to be particularly problematic in terms of treating those with a diagnosis, as those with a diagnosis require extended therapeutic contact to enable relationship building and recovery. Operating with less than optimal staff numbers was felt to contribute towards negative perceptions, with service users being seen as ‘demanding’ or ‘manipulative’ and taking time away from other service users.

> Participant 4 “I think particularly with this sort of client group, because I would say they can be quite demanding of time, maybe not the easiest behaviour to manage at times, and there's not enough staff to do it and then that kind of feeds into the sort of negative perceptions of the diagnosis”

> Participant 11 “people with personality disorder will often get care and response and a service at the expense of those say with an F2 diagnosis because they don't typically seek out help, they are the quiet people in your caseload until they become unwell and they need to be admitted to hospital, but they don't get routine care especially now, especially in this climate where we're getting no staff, where the way that we work has completely changed. And I think that's hugely challenging and I think that's got the potential to reinforce some of that stigma for staff because it’s like, I can’t deal with those people because those people are, you know, demanding and shouting and wanting more”

Links and access to information between community, inpatient and specialist services (i.e. addictions) were seen to lack integration and joined up thinking, impacting what was available for the individual and the information available to staff. This was felt to be particularly problematic if a client was presenting in crisis or being denied necessary additional support crucial to management and recovery (i.e. additions).

> Participant 1 “I don't think it's something historically within the prison service in particular and in relation to managing patients with personality disorder diagnosis or not even diagnosis with sort of indications that they may have difficulties with their personality. I don't think there is as much collaboration as there should be or could be”

> Participant 2 “…trying to access other services. For instance, you know if things, like when I'm, you know, trying to work with addiction services or social work as well and again, because I'm sure because of pressures on those services as well sometimes, there's been issues like the referral got lost somehow in the system and I had to put it in again to social work and with IT was one thing after another with this one particular client when I was trying to get them some social work input that would enable me to do the therapeutic work with them better”

> Participant 18 “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”

Staff attitudes and consistent approaches when working as part of a team were seen as a challenge. Specifically, teams were felt to be ‘split’ due to lack of shared language and approach towards treatment, in addition to perceived unrealistic expectations on what care can be offered. This was also expressed by some staff to result in service users being seen to be ‘someone else’s problem’.

> Participant 1 “if you got that shared language that shared understanding you're all singing from the same hymn sheet, that enables that person to, I guess, manage and recover and for us to help that person manage themselves a bit better. Than if we're all doing different things or if there isn't that understanding and you're kind of just firefighting”

> Participant 17 “I suppose another difficulty is understanding from other groups of professionals that may be involved, and I think it again, it comes back to training, let's say I'm working with prison officers or police officers or social care staff, their training might not be as good within the area of personality disorder, and then their expectations of what I can do or what mental health services can do is unrealistic. And again, I think it's about that whole team working together, sometimes that's something that doesn't work as well”

> Participant 8 “so I think that for people, for example, in accident and emergency whose experience of people with personality disorders, people who behave like this, they don't understand it. They don't feel that they have time for it, and therefore they're not sympathetic towards it and the more that that happens, that kind of creates that culture of bias against this patient group and they become “they're not even our patients, they're mental health patients”

Additionally, negative attitudes or misconceptions of those with a diagnosis among some senior staff was felt to be particularly unhelpful when younger, newly qualified staff were entering services. This was felt to increase the opportunity for the opinions and practice of junior staff to be shaped by these attitudes. However, training and education were thought to be significant tools to improve these attitudes.

> Participant 14 “unfortunately, when people don't have that information in their training days, they come onto the wards and unfortunately they can be influenced by other colleagues who may not have a positive opinion of someone with a personality disorder”

> Participant 11 “I think that just re-stigmatises and re-excluded people with that set of symptoms. And I think people's expedience, people with lived experience, who have accessed services have probably encountered that kind of negative judgment and dismissive attitude, and that has reinforced this stigma and I guess misunderstanding of the diagnosis. So I think I think again, it's sort of a 2 dimensional thing. It's both people have experienced the exclusion and the negative judgment and we as a service have been particularly bad at excluding and negatively judging”

Managing patient relationships was another challenge, in part because of the nature of patients past personal experiences and experiences of services. Being able to build therapeutic alliances was seen to take extra work and effort. Mismanaged or misaligned approaches to relationships were seen to have the potential to be further traumatising, as such considerable emphasis was given to open, honest, empathic communication. However this was viewed in balance with not fostering “dependency” and of being aware of other influences on recovery (family, addictions, etc.)

> Participant 16 “at the start they probably all they see is just another person that's coming in, taking to them and that…”so he's just somebody else going to come in and when you get the first opportunity to pass you will pass me over to somebody else and that's what's going to happen”, because that's historically what's happened, that has happened in community mental health teams previously if I'm honest”

> Participant 4 “Obviously you need to be careful, like I have had people with dependent personality disorder which you maybe want to sort of do the opposite because you don't want to create more of a dependency but I do think within reason it needs to be quite intensive, consistent, same approach, use lots of boundaries put in place and followed”

> Participant 13 “external factors now that are keeping it going, with parents and them you know, being dead invalidating…You know, so sometimes recovery is not all…yeah they can do so much and external factors can stop recovery”

> Participant 19 “difficulties also lie in the fact that there is a lot of reinforcement happening within families. Families get burnt out from dealing with kind of hot and cold black and white or from very extreme reactions or even unhelpful coping strategies”

Staff expressed that team approaches can offer significant support, but these can become misaligned when a team does not share the same vision, potentially increasing stigma and ‘othering’ of service users. The lack of provision in Scotland at present for those with a diagnosis is partially explained by lack of training, however sub-optimal staff numbers likely pose additional impact. Those with a diagnosis require time to build trust and rapport with staff, however present staff numbers means there are often unrealistic expectations on how this can be done. This additional staff pressure can potentially lead to negative perceptions flourishing, influencing junior staff; with those who legitimately need more time and input being viewed as ‘demanding’. Staff also expressed that when an individual is involved with more than one or with multiple practitioners/services, a lack of integration and information sharing can mean that an individual has to continually disclose their story and access to documentation (particularly in times of crisis) can be delayed, causing undue distress and delays in treatment.

What’s working well?

To enable good practice to be shared across Scotland, we examined what staff felt was being done well within services (see figure 4, page 24 for visual representation of areas of rewards and good practice). In terms of good practice, staff felt provision of interventions and dedicated services and pathways was an area of pride. Additionally, staff mentioned being part of a team that was supportive and shared the same vision as well as having the ability to be flexible in approaches. The impact of good practice was seen by changing attitudes towards those with a diagnosis among staff/services and in relation to Ayrshire and Arran specifically; the board wide roll out of Decider skills training. Staff also found considerable rewards to their work, such as seeing clients engaging with and gaining trust in services and practitioners. Also, seeing clients make wider improvements in their life (e.g. improved relationships with family, returning to education etc.) was also mentioned as was clients moving on from services. Increased skills and confidence as a practitioner also factored as an area of reward in the work.

Figure 4. Areas of rewards and good practice from staff interviews

Conclusions

This portion of the evaluation work within PDIP sought to understand staff perceptions of challenges to providing high quality care. Synthesis of outcomes from the survey and the one to one interviews highlight several barriers:

- Lack of early career education and/or training specific to personality disorder
- Inequitable access to supervision across staff groups, specifically among nursing
- Inequitable access to training opportunities, particularly for non-psychology/psychiatry staff in low intensity interventions (Decider/STEPPs)
- Considerable barriers in access to evidence based therapies, with specialised interventions not being available across all NHS boards
- Inflexibility in service design, which can inhibit engagement for those with a diagnosis
- Staff pressures, inclusive of recruitment/retention, staff being unable to dedicate necessary time to this service user group, potentially reinforcing negative attitudes as well as the emotional impacts of working with a service user group who can present as high risk
- The approach to diagnosis is inconsistent, and isn’t always approached in an empowering way that incorporates shared understanding and collaboration, which can reinforce self-stigma and contribute to misunderstandings.

There is a desire among staff for change in current service operation; with broad consensus on challenges posed to delivering high quality care. Whilst those with a diagnosis are only thought to make up 10% of the general population, they also have high engagement with services and high levels of risk associated with their diagnosis[2]. As such, it is a duty for those who provide services to ensure that there is equitable, timely access to care in an environment that is validating and non-stigmatising.

> Participant 6 “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, that's not feasible and we need, we need to find a way to be better”

Recommendations

Based upon the overall outcomes from the staff engagement work, the following recommendations are made in respects to improving high quality care:

- A consistent, standardised approach to diagnosis based on information sharing and shared understanding is applied, ensuring that those being given a diagnosis have full understanding of the relationship between current difficulties and early life/developmental trauma.

- NES enabled education specific to personality disorder for early career entries into mental health services and for services that are likely to have contact with this service user group (i.e. occupational therapists, physiotherapist, A&E staff, etc.).

- Top up education available throughout career path to ensure competency in respect to trauma informed care and best practice.

- Peer education and training opportunities should be enabled and maximized, facilitating an approach that maximizes opportunities, whilst also being sustainable and with the additional benefit of enhanced peer support. An example of this is the approach taken within the STEPPs initiative in Greater Glasgow and Clyde.

- Increased access to supervision across staff groups that encompasses caseload supervision and wellbeing support.

- Increased access to recommended specialised psychotherapies, enabling equitable access across the country.

- Services adapt to increase their flexibility and pivot from a ‘disengage-discharge’ model towards a model that may allow for more leniency in attrition and facilitate top up contact for clients during periods of distress. This would reduce the need for having to re-approach and re-engage with services. This may also avoid inpatient and crisis care (seen to be harmful).

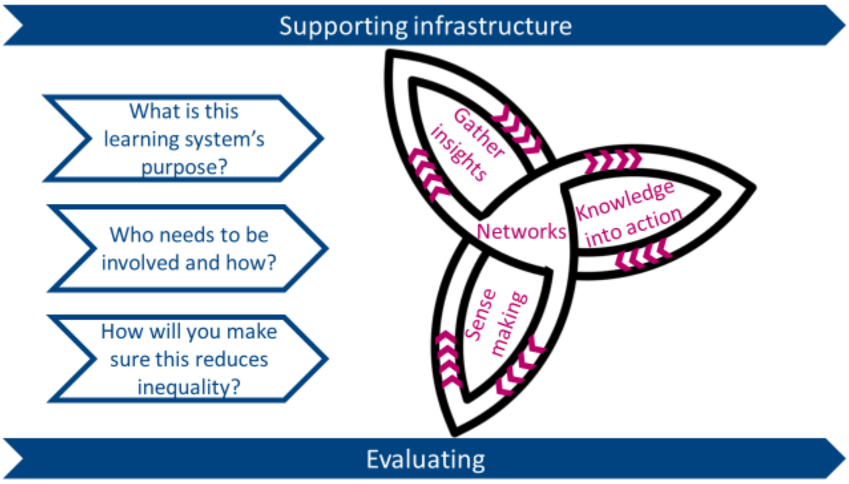
- Improved communication within and between services, improvements in record keeping and sharing (potentially via systems such as EMIS).

Appendix G Evaluation of webinars and workshops from the PDIP learning system

Summary

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 PANEL principles as a human rights based approach – we considered Participation, Accountability, Non-Discrimination, Empowerment and Legality. 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. In practice, for example, 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).



PDIP 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:

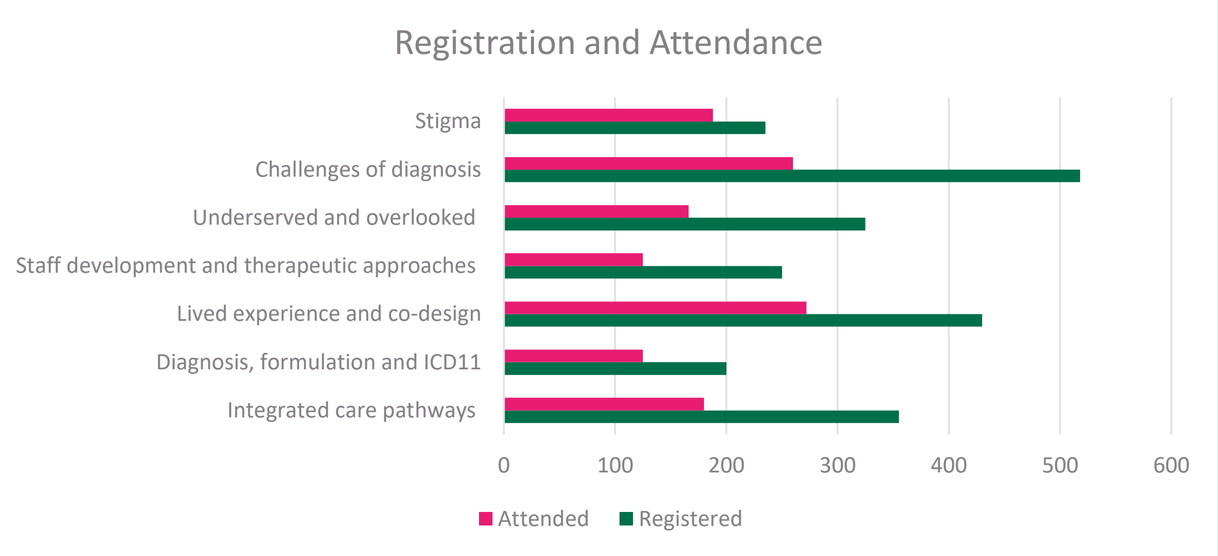
1. Programme launch webinar taking place in May of 2022
2. Integrated Care Pathways and specialist services
3. Under-served and often overlooked groups
4. Diagnosis and formulation
5. The challenges of diagnosis
6. Lived experience and co-designed services
7. Staff development and therapeutic approaches
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.

Evaluation outcomes

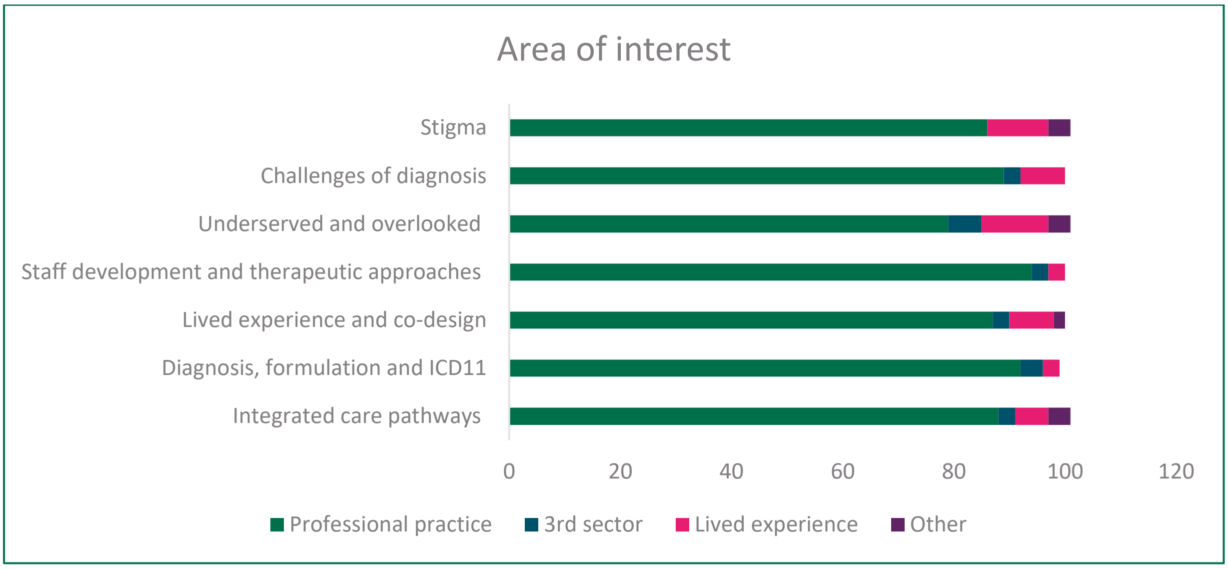
The webinar and workshop series launched on the 31st of May 2022, and there have been 10 events to date (31.03.23), with an introductory event to open the series and a closing event at the end of PDIP phase one. Each event was evaluated, with questions being posted live using MS teams. Key outcomes from eight of the events are described below. Evaluation focused on six key areas, specifically area of interest from attendees (i.e. professional practice, lived experience, 3rd 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 attendance. For most of the events across the series (see figure 1), approximately 50% of those who registered attended.

Figure 1. *Engagement and attendance with PDIP events*



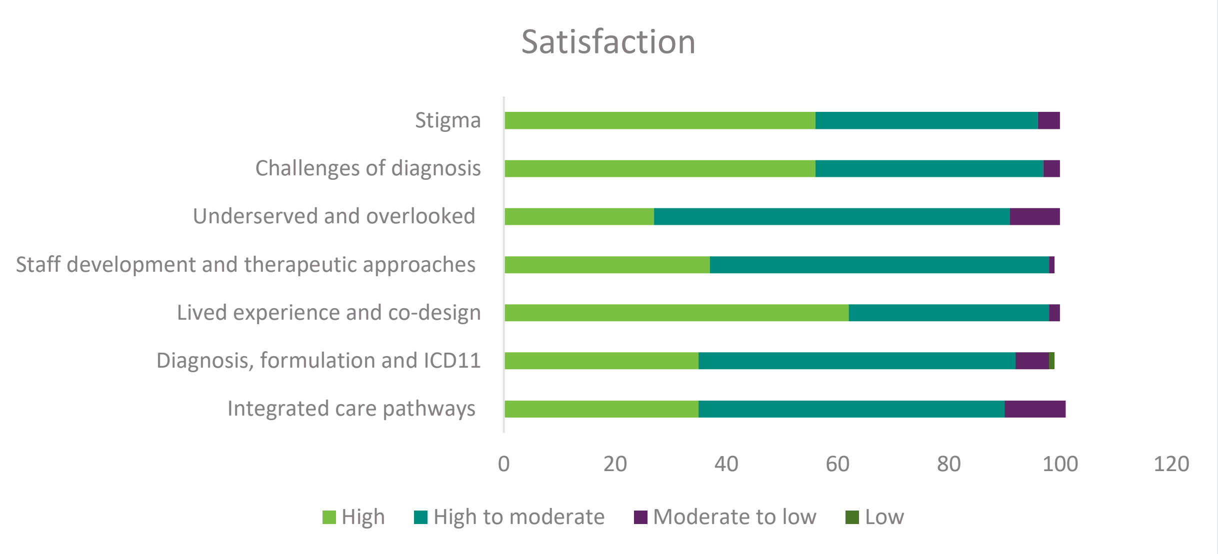
Outcomes indicate that the most common attendees were those from professional practice. This was consistent across all events. Figure 2 displays the areas of engagement across professional practice, lived experience, 3rd sector and other (e.g. family, carers, etc.) from each event across the series.

Figure 2. *Area of attendee interest*



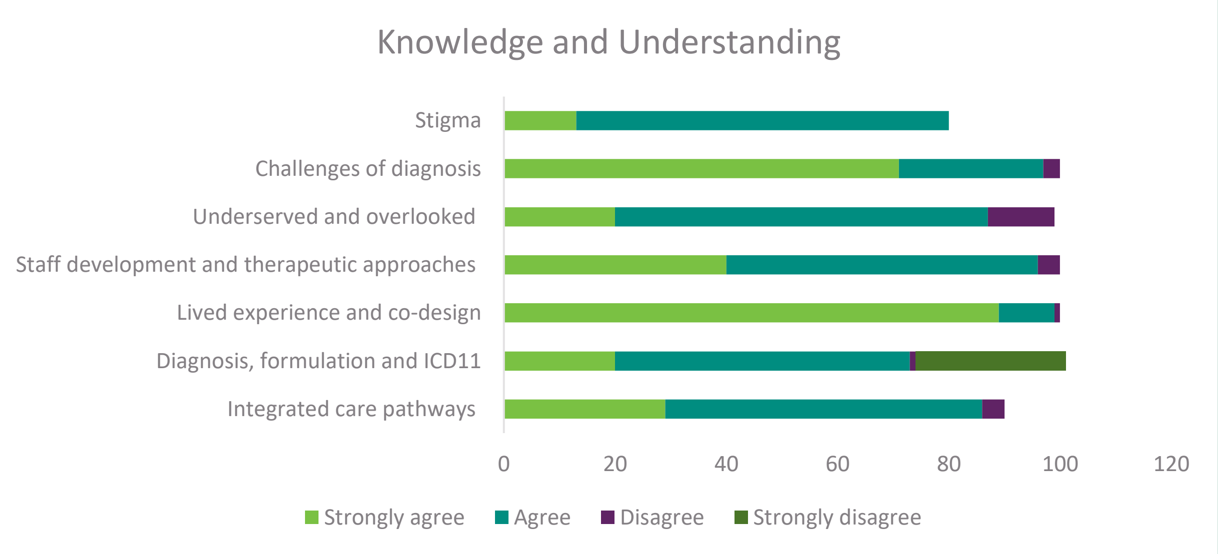
There were considerable levels of participant satisfaction across the events (see figure 3), with attendees rating their satisfaction with the content of the webinar/workshop as being either high or high to moderate.

Figure 3. *Attendee satisfaction with event content*



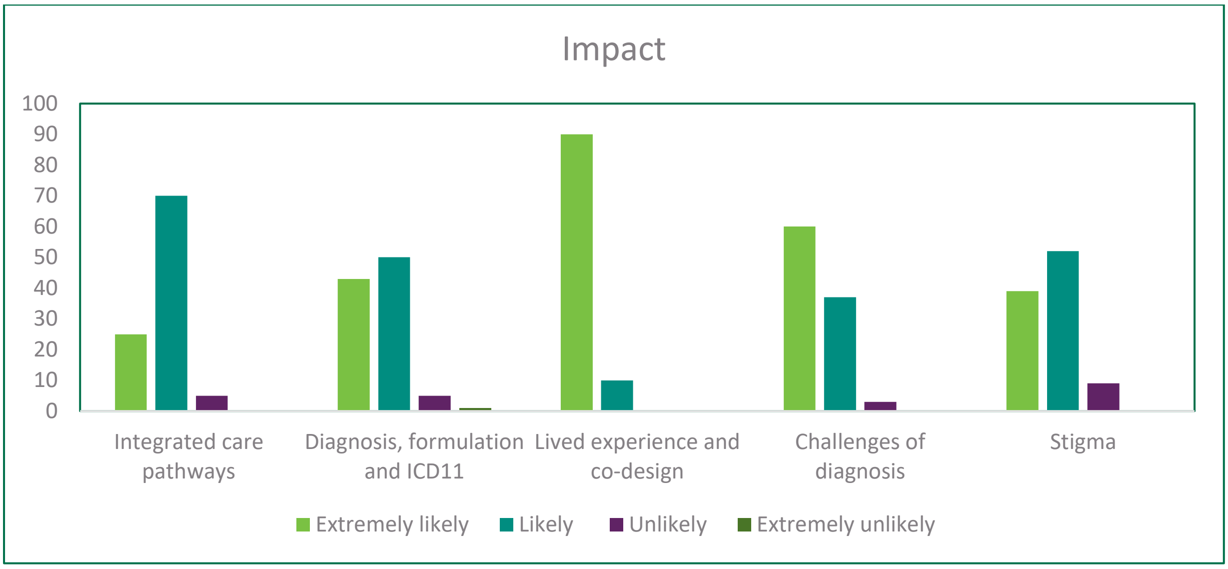
A key feature of the webinar and workshop series was sharing knowledge and information. There was considerable agreement across events that knowledge and understanding was increased due to attendance. The exception to this was the Diagnosis, Formulation and ICD 11 event. Approximately 27% of attendees of this event strongly disagreed that attendance had increased their knowledge and understanding. However, to provide some context, most attendees across events were from professional practice (as seen from figure 2). 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 ICD11.

Figure 4. *Knowledge and understanding gained through event attendance*



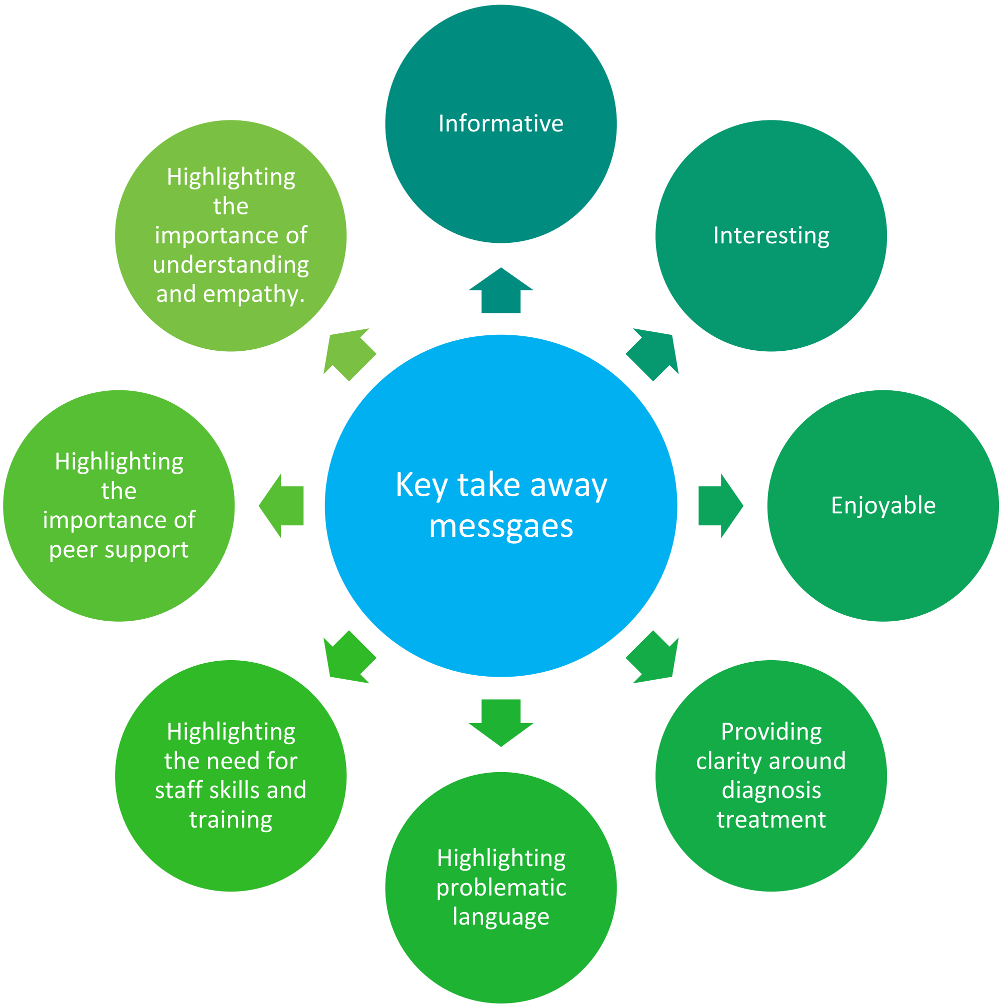
Impact of knowledge gained going forward (either professionally or personally) was an additional area of evaluation. Again, most attendees rated that the knowledge and understanding that they gained through the event would have future impact for them.

Figure 5. *Impact of knowledge going forward*



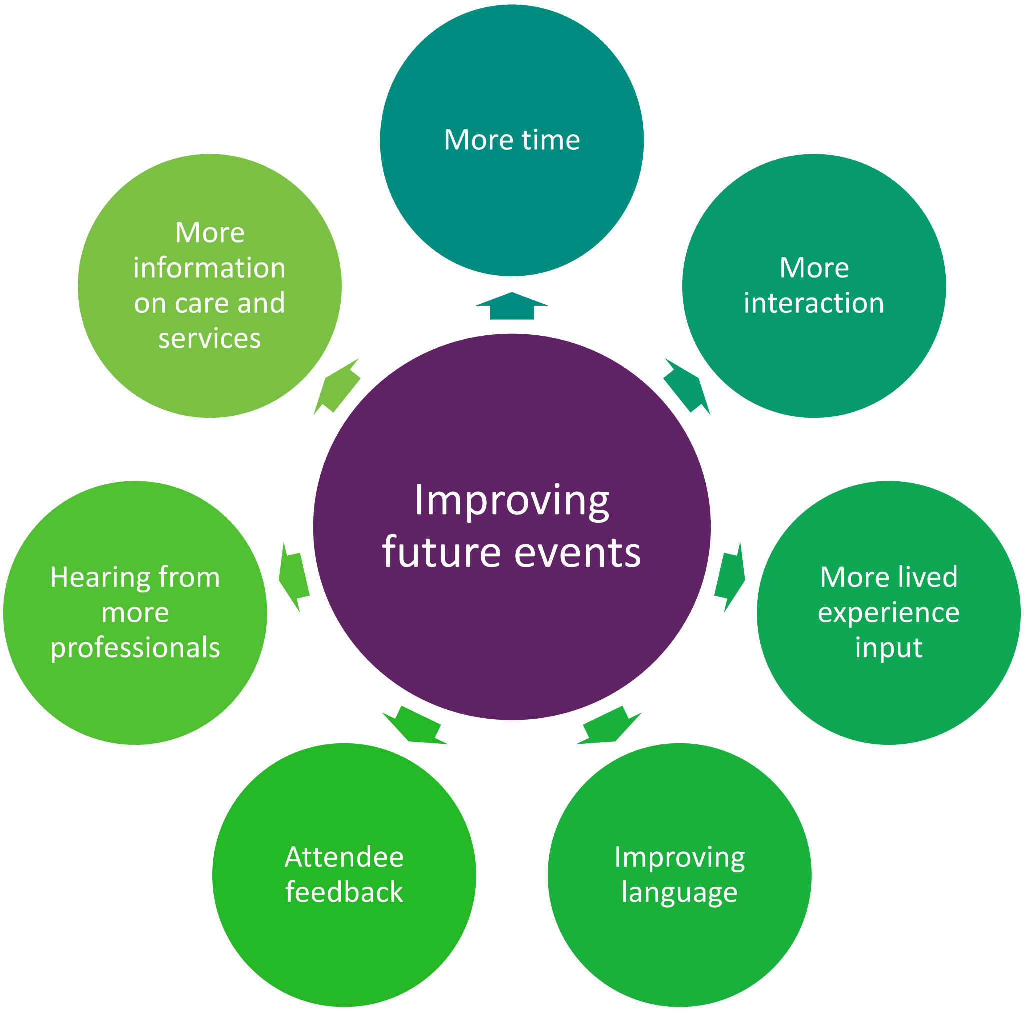
Attendees at each event were offered the opportunity to give their views on the key take away messages and what they believed could improve future events in open response questions. This feedback involved descriptions of events including: informative, enjoyable, interesting. It was also felt that events 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. Attendees key take away messages were synthesised and are shown in figure 6.

Figure 6. *Attendee descriptions of events*



Attendees were also asked what they felt would improve future events. The following provides a synthesis of attendee suggestions (figure 7).

Figure 7. *Improving future events*



The events on staff development and stigma included targeted questions on what could assist in achieving improvements in these specific areas. Attendees suggested the following:

Staff

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

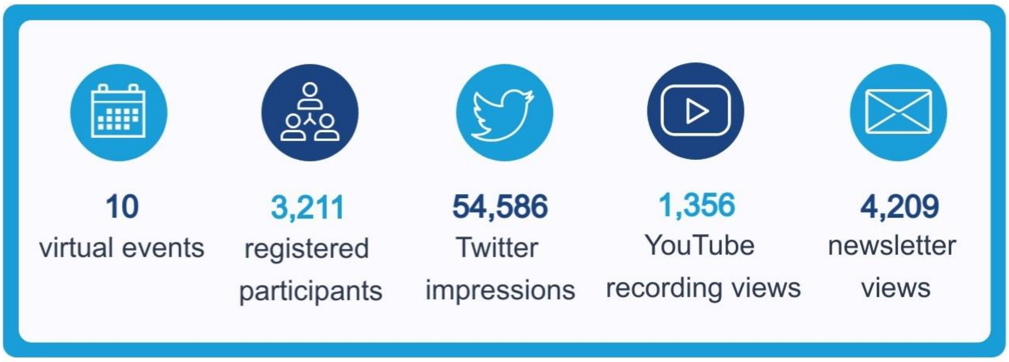
Stigma

- 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.

Conclusions


10 virtual events

3,211 registered participants

54,586 Twitter impressions

1,356 YouTube recording views

4,209 newsletter views

Evaluation of the PDIP series of webinar and workshop events has shown that there is considerable interest and appetite for engagement within this area, particularly for those from professional practice. This evaluation has shown that those who attended the events felt that these 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 webinar and workshop events would have impact for them going forward. This was a key aim of the events, 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, and these map well to the findings of the lived experience engagement and staff engagement, particularly around language, staff training and education as well as the importance of lived experience voices and input in improving services.

Appendix H
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